



End-of-life nursing education: Enhancing nurse knowledge and attitudes

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ABSTRACT

Aim: To evaluate the effectiveness of a palliative and end-of-life care nursing education program on nurses' knowledge and attitudes toward caring for patients with advanced serious illness or nearing death.

Background: It is projected that 9 million Americans will be over 85 years old, in the year 2030; many will be living with disabilities and serious medical conditions.

Expanding access to palliative care resources and knowledgeable providers is essential for meeting the future demands required by the aging population.

Methods: A quasi-experimental research design with pre-test and post-test measures was utilized. Potential sample included 134 nurses who participated in a 6-week, 12-hour End-of-Life Nursing Education Consortium (ELNEC) Core Curriculum© educational program. Changes in knowledge were measured using The Palliative Care Quiz for Nursing (PCQN) (n = 61), while changes in attitudes in caring for dying patients were measured using the Thanatophobia Scale (TS) (n = 57).

Results: Results suggest that while post-test PCQN knowledge scores increased significantly (t = -7.498; p = .000), practicing nurses were somewhat lacking in EOL care knowledge answering 13/20 questions correctly before, and 15/20 questions correctly after the educational intervention. Results also indicated that the sample had positive attitudes in caring for this patient population initially, but that attitudes improved significantly post-intervention (t = 3.944; p = .000).

Conclusions: Results support the use of the ELNEC© curriculum for EOL education among this sample, suggesting that educating practicing nurses about EOL is an effective mechanism for both increasing knowledge and improving attitudes. Results also suggest that more education is warranted.

1. Introduction

End-of-Life care is a complex phenomenon, and often the affected patients, as well as the nurses and other team members providing care are not prepared to face the challenging issues involved (AACN¹, 2019). Originally supported by a grant from the Robert Wood Johnson Foundation, researchers from the City of Hope, and the American Association of Colleges of Nursing (AACN) identified gaps in end-of-life and palliative care education within nursing programs. As a result, nationally recognized palliative care experts within the two entities developed the End-of-Life-Nursing-Education-Consortium (ELNEC)© curriculum with extensive input from advisory board members and reviewers. Their goal was to educate current practicing nurses, as well as the future-nursing workforce through education of nursing students (AACN², 2019).

Although the ELNEC curricula has been established for two decades, many nurses in current practice lack the necessary knowledge of related care for this patient population, because they graduated from programs that had not incorporated this content. Furthermore, the current field of palliative care has rapidly advanced to include national clinical practice guidelines for the delivery of evidence-based, high quality palliative care (National Consensus Project, 2018). To this end, the AACN and researchers from the City of Hope (Ferrell, Malloy, Mazanec, & Virani, 2016) recommended competencies and guidelines for educational programs regarding this content area be developed and disseminated (AACN¹, 2019).

Within the United States, the need to educate nurses on the topic of palliative care is urgent. By 2030, it is projected that 9 million Americans will be over 85 years old; many will be living with disabilities and serious medical conditions (National Quality Forum, n.d.).

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Expanding access to palliative care resources and having knowledgeable providers are essential for meeting the future demands required by the aging population. Recommendations by the Institute of Medicine (IOM) report (2015), *Dying in America – Improving Quality and Honoring Individual Preferences near the End of Life*, suggests that all educational institutions should provide palliative care education and that “all clinicians across disciplines and specialties who care for people with advanced illness should be competent in basic palliative care, including communication skills, interprofessional collaboration and symptom management.” Further, the American Nurses Association and the Hospice and Palliative Nurses Association encourage nurses to take leadership to transform and advance this care (*American Nurse Today*, 2017).

Thus, it is desirable to educate nurses about End-of-Life/Palliative care, so that they can render ethically sound, high quality care to people at end-of-life, while maintaining patient dignity, cultural/spiritual needs, symptoms and pain, and then guiding both patient and family through this period of loss, grief, and bereavement (*ELNEC-Core Curriculum*©, 2016).

