

# Expanding palliative care nursing education in California: the ELNEC Geriatric project

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## Abstract

In the past decade, the Robert Wood Johnson Foundation's 2002 report *Means to a Better End: A Report on Dying in America Today* and other studies brought attention to deficiencies in care of the dying in the USA. Palliative care's mandate is to promote a 'good death' through expert symptom management and compassionate care that addresses the psychosocial needs and dignity of persons at the end of life. The End-of-Life Nursing Education Consortium (ELNEC) Geriatric 'train-the-trainer' project was launched in 2007 to increase the knowledge and educational skills of nurses and unlicensed staff providing end-of-life care for older adults in nursing homes, skilled nursing facilities, long-term care, and hospices. From 2007 through 2009, 351 California-based nurses and nursing home staff attended one of four ELNEC Geriatric courses. This paper describes programme development, implementation, follow-up evaluations, and examples of participants' use of the ELNEC Geriatric curriculum.

**Key words:** Palliative care ● Nursing ● Education ● ELNEC ● End of life

the older people are, the more likely they will need care and will die in a nursing home (Sherman et al, 2004; Wilson, 2010).

The experience of dying in nursing homes has been documented as lacking many aspects of quality care (Miller et al, 2007). Pain and symptom management as well as many other areas that affect quality of life, such as end-of-life planning, communication, grief and bereavement support for families and staff, and coordination of care, need improvement (Teno et al, 2004a; Teno et al, 2004b; Furman et al, 2006; Kapo et al, 2007; Miller et al, 2007; Hanson et al, 2008; Malloy et al, 2010). In 2006, the California HealthCare Foundation (CHCF) reported that a majority of Californians surveyed about death and dying were 'somewhat concerned' to 'very concerned' about care at the end of life (Citko and Lake Research Partners, 2006). This article describes a Californian programme to educate nurses and unlicensed staff in providing end-of-life care for older adults in nursing homes, skilled nursing facilities, long-term care facilities, and hospices. It looks at the development of the programme, its implementation, participants' follow-up evaluations, and their self-reported practical outcomes.

## Background

Many barriers to improving end-of-life care in nursing homes have been identified (Ersek and Wilson, 2003; Meier and Sieger, 2008). These include:

- High staff turnover
- Understaffing
- Low pay
- Burdensome regulatory requirements
- Low reimbursement for palliative care in nursing homes
- Lack of palliative care education.

Certified nursing assistants, who have had little formal training in palliative and end-of-life care, provide the majority of direct care, under the supervision of a licensed vocational nurse or

It is expected that, by 2020, 40% of all deaths in the USA will occur in nursing homes (Brock and Foley, 1998; Bercovitz et al, 2008). This trend of dying in nursing homes or similar care settings is also becoming more common in other countries with aging populations (Froggatt and Payne, 2006; Hirakawa et al, 2009; Lo et al, 2010). However, these statistics do not adequately describe who is dying in nursing homes or their needs. Persons living in nursing homes or residential care facilities are likely to be over the age of 85, be female, need help with activities of daily living, and suffer from Alzheimer's disease or other dementias (Spillman and Black, 2006). More people in the USA are living longer, and the fastest growing segment of the population is those who are 85 years and older (Vincent and Velkoff, 2010). Nursing homes are a common place of death for the 'oldest old', and in the USA 45% of those who died aged 85 years and older were reported to have died in one in 1998 (Flory et al, 2004). In fact,

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registered nurse. Often the director of nursing may be the only registered nurse on staff (Fleming and Kayser-Jones, 2008; Meier and Sieger, 2008; McConnell et al, 2010).

