Abstract

Care of patients at the end of life is contingent on adequate preparation of health care providers. Nursing, as the predominant caring profession in end-of-life (EOL) care, must achieve competence in physical and psychosocial care of patients and families facing terminal illness. Previous research has demonstrated that nursing education has not prepared nurses to provide optimum EOL care. To date, there has not been a unified or organized effort to broadly address the preparation of nurses in EOL care. This article describes one national project, the End-of-Life Nursing Education Consortium (ELNEC), which was developed as a comprehensive effort to improve EOL care by nurses in the United States. The ELNEC project consists of EOL education for various nursing audiences: the undergraduate faculty; continuing education providers; pediatrics; oncology; and the graduate faculty. This organized effort is a major step towards strengthening nursing knowledge in EOL care to improve care of the dying.

The End-of-Life Nursing Education Consortium (ELNEC) project is a national education initiative to improve end-of-life (EOL) care in the USA. The project provides training for undergraduate and graduate nursing faculty, continuing education (CE) providers, staff development educators, pediatric and oncology-specialty nurses, and other nurses in EOL care so they can teach this essential information to nursing students and practicing nurses. The project, which began in February 2000, received a major grant from The Robert Wood Johnson Foundation and additional funding from the National Cancer Institute, the Aetna Foundation, and the Archstone Foundation. The purpose of this paper is to describe the ELNEC project as an example of palliative care nursing education.

To date, over 2,445 nurses representing all 50 states have received ELNEC training and are sharing this new expertise in educational and clinical settings. ELNEC trainers are hosting professional development seminars for practicing nurses, incorporating ELNEC content into nursing curriculum, partnering with local hospice groups and student associations to share resources, writing editorials about the need to improve EOL care, hosting regional training sessions to expand ELNEC's reach into rural and underserved communities, presenting ELNEC at national and international conferences, and improving the quality of nursing care in other innovative ways. Over the next few years, project leaders estimate that ELNEC trainers will touch the lives of 8.75 million people facing the end of life.

The ELNEC project is administered by the American Association of Colleges of Nursing (AACN) and the City of Hope National Medical Center of Los Angeles and the faculty includes a cadre of nurse leaders from around the country. Prior to implementing the ELNEC curriculum, the City of Hope investigators had done extensive work documenting the deficiencies in EOL care. A study conducted and published in 1999 documented that 50 of the leading textbooks used in the United States nursing schools included only 2% of content with any relationship to EOL care (Ferrell et al., 1999a). Additional studies by the investigators documented the extensive concern by practicing nurses of the need for improved care for patients facing the end of life (Ferrell et al., 2000). The ELNEC curriculum also builds extensively on major national reports such as work by the Institute of Medicine documenting the importance of professional education in improving EOL care (Field and Cassel, 1997).

The curriculum was developed through the work of nationally recognized palliative care experts with extensive input from the advisory board and reviewers. The curriculum is revised regularly based
Evaluation of the end-of-life nursing education consortium project in the USA

on participant recommendations and new advances in the field, and is modified for each distinct audience. The curriculum focuses on core areas in EOL care reflecting AACN's 1998 publication Peaceful Death: Recommended Competencies and Curricular Guidelines for End-of-Life Nursing Care (American Association of Colleges of Nursing, 1998). This document outlines specific aspects of professional nursing care considered requisite for each graduate. The ELNEC-core content is divided into nine modules (Table 1).

Course participants were selected using a competitive application process. Each participant received a comprehensive 1,000-page syllabus, textbooks, and a wealth of resources and strategies to teach the course content to others. Teaching materials are furnished in hard copy as well as on a compact disk (CD) so nurse educators can use them efficiently for their own instructional purposes. An example agenda from a 3-day course is included (Figure 1). The ELNEC programmes are 'train-the-trainers' courses, meaning that participants are taught both the content of palliative care as well as teaching methods. All participants are expected to disseminate the education to teach others. Therefore, it is not intended for nurses wishing to advance their own knowledge only, but rather for those who will also teach others about palliative care.