Responding to the *American Nurses Association's – Call for Action, “Nurses Lead and Transform Palliative Care”* (2017), one school of nursing set out to improve palliative and end-of-life care education for practicing nurses in the local community. The *ELNEC*© (2016) program was offered as continuing education over a six-week timeframe, once in the fall of 2017 and again in the spring of 2018.

The purpose of this study was to evaluate the effectiveness of a palliative and end-of-life care nursing education program on nurses' knowledge and attitudes toward caring for patients with advanced serious illness or nearing death. The research question was:

What is the effect of the End-of-Life Nursing Education Consortium (ELNEC)© Core Curriculum on nurses' palliative and end-of-life care knowledge and attitude toward caring for the dying patient?

2. Methods

2.1. Design

The study utilized a quasi-experimental research design with pre-test and post-test measures. Institutional Review Board approval was attained from the primary institution prior to study implementation.

2.2. Recruitment, participants and setting

A program advertisement flyer was developed by the research team, and distributed to local community clinical agency liaisons for posting within each agency. Agencies included: acute, long term and home care settings. Follow up phone calls to agency liaisons were initiated by the team to answer agency questions, as well as to provide detailed program information.

Participants consisted of a convenience sample of professional registered nurses (RNs) from one county within the state of CT. Inclusion criteria were: a) RN; b) ability to communicate in English; and c) age 21 years or older. All persons meeting inclusion criteria and willing to sign informed consent were invited to voluntarily participate in the study. Those who did not wish to participate in the study but were still interested in attending the ELNEC program were welcomed, however they did not sign consent, nor did they complete pre- or post-test measures. A G-Power analysis was conducted to determine a desired sample size of 27 participants, using a standard power of 0.8, along with an effect size of 0.5, and an alpha equal to 0.05. A large classroom within a school of nursing at a northeastern University served as the study setting.

2.3. Education intervention

The educational intervention was a presentation of the 2016 ELNEC

Core Curriculum©, developed by the City of Hope and the American Association of Colleges of Nursing (AACN¹, 2019; AACN², 2019; *ELNEC-core Curriculum*©, 2016). The program consisted of eight modules: Palliative Nursing Care; Pain Management; Symptom Management; Ethical Issues; Cultural and Spiritual Considerations; Communication; Loss, Grief, and Bereavement; and the Final Hours. This ELNEC curriculum was presented once weekly in the evenings over a period of six consecutive weeks for a total of 12 educational hours. The instructors were certified ELNEC trainers and had expertise in palliative care nursing, and 12 educational contact hours approved by the CT Nurse's Association were awarded to program completers.

2.4. Data collection

One week prior to the start of the ELNEC© program, a research assistant distributed packets to each clinical agency's liaison, who then distributed them to registered participants. Packets included introductory letters describing the study, consent forms, instructions for voluntary pre-test completion, a demographic survey, and two pre-tests: the Palliative Care Quiz for Nursing (PCQN) (Ross, McDonald, & McGuinness, 1996); and the Thanatophobia Scale (TS) (Merrill, Lorimer, Thornby, & Woods, 1998).

Participants were asked to complete packets prior to attending the first ELNEC session without using outside resources to answer pre-test questions, and to bring completed packets to session one. To ensure anonymity, an administrative assistant collected the pre-test packets as participants arrived on-site to attend the first session (week one). At the end of the final on-site session (week six), post-tests (the PCQN and the TS) were distributed to participants, completed in the classroom, and then returned to the ELNEC classroom instructor who was not on the research team. A numeric coding system was utilized to facilitate the collection of de-identified data and to match pre- and post-test data.

2.5. Instruments

The Palliative Care Quiz for Nursing (PCQN) (Ross et al., 1996) was used to measure nurses' palliative care knowledge. The PCQN consists of 20 items that require a true/false/or don't know answer and has demonstrated an internal consistency of 0.78. Scores may range from 0 to 20, with a higher score indicating higher knowledge. The Thanatophobia Scale (TS) (Merrill et al., 1998) was used to measure attitudes toward caring for dying patients. The TS consists of seven items and has a reported Cronbach's alpha of 0.84 at pre-test and 0.85 at post-test (Mason & Ellershaw, 2004). Subjects rate how much they agree or disagree with the statements of negative attitudes toward caring for dying patients using a Likert scale (1–7) for a total final score of a minimum of 7 to a maximum of 49, with higher scores indicating more negative attitudes. Thus, participants with higher scores may experience difficulty in working with dying patients (Blood & Park, 2013).