Palliative care nursing education that addresses pain and symptom management as well as psychosocial and spiritual needs can significantly reduce suffering and provide comfort and dignity to dying patients and families (Grossman, 2007; Coyle, 2010). Nurses and all nursing home staff need adequate resources, education, and training to fill their increasingly important roles caring for older adults at the end of life (Ersek and Wilson, 2003; Ersek and Ferrell, 2005; Ersek et al, 2005; Goodridge et al, 2005; Heals, 2008; Meier and Sieger, 2008; McConnell et al, 2010; Wilson, 2010). A recent study identified education of certified nursing assistants and other nursing home staff in end-of-life care as a significant factor in improving the quality of nursing home care (Zheng and Temkin-Greener, 2010).

In response to the need to improve palliative care education for nurses, the American Association of Colleges of Nursing (AACN) and the City of Hope Medical Center began a collaboration in 1998 to develop the End-of-Life Nursing Education Consortium (ELNEC), a national education programme specifically for nurses (AACN, 2011). The first curriculum, ELNEC Core, was implemented in 2001. This curriculum focuses on core areas in end-of-life care, reflecting the AACN's recommended competencies and curricular guidelines (AACN, 1997). Since the core curriculum was launched, five additional ELNEC curricula have been developed to meet the end-of-life educational needs of nurses in pediatrics, oncology, graduate nursing, critical care and, most recently, geriatric long-term care.

In order to directly target the palliative care educational needs of nurses and certified nursing assistants in nursing homes and long-term care settings, the ELNEC Geriatric curriculum was created by merging the ELNEC Core curriculum with the Palliative Care Educational Resource Team (PERT) curriculum. The PERT programme is an effective educational model to improve palliative care practice for licensed nursing staff and nursing assistants working in nursing homes and long-term care (Ersek et al, 2005; 2006). The nursing assistant education components of the PERT programme were integrated into the ELNEC Core modules, resulting in sections specifically designed for use in the education of certified nursing assistants or other unlicensed personnel working in long-term care facilities (Kelly et al, 2008).

### The effort in California to provide end-of-life education

Supported by two charitable foundations, California-based nurses were able to attend one of five ELNEC Geriatric courses from 2007 to 2010. The objective was to improve end-of-life care for California's older adults. The CHCF provided funding in 2006 for the development of the ELNEC-Geriatric curriculum and one 'train-the-trainer' course in each of 2007 and 2008. The Archstone Foundation provided support for three additional courses in 2008–2010.

California-based nurses and other staff who worked in long-term care, skilled nursing facilities, and hospices that serve these facilities or provide care to geriatric patients were eligible to apply. Applicants were selected based on their work setting, role as an educator, or ability to enhance palliative care education in their facility. As part of the process, the application to attend one of the courses included a pre-course survey, agreement to participate in two follow-up surveys (one after six months and one after twelve) to report on progress in achieving self-set goals for disseminating the ELNEC programme training, and a letter from the facility supervisor or administrator in support of the participants' goal implementation.

The CHCF-funded courses offered lower cost registration and required that participants attend in teams with a nurse as the team leader. The Archstone-supported courses covered all registration costs and did not require teams.

### Programme goals and description

A significant aim of the ELNEC Geriatric training programme is to not only educate nurses in end-of-life care but also, as a train-the-trainer programme, provide them with the motivation, educational resources, and materials to educate other nurses, nursing assistants, and staff on return to their facilities. The ELNEC train-the-trainer model has been successful in increasing end-of-life education for nurses in other health-care settings (Ferrell et al, 2006; Kelly et al, 2008; Virani et al, 2008). The approach promotes wide dissemination of ELNEC content and rapidly creates a pool of nurses prepared to provide education to improve care for those at the end of life.