ELNEC project components

Undergraduate education

Undergraduate faculty members were prioritized as the first group to be targeted in the ELNEC project. The investigators believe that impacting on the education of nurses as they enter practice will improve EOL care. A paper published by Ferrell et al (2005) provided 1-year follow up of the faculty members attending the first five conferences focusing on undergraduate education. Data from the 502 faculty members who represented 461 different nursing programmes were reported. The participants represent all 50 states in the USA. The attendees rated the ELNEC curriculum at the 1-year follow up as 8.45 on a scale of 0 (helpful) to 10 (very helpful). Faculty had taught an average of 50 students per programme in the ELNEC programme in this first year of follow up.

In addition, the amount of time in the curriculum devoted to any EOL topic increased from the pre-course mean of 18.59 hours to a post-course mean of 28.72 hours ($P < 0.001$). Evaluation also included a follow up of 617 nursing students who were taught the curriculum in participating schools in order to document their mastering of EOL content. There was significant improvement in knowledge in six of the nine content areas and in the overall knowledge of EOL care following their receiving the ELNEC content through their curriculum. The undergraduate faculty was also very active in other areas as a result of attending the ELNEC curriculum including teaching ELNEC outside of the nursing programme in the community and faculty members attending other continuing education conferences on palliative care. There are now a total of 646 baccalaureate and associate degree faculty members who are ELNEC trainers (Ferrell et al, 2005).

CE providers

Following the launch of the ELNEC curriculum for undergraduate education, the next target audience was CE providers. The intent of this training programme was to reach nurse educators or staff development coordinators in clinical settings in order to impact on practicing nurses. The curriculum was modified slightly from the focus on undergraduate students to the education for practicing nurses. A 1-year follow up has been conducted on the first three national conferences for CE providers, which included 261 educators attending these courses. A study by Malloy et al (2006a) summarizes the key results of this educational endeavour. Attendees came from

<table>
<thead>
<tr>
<th>Table 1. ELNEC core curriculum modules</th>
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<tbody>
<tr>
<td>Nursing care at the end of Life</td>
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<tr>
<td>Pain management</td>
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<tr>
<td>Symptom management</td>
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<tr>
<td>Cultural considerations in end-of-life care</td>
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<td>Ethical/legal issues</td>
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<tr>
<td>Communication</td>
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<tr>
<td>Loss, grief, and bereavement</td>
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<tr>
<td>Achieving quality care at the end of life</td>
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<tr>
<td>Preparation for and care at the time of death</td>
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49 of the 50 states in the USA. Primarily, they represented clinical staff development in hospital settings but there were also attendees from specialty nurse organizations, independent CE providers, and state nursing associations. Other clinical settings such as home health, outpatient, long-term care, and hospices were also represented.

One month follow up of these participants also indicated overall helpfulness of the ELNEC curriculum as 9.0 on a scale 0=not helpful to 10=very helpful.

### 3-day course agenda

**Day 1**
- 1730 - 1800: Registration/hospitality reception
- 1800 - 1810: Welcome/introduction
- 1810 - 1820: Overview of participants
- 1820 - 1900: Overview of the ELNEC — core curriculum and resources
- 1900 - 2000: Module 1: nursing care at the end of life lecture
  - Video segment — Final Blessing
- 2000 - 2100: Hospitality reception

**Day 2**
- 0730 - 0800: Registration/continental breakfast
- 0800 - 0845: Module 1: nursing care at the end of life training session
  - Listening exercise
  - Loss exercise
- 0845 - 0945: Module 2: pain management lecture
- 0945 - 1005: Break
- 1005 - 1050: Module 2: pain management lecture (cont)
- 1050 - 1150: Module 5: cultural considerations in end-of-life care lecture
  - Video segment — Angola
- 1150 - 1300: Lunch
- 1300 - 1415: Module 3: symptom management in the elderly lecture
- 1415 - 1435: Break
- 1435 - 1545: Module 2 and 3: pain and symptom management training session
  - Individual case studies discussion
  - Roundtables
- 1545 - 1600: Goal refinement
- 1600 - 1615: Implementing ELNEC in your facility
- 1615 - 1630: Daily evaluation/wrap up