2.6. Data analysis

Statistical Package for the Social Sciences (SPSS), Version 22 (IBM Corporation, 2013) was utilized for data analysis. Descriptive statistics and frequencies were utilized for demographic data. Paired match *t*-tests were conducted to analyze differences between the means of pre- and post-test scores of the survey items.

Utilizing aggregate data (non-matched), additional correlations were conducted to explore relationships between selected variables, specifically: a) Pre-education intervention: RN age and palliative care knowledge (PCQN), and attitudes toward caring for the dying (TS); b) Pre-education intervention: years of RN work experience and palliative care knowledge (PCQN), and attitudes toward caring for the dying (TS); and c) Post-education intervention: level of knowledge (PCQN) and attitudes toward care for dying patients (TS). Statistical significance (α) was defined as a probability level less than or equal to 5% ($p < .05$).

Table 1
Demographic Data (n = 52 respondents fully completed demographic data).

	n	Mean (years)	%
Age	52	49.34	
Gender:			
Female	49		94%
Male	3		6%
Race:			
White	40		77%
Black	6		11.5%
Hispanic	4		7.7%
Asian	2		3.8%
Highest			
Education:			
Vocational	8		15.4%
BSN	24		46.2%
Master's	17		32.7%
Doctoral	1		1.9%
Other	2		3.8%
Work with terminally ill patients:			
Yes	45		86.5%
No	7		13.5%
Work with palliative care patients:			
Yes	47		90%
No	5		10%

3. Results

While a total of 134 nurses agreed to participate in the study during the data collection period (fall 2017- spring 2018), approximately 46% (n = 61) of the total sample completed both PCQN surveys (pre and post), and approximately 43% (n = 57) completed both TS surveys (pre and post). Participants were predominantly white (77%) females (94%), with a mean age of 49 years. Nearly one half of the group (46.2%) was baccalaureate prepared and approximately one third of the sample (32.7%) had attained masters' level education. The majority of the sample (90%) stated that they used palliative care methods in their current work, and most of the sample (86.5%) worked with patients that were terminally ill (Table 1).

3.1. Effect of education on knowledge and attitudes

3.1.1. PCQN

There was a statistically significant difference from matched pre- to post- PCQN test scores (n = 61) (t = -7.498; p = .000), (Table 2), indicating that participants' knowledge improved post-ELNEC educational intervention. Average pre- test PCQN scores indicated that RNs answered 13/20 questions correctly, increasing to 15/20 answered correctly post-ELNEC session participation.

3.1.2. TS

Similarly, there was a statistically significant difference from matched pre- to post-TS test (n = 57) (t = 3.944; p = .000), (Table 2) concerning attitudes toward caring for patients with serious illness, suggesting improved attitudes. That is, the data suggests that the attitudes became less negative post- ELNEC educational session participation.

Mean pre-session TS scores by question ranged from 1.70–2.25, improving significantly post-session to a range of 1.54–1.92 per

Table 2
Results of PCQN and TS paired samples test.^a

	Df	t	Sig. (2-tailed)
PrePCQN-PostPCQN	60	-7.498	0.000
PreTS-PostTS	56	3.944	0.000

^a (PCQN n = 61; TS n = 57).

question and an overall TS improved score from pre- (14.92) to post- (11.97) sessions (Table 3).

3.2. Additional exploratory correlations

For this sample, using aggregate data, there was no significant correlation between RN age or years of work experience and the total pre-education intervention level of knowledge: Pre-test PCQN score (age: r = -0.005; p = .968; years of experience: r = -0.017; p = .888) (Table 4). Nor was there a significant relationship pre-education intervention between RN age or years of nurse work experience and the pre- test TS score (age: r = -0.177; p = .162; years of experience: r = -0.056; p = .661) (Table 5).