The ELNEC Geriatric curriculum consists of nine modules, which include the essentials required for training personnel to provide high quality palliative care to a geriatric population at the end of life. The modules are:

- Principles of palliative care
- Pain management
- Symptom management

*‘Palliative care nursing education ... can significantly reduce suffering and provide comfort and dignity to dying patients and families.’*

## Box 1. ELNEC Geriatric programme content by module

### Principles of palliative care

- 'Quality of life' includes physical, psychological, social, and spiritual wellbeing
- Palliative care begins at the time of diagnosis of a life-limiting condition or when quality of life is decreasing owing to chronic conditions or ageing
- Educating not only nurses but also nursing assistants is key to providing good palliative care

### Pain assessment and management

- Pain assessment in verbal and non-verbal patients
- Pharmacological and non-pharmacological management
- Nursing assistant role in observing, reporting, and relieving pain

### Management of other symptoms

- Respiratory and gastrointestinal symptoms
- General fatigue and weakness, depression, anxiety, delirium, agitation, and confusion
- Nursing assistant role in observing, reporting, and being a patient advocate

### Goals of care and ethical issues at end of life

- Defining the goals of care, by choosing options for optimal end-of-life care, will guide treatment
- Ethical issues

### Cultural and spiritual considerations

- Different cultures and world views
- Ethnicity, race, gender, age, religion and spirituality, sexual orientation, socioeconomic status, and differing abilities all contribute to illness experiences and end-of-life decisions

### Communication at end of life

- Therapeutic communication
- Working with families and managing conflict

### Loss, grief, and bereavement

- Loss of home, friends, and function
- Helping the family/helping ourselves

### Ensuring quality end-of-life care

- A commitment to improving processes and satisfaction with care to ensure the best possible outcome
- Deliberate method of implementing goals

### Preparation for and care at time of death—staff, patient, and family

- Life review, talking to non-responsive patient
- Recognition and management of signs and symptoms of dying process
- Care following death

- Goals of care, including advance care planning and ethical issues
- Cultural and spiritual considerations
- Essentials of communication, including working with difficult family dynamics
- Loss, grief, and bereavement
- Ensuring quality end-of-life care
- Preparation for and care at time of death (see Box 1 for module descriptions).

The ELNEC Geriatric curriculum differs from other ELNEC curricula because it includes educational sections for nurses as well as for nursing assistants and other unlicensed staff. In all health-care settings, unlicensed staff play a key part in the care of geriatric patients. Training unlicensed staff in the principles of palliative care often helps them to feel more a part of the health-care team (Zheng and Temkin-Greener, 2010). Nursing aides can participate in comfort care in a variety of ways, from positioning for comfort to empathetic listening (Ersek and Wilson, 2003).

The courses, led by the ELNEC Project Team and nursing faculty (with expertise in geriatric palliative care), consisted of a two-day train-the-trainer programme of didactic lectures, role play, case studies, modelling of the course educational strategies, and video clips. They highlighted issues in palliative care and offered opportunities for discussions with ELNEC faculty and for networking with peers (Ferrell et al, 2005). Participants received a 1000-page printed syllabus (updated annually), a palliative care textbook, and a CD of programme materials, including PowerPoint slide presentations, references, resources, case studies, teaching strategies, and additional supplemental materials that can be used or adapted for teaching end-of-life care.

## Evaluation

### Course participants

A total of 351 people participated in the first four courses (a fifth course was offered in 2010). The participants were from Southern California (64%), Central California (15%), and Northern California (21%). Table 1 lists other demographic descriptors of the participants. In addition to these data, the participants reported an average of slightly more than 13 years working in geriatric care. They had spent an average of six years working in their current positions. Based on the course evaluations, the participants rated the course overall as 4.8 on a scale of 1 (low) to 5 (high).

### Pre-course survey

In the pre-course survey, the majority of the participants indicated that their organizations had offered end-of-life education programmes in the previous two years. The topics of pain management, communication, and nursing care at the end of life were reported as being the most frequently offered. The participants were also asked their opinions about end-of-life care. They rated the importance of end-of-life care education for geriatric nursing very highly, with an average rating of 9.79 out of 10 (0 = not important; 10 = very

important). They rated the receptiveness of facility staff to increased end-of-life education at 8.76. By contrast, they rated the effectiveness of nurses in their community in care of the dying at 6.83, which may have indirectly reflected the participants' understanding that more opportunities for end-of-life education are needed to improve community standards for care of the dying.