**Day 3**
- 0730 - 0800: Registration/continental breakfast
- 0800 - 0900: Module 6: communication lecture
  - Video segment — Wit-The Shootist
- 0900 - 1015: Module 4: ethical issues in palliative care nursing lecture
  - Video dramatization — Claire’s Story
- 1015 - 1030: Break
- 1030 - 1215: Module 4, 6, 7 and 9: training session: role play — application of ethical issues; communication; loss, grief and bereavement; and preparation for and care at the time of death
- 1215 - 1315: Lunch
- 1315 - 1415: Module 9: preparation for and care at the time of death lecture
  - Video segment — My Life
- 1415 - 1500: Module 8: achieving quality care at the end of life lecture
- 1500 - 1515: Break
- 1515 - 1615: Module 7: loss, grief, and bereavement lecture
  - Video segment — Steel Magnolias
- 1615 - 1645: Program summary/evaluation

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**Oncology**

The National Cancer Institute also funded the ELNEC-oncology training programme. This programme, which began in 2003, trains oncology nurses who are members of the Oncology Nursing Society (ONS) to disseminate palliative care education through their local ONS chapter to improve care of cancer patients and their families. To date, 206 oncology nurses, representing 111 out of 204 ONS chapters have attended. One more course will be held in September 2006.

This project builds on the ELNEC-core curriculum, but focuses on the unique needs of cancer patients. Oncology nurses are encouraged to integrate palliative care into all aspects of cancer care from survivorship through EOL care.
# Table 2. List of ELNEC trainers involved in international outreach

<table>
<thead>
<tr>
<th>Name of ELNEC Trainer</th>
<th>Continent/Country</th>
<th>Activities</th>
</tr>
</thead>
</table>
| Margaret Barton Burke         | AFRICA            | South Africa                                                                                                                                | Presented ELNEC and consulted at University of Witswaters.  
| Carmen Erickson-Hurt          | Zambia            | Presented ELNEC to four Zambian military nurses. These nurses will begin a palliative care programme in a military hospital in Zambia.        |
| Martha Highfield              | Nigeria           | Provided pain management information to the owner & Chief Medical Officer of Maranatha Hospital in Aba, Nigeria.                             |
| Adenike Onibokun              | Nigeria           | Lecturer at the University of Ibadan                                                                                                       |
| Marie Sines                   | Kenya             | Presented ELNEC modules to the program director at Eldoret                                                                             |
| Katherine Crabtree            | THAILAND          | Thailand                                                                                                                                    | Developed a proposed master’s curriculum in palliative care for advanced practice nurses in Thailand.  
| Carmen Erickson-Hurt          | Sumatra           | Developed a certificate program in palliative care for baccalaureate nurses in Thailand.                                                 |
| Martha Highfield              | China             | Taught end-of-life content at 2 universities in Thailand.                                                                                  |
| Carol Long                    | Philippines       | Thailand                                                                                                                                   | Worked with those affected by the December 2004 tsunami.  
| Marianne Matzo                | Japan             | Educated Thai nurses regarding pain assessment and management.                                                                             |
| Sayaka Sakamoto               | Japan             | Was a guest lecturer and consultant on palliative care issues at Municipal Health Bureau in Guangzhou, China.                                  |
| Roger Strong                  | China and Japan   | Taught ELNEC, sponsored by Global Caring Nurses Foundation, Manila and Cebu, Philippines.                                                 |
| Carole Kenner                 | AUSTRALIA         | New Zealand                                                                                                                                | Master’s program development and teaching in Palliative Care Nursing at Tenshi Graduate School utilizing ELNEC modules.  
| Carole Kenner                 | Australia         | Sapporo, Japan and International Cancer Nursing Seminar in Tokyo and Osaka.                                                                |
| Sayaka Sakamoto               | China and Japan   | Translating ELNEC ethics module into Japanese.                                                                                              |
| Roger Strong                  | Russia            | Presented ELNEC as an example of teaching EOL care.                                                                                         |
| Carla Dias                    | SOUTH AMERICA     | Brazil                                                                                                                                     | Translating Cure4Kids ELNEC curriculum into Portuguese, Instituto de Oncologia Pediatrica – GRAACC in Sao Paolo, Brazil.  
| Carol Long                    | Russia            | Presented at Neonatal, Flight and Emergency Nurses Conference, Christchurch, New Zealand.                                                    |
| Melanie Steilen               | Russia            | Presented at Women’s and Children’s Hospital, Adelaide, South Australia.                                                                     |
| Marilyn Stoner                | BRAZIL            | Presented at International Russian Nurses Conference on pediatric end-of-life issues.                                                      |
| Ayda Nambayan                 | INTERNATIONAL     | Brazil                                                                                                                                     | Taught ELNEC in St. Petersburg for physicians and nurses.  
| Ayda.nambayan@stjude.org      |                                                                | This on-line presentation of ELNEC – Pediatric Palliative Care was a collaborative effort among Cure4Kids of the International Outreach Program of St. Jude Children’s Research Hospital, the City of Hope Medical Center and the American Association of Colleges of Nursing. In the first four months since it has gone worldwide, this site has been accessed by 2627 people with the majority from low resource countries.  
| carlagdas@uol.com.br          |                                                                | www.Cure4Kids.org                                                                                                                           |
| carollong@cox.net             |                                                                |                                                                                                                                              |
| Melani@citazetti.org          |                                                                |                                                                                                                                              |
| mstoner@Exhange.fullerton.edu |                                                                |                                                                                                                                              |
The 1-year follow-up evaluation of these oncology attendees is still in progress. However, feedback from the 12-month evaluation indicates that these nurses have also been very effective and productive in their ELNEC dissemination activities. The original intent was dissemination through the ONS chapters but it appears that these nurses are also actively disseminating the ELNEC oncology curriculum within their own work settings.