However, a correlation analysis conducted between level of knowledge (post-test PCQN score) and attitude toward caring for dying patients (post-test TS score) after attending ELNEC sessions (n = 112) suggested there was a weak but significant relationship found between the two (r = -0.290; p = .002) (Table 6).

4. Discussion

While more than 80% of the participants stated that they used palliative care methods and cared for the terminally ill in their current work, mean pre-test PCQN scores indicated that this sample lacked knowledge in the care that they were currently providing. That is, among the 61 matched pairs, the mean pre-PCQN score was 12.6, or participants answered approximately 13 out of 20 questions correctly (the equivalent of scoring 65% if scores were based on 100 points), about the care of dying patients, prior to receiving the educational intervention. This finding suggests that although this sample of nurses was providing care for those with serious illnesses or for those who were dying, ongoing education in this area may be warranted for nurses in similar settings despite their current work experience. There was a significant improvement in PCQN scores post-education, which was not an unexpected finding. However, although improved post-PCQN scores supported the use of the ELNEC program for enhancing knowledge in this sample, these scores too were somewhat lower than anticipated, with a mean of 15 of 20 questions answered correctly (the equivalent of a 75% if scores were based on 100 points). Educators did not "teach to the PCQN test," but rather, used the standardized ELNEC core materials that they were trained and certified to use.

Therefore, findings related to lower grades may simply be a result of information on the PCQN not being included in the ELNEC content. Regardless, it is still notable that in this sample, caregivers of dying patients scored only low to average grades on an exam about the same.

In review of the TS pre test results, participants reported positive attitudes about caring for dying patients. With a possible range of scores of 1–7 for each question on the TS, and lower scores indicating more positive attitudes, mean pre- TS scores ranged on the lower end of the scale: 1.70 to 2.25 per question. This range, although already low, improved significantly post-education, with a range of 1.54–1.92 per question (Table 3). Further, the TS overall mean scores also improved from pre- (14.92) to post- (11.97) test, with a minimal possible score of 7, and a maximum possible score of 49. This finding suggests that nurses who attended the ELNEC program already had favorable attitudes about caring for those at end-of-life but were seeking education regardless.

However, the improved post-education TS scores in the current study differ from results found in a prior study conducted with undergraduate medical students (Sweeney et al., 2014), where no difference in TS scores was found pre- to post- educational sessions. Sweeney and colleagues did not use the ELNEC Core Curriculum® to educate the students, but rather presented 12 weekly, 2-hour sessions with content selected by the researchers to compliment a previously existing European Association of Palliative Care core curriculum (Sweeney et al.). The different findings regarding attitude change may be a result of the

Table 3
TS mean scores by question (n = 57).

	Mean pre score	Mean post score
Dying patients make me feel uneasy	2.22	1.92
I feel pretty helpless when I have terminal patients on my ward	2.25	1.72
It is frustrating to have to continue talking with relatives of patients who are not going to get better	1.97	1.66
Managing dying patients traumatizes me	1.70	1.54
It makes me uncomfortable when a dying patient wants to say goodbye to me	2.07	1.75
I don't look forward to being the personal nurse of a dying patient	2.03	1.72
When patients begin to discuss death, I feel uncomfortable	2.19	1.66
	Total pre score	Total post score
	14.92	11.97

Table 4
Correlation results between total pre-PCQN score and age and years of experience using aggregate data.

	n	r	Sig.(2-tailed)
Age	68	-0.005	0.968
Years of experience	67	-0.017	0.888

Table 5
Correlation results between total pre-TS score and age and years of experience using aggregate data.

	n	r	Sig. (2-tailed)
Age	64	-0.177	0.162
Years of experience	63	-0.056	0.661

Table 6
Correlation results between post-PCQN and post-TS scores, using aggregate data.

	n	r	Sig. (2-tailed)
Relationship between post PCQN and post TS scores	112	-0.290	0.002

different composition of participants: seasoned registered nurses (RNs) versus medical students or from the different educational intervention used.