### *Twelve months post-course survey*

Twelve months after the course, the participants were asked to complete another survey. In total, 308 of the 351 participants responded (87.75%). In addition to evaluating how successful the participants were in achieving their goals (see next section), the survey repeated some of the pre-course questions about attitudes toward end-of-life care and education. Two of these provide insight into the positive impact of the ELNEC Geriatric training programme.

In answering the question, 'How effective is your work setting in teaching end-of-life content?' in the pre-course survey, participants rated their work setting as 5.86 out of 10. Twelve months after the course, the participants provided a mean rating of 7.65, illustrating that they felt their workplace was now much better at teaching end-of-life content ( $P < 0.001$ ).

The second question, 'How receptive would your staff be to increased end-of-life care education?' revealed interesting perspectives. Before the course, the participants felt that their staff were very likely to be receptive to additional end-of-life care education, and provided a mean rating of 8.76 out of 10. Twelve months after the course, the mean rating was slightly lower, at 8.17, illustrating that the participants now felt slightly less positive about their staff's receptivity ( $P < 0.001$ ) (although a score of 8.17 still indicates that they were thought to be very receptive). This change most likely reflects the reality that the participants faced when they returned to their facilities and began trying to implement their goals. Course participants are often very enthusiastic about going to ELNEC training, and they assume that their staff will be just as excited. However, there are very real barriers to passing on the lessons learnt, such as a lack of time for educating staff and costs associated with doing so. Especially in long-term care settings, it is very difficult to give staff time off (with or without pay) for class attendance. In addition to these barriers, a review of the responses from the twelve-month participant surveys indicated that reasons for delays in holding education programmes or failures in goal implementation were lack of time, inability to be relieved from patient care, and lack of administrative support.

**Table 1. Demographics of ELNEC Geriatric training programme participants (n=351)**

| Variable  | n (%)      |
|---|------------|
| <b>Gender</b>   |            |
| Female  | 313 (89.2) |
| Male  | 24 (6.8)   |
| Not reported  | 14 (4.0)   |
| <b>Ethnicity/race</b>   |            |
| Caucasian   | 210 (59.8) |
| Asian   | 61 (17.4)  |
| Hispanic/Latino   | 31 (8.8)   |
| African American  | 13 (3.7)   |
| American Indian   | 3 (0.9)    |
| Other/not reported  | 33 (9.4)   |
| <b>Type of facility*</b>  |            |
| Skilled nursing facility  | 148 (48.5) |
| Hospice serving long-term care facilities   | 106 (34.8) |
| Long-term care facility   | 90 (29.5)  |
| Acute care facility (hospital)  | 38 (12.5)  |
| School of nursing   | 7 (2.3)    |
| Other   | 21 (6.9)   |
| <b>Job titles</b>   |            |
| Staff nurse   | 70 (19.9)  |
| Director  | 64 (18.2)  |
| Manager/supervisor/team leader  | 63 (17.9)  |
| Educator  | 47 (13.4)  |
| Coordinator   | 29 (8.3)   |
| Clinical nurse specialist/advance practice nurse  | 16 (4.6)   |
| Licensed vocational nurse   | 16 (4.6)   |
| Social worker   | 16 (4.6)   |
| Certified nursing assistant   | 8 (2.3)    |
| Chaplain  | 2 (0.6)    |
| Not reported  | 20 (5.7)   |
| <b>Highest educational degree reported</b>  |            |
| Vocational training   | 39 (11.1)  |
| Associate's degree  | 117 (33.2) |
| Bachelor of Science in Nursing  | 55 (15.7)  |
| Master of Science in Nursing  | 37 (10.5)  |
| Master of Social Work   | 14 (4.0)   |
| Doctorate of Philosophy or Education  | 13 (3.7)   |
| Other   | 35 (10.1)  |
| Missing   | 41 (11.7)  |
| *Percentages are greater than 100% owing to participants working in combined service facilities. ELNEC, End-of-Life Nursing Education Consortium. |            |