Graduate education
A grant from the National Cancer Institute began in 2002 to meet the special needs of faculty teaching in graduate nursing education programmes. The first of four ELNEC-graduate courses occurred in June 2003. To date, a total of 220 graduate nursing faculty member, representing every state in the USA and 210 out of 400 graduate nursing programmes, have attended. One additional ELNEC-graduate course will take place in June, 2006. These courses are intended to support faculty in integrating the important role of advanced practice nursing in EOL care. Clinical specialists, nurse practitioners, managers, adminis

Table 3. Principles of professional education

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<tr>
<th>Characteristics of effective professional education</th>
<th>Application to the ELNEC curriculum</th>
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<tr>
<td>Education is based on a current, evidence-based curriculum.</td>
<td>The ELNEC curriculum resulted from extensive input from expert nurses using best available literature and evidence. The curriculum is continuously updated with revised versions made available to previous participants.</td>
</tr>
<tr>
<td>Adult learning is facilitated by diverse and interactive learning strategies.</td>
<td>The 3-day ELNEC training programme includes about 9 hours of lecture time with the remaining time devoted to interactive activities including case studies, small group discussion, role play, videos, journaling and non-drug labs. The syllabus includes the interactive learning activities and materials to facilitate use in dissemination efforts.</td>
</tr>
<tr>
<td>Professional education in palliative care recognizes the influence of personal experiences and grief.</td>
<td>The consistent experience across all ELNEC courses is that many participants have recent or current personal loss and/or illness experiences. Courses include loss exercises and opportunities for personal reflection and individual support.</td>
</tr>
<tr>
<td>Training programmes acknowledge limited funds are available to educators.</td>
<td>Project funding has been allocated to provide the greatest support to the participants including no cost/minimal cost for course registration, materials and travel support.</td>
</tr>
<tr>
<td>Success in dissemination efforts is dependent upon access to user friendly, efficient teaching resources.</td>
<td>The ELNEC materials consists of a 1000 page syllabus which includes extensive faculty lecture outlines, PowerPoint slides, bibliographical, case studies, resource lists, etc. All material is provided in hard copy and on compact disk.</td>
</tr>
<tr>
<td>ELNEC Connections quarterly newsletter is distributed</td>
<td>Educational projects require methods of reinforcement.</td>
</tr>
<tr>
<td>Interdisciplinary collaboration is important in education efforts.</td>
<td>ELNEC has been designed as a nursing education programme, the investigators have collaborated closely with colleagues in medical education, primarily through the Education on Palliative and End-of-life Care (EPEC) project. The ELNEC curriculum strongly emphasizes interdisciplinary care and has worked collaboratively with other disciplines in regards to EOL education (i.e. medicine, social work, etc.).</td>
</tr>
<tr>
<td>Flexibility and continuous improvement is important for educational programmes.</td>
<td>The ELNEC curriculum is a consistent 'work-in-progress'. Evolution of the project has resulted in separate curriculum and projects for graduate education, pediatrics and oncology.</td>
</tr>
<tr>
<td>Structured evaluation is necessary to insure quality programmes.</td>
<td>Acceptance into an ELNEC course is by competitive selection based on an extensive application. Formal written evaluation at 6 and 12 months documents outcomes.</td>
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</table>
trators and clinical educators are critical to the advancement of palliative care.