Also, in the current study, there was a statistically significant finding, albeit a weak relationship, between level of knowledge after nurses participated in the ELNEC program, and their attitudes toward caring for the dying ($r = -0.290$; $p = .002$). This relationship between knowledge and attitudes suggests that using current evidence based holistic curriculum focused on the care required for this client population and their families, may in fact, help nurses to improve attitudes that they may harbor as a result of knowledge deficits.

In the current study, PCQN and TS findings can be compared to findings in a study conducted by Wilson, Avalos, and Dowling (2016). Wilson and colleagues utilized a cross-sectional research design and used the PCQN and TS to survey nurses working with patients in seven older person care centers (community hospitals and nursing homes). The researchers analyzed various factors related to three different types of palliative care education, setting, knowledge, and attitudes. Participants self reported the type of palliative care education they had undergone (if any), and then completed the instruments. There is no mention as to whether or not any of the research participants used the ELNEC Core Curriculum. However, many participants attained the European Certificate in Essential Palliative Care (ECEPC). The researchers reported a mean (SD) PCQN score of 11.8, with a range of scores from 5 to 18, and suggested scores indicated that nearly half of the participants had a moderate level of palliative care knowledge. Wilson and colleagues found no significant correlation between nurse's

age and PCQN score, which was similar to the exploratory results in the current study (See Table 4). In contrast to the results of Wilson and colleagues, exploratory results in the current study did not find that increased years as a registered nurse significantly improved knowledge and attitudes toward care for the dying (See Tables 4 and 5). For the current sample of nurses, this result supports the dire need for continuing education on the topics of palliative and end-of-life care, as education in this field has rapidly expanded.

Furthermore, Wilson et al. (2016) found no significant difference on the PCQN between those who had some form of palliative care education, versus those who had no education. However, participants that attained the European Certificate in Essential Palliative Care (ECEPC) education scored higher on the PCQN (Wilson et al., 2016). This finding supports recommending more extensive education, such as ECEPC or ELNEC, as the national evidence based curricula appears to provide more thorough learning than other types of education, such as informal short education sessions and in-services.

Lastly, Wilson et al. (2016) report a moderate negative correlation between total PCQN and TS scores, suggesting similarly to the current study, that as palliative care knowledge increased, so too did positive attitudes toward caring for dying patients. Findings in the current study are important because they suggest that given a sample of experienced nurses, positive attitudes and working with a particular patient population (acute, long term, and home care) do not necessarily indicate sufficient care- knowledge or best practices in palliative care and end-of-life care. It supports the need to assess levels of nurse knowledge, and to provide ongoing education as needed to ensure continued high quality care.

5. Limitations

Study limitations include the use of a fairly homogeneous, convenience sample of nurse participants, making it difficult to generalize findings to a larger population.

Limitations also include using a variety of participant care settings (acute, long term, and home care). While these limitations exist, the research team did not wish to exclude nurses from the program offering; the goal was to reach as many area nurses as possible given the known value of the ELNEC program.

Additionally, because pre-tests were distributed and completed outside of the research team's view, it is possible the participants used resources to answer the pretest questions. If this occurred, then it could have resulted in higher pre-test scores, however this is an unknown. It is important to note that the post-tests were distributed and completed on-site with the ELNEC instructor present, thus, participants answered questions from their own knowledge.

Lastly, while a relationship was found between knowledge and attitudes, researchers cannot conclude that this was a cause/effect relationship merely that a weak relationship existed.

6. Future research

Although study findings suggest a relationship between knowledge and attitudes, future research should focus on measuring the actual effect of one on the other, through regression analysis. Additionally, to further the body of knowledge, the literature would benefit from studies that measure actual practice change, specific to practice area (acute, long term, or home care), as a result of participating in a program that enhances knowledge and/or attitudes. It would be beneficial to survey nurses about the type of education they would most prefer in the areas of palliative and/or end-of-life care, so that particular teaching pedagogies and presentation formats can be used. For example, simulation use and role-play may be more effective for certain topics, rather than other modalities when attempting to enhance knowledge and attitudes on end-of-life and palliative care.