### *Participant goals*

During the course, each participant was asked to write down three goals that they would like to achieve in the next six-to-twelve months in

**Table 2. The ELNEC Geriatric training modules most frequently taught to others by the programme participants**

| Group taught   | Modules*   |
|--|--|
| Licensed staff (registered nurses and licensed vocational nurses)  | <ul style="list-style-type: none"> <li>● Pain management</li> <li>● Principles of palliative nursing care</li> <li>● Symptom management</li> <li>● Communication</li> </ul>                                |
| Certified nursing assistants   | <ul style="list-style-type: none"> <li>● Loss, grief, and bereavement</li> <li>● Pain management</li> <li>● Communication</li> <li>● Symptom management</li> </ul>   |
| Other disciplines (social workers, chaplains, and administrators)  | <ul style="list-style-type: none"> <li>● Communication</li> <li>● Principles of palliative nursing care</li> <li>● Loss, grief, and bereavement</li> <li>● Ensuring quality care at end of life</li> </ul> |
| Professionals outside the facility/in the community (nursing and medical students, hospice volunteers, and other hospice, nursing home, and long-term care facility staff) | <ul style="list-style-type: none"> <li>● Pain management</li> <li>● Principles of palliative nursing care</li> <li>● Symptom management</li> <li>● Ensuring quality care at end of life</li> </ul>         |

\*Listed in order of descending frequency. ELNEC, End-of-Life Nursing Education Consortium.

relation to end-of-life care in their organization. The purpose was not only to allow the ELNEC team to track changes that resulted from the course, but also to give participants concrete objectives to work toward. At six and twelve months after the course, participants were mailed surveys and asked about how they were progressing.

In the twelve-month survey, the participants were asked to report on the number of ELNEC educational programmes or in-services they offered for staff and to provide an update on how well they had implemented their goals. The 308 respondents reported holding 1493 courses, utilizing all nine ELNEC modules. Of these, 50.3% were for registered nurses and licensed vocational nurses, 40.5% were for certified nursing assistants and other unlicensed staff, and 9.2% were for other disciplines, such as social workers, chaplains, and physicians. Participants reported educating a total of 11 170 registered nurses and licensed vocational nurses, 9008 certified nursing assistants, and 2057 other health professionals, for a total of 22 235. Across all disciplines, in all educational programmes, the modules taught most often, in order by number of staff reported, were:

- Pain management
- Loss, grief, and bereavement
- Principles of palliative nursing care
- Communication
- Symptom management
- Cultural/spiritual considerations

- End-of-life care ethics and goals of care
- Preparation and care at the time of death
- Ensuring quality care at the end of life.

Education using ELNEC modules falls into four categories: educating licensed staff (registered nurses and licensed vocational nurses), educating certified nursing assistants, educating other disciplines, and educating professionals outside the facility. The most commonly taught modules for each of these categories, as reported in the twelve-month participant surveys, are shown in *Table 2*. The module topics presented most frequently to staff were selected by the ELNEC trainers based on their assessment of staff training needs to manage and improve end-of-life care within their facility.

The ways the ELNEC trainers reported using and adapting the modules predominantly fell into three categories: full-day classes, the ‘module-a-month’ model, and short (typically 15–20-minute) in-services. Full-day classes were most often used in an orientation setting but occasionally were used for annual education days in hospitals. One participant reported holding six hospital-wide, full-day education programmes for registered nurses and licensed vocational nurses. The module-a-month method was the most frequently used model, and administration and health personnel seem to be amenable to a one-hour class on end-of-life care once per month. Using this model, participants are taught all nine modules in less than one year. Other sites primarily used short in-services, typically for 15–20 minutes once or twice per week. One participant reported providing monthly in-services for the night shift staff, including certified nursing assistants. Another reported providing weekly in-services at interdisciplinary team meetings until they developed a protocol for end-of-life care that was continued as monthly end-of-life in-services. This participant also held separate in-services for primary care physicians and pharmacists on pain management.