The graduate educators have been extremely productive and it has been gratifying to see not only the inclusion of palliative care content within an existing curriculum but also several graduate programmes initiating palliative care specialties within their graduate nursing programmes. A paper has been published based on the follow up of the first 60 graduate nursing programmes represented in the ELNEC graduate training. A very encouraging finding was that the mean hours of EOL content added to the graduate nursing curricula as a result of attending ELNEC graduate courses was a 18.4 (Paice et al, 2006). Graduate faculty members have also reported additional outcomes from attending the ELNEC-graduate training course such as continuing their education through other CE conferences on palliative care, becoming involved in committees or task forces focused on palliative care, and joining a palliative care organization.

Reinforcement efforts
The ELNEC project has included several reinforcement efforts to support the trainers following the courses. This includes: a website; a newsletter; publications; and awards.

Web site: The ELNEC project is described in detail at www.aacn.nche.edu/ELNEC. ELNEC Trainers use the complete list of trainers found on the web site to locate colleagues with whom to consult and partner. Those outside the ELNEC network can also use this list to contact EOL experts as consultants and instructors.

Newsletter: The quarterly newsletter, ELNEC Connections is sent to ELNEC trainers, deans/directors of AACN member schools, various end-of-life agencies and projects, and media representatives. ELNEC Connections provides information on end-of-life care and offers a forum through which the network of ELNEC trainers can stay in contact and share successful education strategies. The newsletter is available online at www.aacn.nche.edu/ELNEC/connections.htm.

Publications: The American Journal of Nursing (AJN), the official journal of the American Nurses Association, launched a bimonthly continuing education series on palliative nursing care that featured the ELNEC project (Ferrell and Coyle, 2002). The series used actual case studies to improve the way nurses care for dying patients. The series can be viewed online at www.aacn.nche.edu/ELNEC/ajn.htm or www.ajnonline.com.

In addition to the actual courses, the investigators have been committed to sharing their experiences through the ELNEC teaching with other colleagues. While conducting these numerous courses over the past 5 years, the investigators have learned much about the importance of educational strategies to best teach the palliative care content. As illustrated in the example course agenda (Figure 1) the investigators use a variety of learning strategies in courses including round table discussions, use of videos, laboratory experiences, as well as lectures. Table 2 includes a summary of the principles of professional education that have applied throughout the ELNEC curriculum. The ELNEC investigators and staff have published a series of articles that have shared experiences in teaching palliative care content across the courses (Matzo et al, 2002; Matzo et al, 2003a; Matzo et al, 2003b; Sherman et al, 2002; Sherman et al, 2003; Sherman et al, 2004a; Sherman et al, 2004b; Sherman et al, 2005)

Awards: Excellence in ELNEC Education Awards are presented to ELNEC trainers who have made particularly noteworthy contributions to ELNEC education.

Evaluation
The ELNEC investigators have been aware since the inception of this project, that having evaluation data is critical to determine the outcomes of this extensive project. The ELNEC evaluation across the courses has consisted of several components. Initially, in the application process, attendees complete a detailed application form and an evaluation of current practice and education in palliative care in their setting. This evaluation tool is organized according to the nine components of the ELNEC curriculum. Prior to attending an ELNEC course, the participants also complete a goal form in which they identify goals they would like to achieve if selected to participate in the ELNEC project.

While attending the ELNEC conference, the attendees complete daily evaluation forms to provide feedback to the faculty and the content presented. These
Evaluation data have been extensively reviewed following each course and the investigators have considered ELNEC to be a constant ‘work in progress’ as the investigators continue to improve the curriculum based on participants’ feedback.