7. Conclusion

End-of-life care is a complex phenomenon, often leaving patients, families and providers in a wake of uncertainty and ill-preparedness surrounding this difficult topic (AACN², 2019; IOM, 2014). Lack of related education in nursing programs, coupled with the critical need for health care providers to understand and offer high quality, cost effective care to those with serious illnesses and/or at end-of-life has resulted in a number of strong national initiatives. Offering local palliative and end-of-life care continuing education modules is one way to bridge the palliative care knowledge gap for practicing nurses, and the ELNEC Core Curricula[©] was an effective program to educate current nurses in practice, spanning the continuum of healthcare settings.

References

American Association of Colleges of Nursing (AACN)1 (updated 1/2019). ELNEC fact sheet. Retrieved from <https://www.aacnnursing.org/Portals/42/ELNEC/PDF/FactSheet.pdf>.

- American Association of Colleges of Nursing (AACN)2 (2019). About ELNEC. Retrieved from <https://www.aacnnursing.org/ELNEC/About>.
- American Nurse Today (2017). Calling for all nurses to lead and transform palliative care. 12, 5. Retrieved from <https://www.americannursetoday.com/call-for-action-nurses-lead-and-transform-palliative-care>.
- American Nurses Association (2017). Call for action: Nurses lead and transform palliative care. Retrieved from <https://www.nursingworld.org/~497158/globalassets/practiceandpolicy/health-policy/palliativecareprofessionalissuespanelcallforaction.pdf>.
- Blood, A., & Park, Y. (2013). Critical synthesis package: Thanatophobia Scale. *MedEdPORTAL*, 9, 9629. <https://doi.org/10.15766/mep.2374-8265.9629>. Retrieved from <https://www.mededportal.org/publication/9629/>.
- End of Life Nursing Education Consortium (ELNEC)-Core Curriculum © COH & AACN, 2007, revised January 2016.
- Ferrell, B., Malloy, P., Mazanec, P., & Virani, R. (2016). CARES: AACN's new competencies and recommendations for educating undergraduate nursing students to improve palliative care. *Journal of Professional Nursing*, 32(5), 327–333 (IBM Corp. Released 2013. IBM SPSS Statistics for Windows, Version 22.0. Armonk, NY: IBM Corp).
- Institute of Medicine (2014). Committee on approaching death: Addressing key end of life issues. Dying in America: Improving quality and honoring individual preferences near the end of life. Washington (DC): National Academies Press (US). Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK285681/>.
- Mason, S., & Ellershaw, J. (2004). Assessing undergraduate palliative care education: Validity and reliability of two scales examining perceived efficacy and outcome expectancies in palliative care. *Medical Education*, 38(10), 1103–1110. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/15461656>.
- Merrill, J., Lorimer, R., Thornby, J., & Woods, A. (1998). Caring for the terminally ill persons: Comparative analysis of attitudes (thanatophobia) of practising physicians, student nurses and medical students. *Psychological Reports*, 83, 123–128.
- National Consensus Project for Quality Palliative Care (2018). *Clinical practice guidelines for quality palliative care* (4th ed.). Richmond, VA: National Coalition for Hospice and Palliative Care. Retrieved from <https://www.nationalcoalitionhpc.org/ncp>.
- National Quality Forum. *NQP advanced illness care*. (1996). Retrieved from http://www.qualityforum.org/Projects/n-r/NQP_Advanced_Illness_Care/NQP_Advanced_Illness_Care.aspx (n.d.).
- Ross, M., McDonald, B., & McGuinness, J. (1996). The palliative care quiz for nursing (PCQN): The development of an instrument to measure nurses' knowledge of palliative care. *Journal of Advanced Nursing*, 23(1), 126–137.
- Sweeney, C., Lynch, G., Khashan, A., Maher, B., Murphy, M., & O'Brien, T. (2014). The impact of a medical undergraduate student-selected module in palliative care. *BMJ Supportive & Palliative Care*, 4, 92–97.
- Wilson, O., Avalos, G., & Dowling, M. (2016). Knowledge of palliative care and attitudes towards nursing the dying patient. *British Journal of Nursing*, 25(11), 600–605.