Several participants reported an increase in reporting of pain by certified nursing assistants after they attended in-services on pain management. Through the survey, the assistants reported that they felt empowered by being included in these education programmes and also said they felt better able to help patients. One participant held an impromptu pain in-service after a family complained that their loved one was moaning all the time. The participant talked with the certified nursing assistants about the possibility that the patient was in pain. She said that it was ‘like seeing a light-bulb go on’.

The participants reported innovative ways in which they passed on end-of-life education from the course. One participant created one-page sheets that were posted in the lunch or break room. Another held twice-monthly grief support/reading groups with residents in an assisted living facility. These groups were helping residents in 'moving past minor depression and building self-esteem'. An additional benefit to this group was that families were visiting longer and interacting with other residents in the assisted living facility as well as their loved one. Another participant created a 'comfort kit' with body lotion, soft music, and aromatherapy for nurses, certified nursing assistants, and family to use with dying patients. This same participant also started a 'no one dies alone' programme in her facility, in which even housekeeping and maintenance personnel participated, to ensure that residents near death and with no family had a volunteer to sit with them in their final hours.

Many of the course participants reported feeling more confident about their own skills in end-of-life care. One said:

**'I feel that I can fully implement my nursing skills to better help my patients at the end of life. I can help families understand end-of-life issues including pain management.'**

Another registered nurse said that she is more proactive in discussing advance directives with her patients.

According to the twelve-month follow-up data, the ELNEC curriculum is also being incorporated into nursing education. One participant taught a 'peaceful death' short course based on the ELNEC lessons for pre-licensure students in order to prepare them to care for dying patients. Other participants have included ELNEC modules into Bachelor of Science in Nursing medical/surgical curricula and are working on infusing the entire ELNEC curriculum into various parts of undergraduate nursing and aide education.

## Conclusions

As the number of older adults in the USA and other countries that have ageing populations grows, the need to educate nurses to provide high quality palliative care will intensify. Nursing homes provide end-of-life care for our most vulnerable and frail older adults, many of them with complex medical and psychosocial needs. Palliative nursing care education that prepares nurses to provide competent pain and symptom management and consideration of the 'whole person' will greatly improve the quality of care and quality of life.

Nursing home staff are aware of their need for palliative and end-of-life education. Studies on improving the quality of palliative care in nursing homes have reported that nursing home leaders and staff express the need for quality palliative care educational programmes (Meier and Sieger, 2008; Hirakawa et al, 2009). The evaluations and reports of goal accomplishments returned by the ELNEC Geriatric participants indicate that the ELNEC education is successful in enhancing end-of-life education, skills, knowledge, and confidence for staff at all levels that care for older adults in the long-term care setting. ELNEC trainers readily adapted the ELNEC materials to develop creative educational strategies to meet the staffing and educational needs of their workplace, from the 15-minute in-services to the module-a-month classes. The participants reported rapid dissemination of the ELNEC-based educational programmes to large numbers of licensed and unlicensed staff, as well as to social workers, chaplains, volunteers, and other staff at all levels.

The ELNEC Geriatric courses that ran from 2007 to 2010 could not have been achieved without financial and leadership support from the two California foundations. The significance of the free and reduced-cost registration opportunities is illustrated by the number of applications (over 100) received for the 2010 Archstone Foundation-funded course, which provided free registration. Visionary and focused programme funding from private charitable organizations continues to be needed to provide opportunities for quality palliative care education in nursing homes and other geriatric care settings.

ELNEC training supported increased education, collaboration, and multidisciplinary efforts to make improvements and promote change in end-of life practice. It is the ELNEC team's hope that the ELNEC Geriatric course will continue to be used as a quality educational programme in long-term care and that it will serve as a model programme for educating nurses and ultimately support the best care for older adults at the end of life. 

*'...the ELNEC education is successful in enhancing end-of-life education, skills, knowledge, and confidence for staff at all levels...'*

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