Throughout the course, the participants revise their goals as they become more aware – through their interaction with others and through learning strategies from the faculty for integration of the ELNEC curriculum. The attendees are then sent follow-up evaluation at 6 months and 12 months post-completion of the ELNEC curriculum in order to again rate the effectiveness of their educational programme and to document progress in achieving their goals. These evaluations are conducted by mail or email. A rigorous follow-up process has been accomplished so that the investigators have been able to achieve more than 90% 12-month evaluation across all the courses. This extensive evaluation has been critical to obtaining continued funding for the project and for awareness of the strengths and weaknesses of the programme.

Limitations

The ELNEC project has been a work in progress through a constant process of programme evaluation. The project has been very successful but there have been some limitations. One of the greatest challenges has been to determine the most effective teaching strategies. The investigators have strived to move beyond traditional lecturing to include diverse teaching strategies such as role play, case studies and small group work. The curriculum continues to evolve and the most effective methods are continually sought.

Another challenge had been the limited time available for the conferences. The field of palliative nursing is very complex and it is difficult to cover all of the aspects of palliative care in a short period of time. However, given the nursing shortage and costs to institutions to release nurses for continuing education, time limitations must be adhered to.

Finally, there are many challenges as the course participants attempt to implement ELNEC back in their own work settings. The limited resources, heavy clinical demands and shortage of nurses often make it difficult to implement ELNEC training. The authors have also found it very important to provide ongoing support in the form of the ELNEC website, newsletters and phone support trainers. While enthusiasm is high during the course, the realities of the clinical setting often limit maximum implementation of course goals.

Future plans

The ELNEC project began as an initial effort with priority given to undergraduate educators and second priority of continuing education providers. However, over the past 5 years, the investigators and faculty have been keenly aware of the special needs within the very vast field of nursing. The specialty programmes that have been created for oncology, graduate nursing education, and pediatrics have been extremely successful.

In 2006, the ELNEC investigators hope to launch two additional areas. The first is the area of critical care nursing. The investigators believe that there is an extensive need for addressing EOL care in critical care units, emergency rooms, cardiac care units, and other areas of acute care for critically ill patients and families. The first ELNEC-critical care course is scheduled for implementation in November, 2006.

A second area targeted for the future of ELNEC is the elderly. Geriatric care has been extensively covered in the core curriculum for faculty and CE providers as well as through the graduate educators and oncology projects, but the investigators believe that there are special needs of the older population that should be addressed. Pilot work has begun to develop an ELNEC curriculum specific for the elderly. One of the priority areas targeted for this endeavor will be long-term care settings. The investigators hope to initiate a pilot course of the ELNEC-geriatric curriculum in early 2007.

International implications

Since the inception of the ELNEC project, the investigators have been committed to sharing the resources of the ELNEC curriculum whenever possible. Several guests from outside the USA have attended various ELNEC courses and the investigators have had extensive communication with other nursing colleagues internationally who are interested in palliative care education. One major international dissemination effort
has been the investigator’s collaboration with the St. Jude’s Hospital website (www.CureforKids.org), which has posted a version of the ELNEC pediatric curriculum on this wide-reaching site. Table 3 includes a summary of other international outreach efforts that have been accomplished by ELNEC trainers. The ELNEC investigators are very eager to seek continued activities to collaborate with international colleagues. There are unique aspects within palliative care within various countries and cultures, but many of the basic principles and strategies for improvement are universal. The investigators encourage international colleagues to visit the ELNEC website and to communicate with them regarding ideas for further dissemination of the ELNEC curriculum. Improved EOL care is a universal priority for nurses and international collaboration through the ELNEC project will help achieve that aim.


**Call for papers**

**Special vulnerable populations issue**

Papers are invited for a special edition of IJPN exploring the issue of providing palliative care for vulnerable populations. Authors are welcome to discuss the content of their papers with the editor on (+44) (0)207 501 6714 or email ijpn@markallengroup.com.

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**Key words**
- Nursing education
- Palliative care
- End-of-life care
- Evaluation
- Curriculum development

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