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## Undergraduate Nursing Students' Perception of End-of-Life Care Education Placement in the Nursing Curriculum

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### Abstract

Nursing students, who have been receiving the End-of-Life Nursing Education Consortium (ELNEC) Core training throughout their Bachelor of Science in Nursing program, have a unique perspective of the benefits of this training. In addition, they have insight as to where an online ELNEC module series specifically for undergraduate nursing students would best be integrated within the curriculum. This study used a mixed methods strategy to evaluate students' opinions on the placement of end-of-life care education within the curriculum and their experience of having received ELNEC training previously throughout their program. Senior-level nursing student opinions on the placement of the ELNEC modules within the curriculum were equally divided, with one-third suggesting placement at the sophomore level, one-third suggesting placement at the junior level, and one-third suggesting placement at the senior level. Students also offered a recommendation for an end-of-life care simulation integration into the Bachelor of Science in Nursing curriculum. Students who have been receiving ELNEC training integrated throughout the curriculum reported feeling comfortable with providing end-of-life care after graduation. Themes extracted from students' suggestions on improving end-of-life care education were as follows: (1) The quality and consistency of instruction needs to be enhanced, (2) palliative care education should be delivered using various methods, and (3) methods to assess education on palliative care should be improved. Students reported that ELNEC training helped them to gain insight into the key elements in palliative care, to understand the differences and similarities between palliative care and hospice, and to understand the nurse's role in palliative care and hospice.

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## Keywords

BSN nursing program; end-of-life care; End-of-Life Nursing Education Consortium (ELNEC); hospice; palliative care

A small percentage of persons with advanced disease die at home. Although studies show that most of these patients, who die at home, would prefer to die at home rather than in institutions,<sup>1-4</sup> one of the biggest barriers to honoring this preference has been lack of access to palliative care at home and lack of nursing knowledge to help patients during the transition period.<sup>2</sup> Studies indicate that nurses play a significant role in hospice and palliative care; however, their perception, as well as the perception of the community being served, is that they are not well prepared. Many nurses experience reduced comfort levels and negative attitudes toward providing care for patients and their families at the end of life.<sup>5-7</sup> Studies identify a lack of end-of-life care knowledge and skills among both newly graduated and student nurses.<sup>8,9</sup> This could be related to lack of formal exposure to end-of-life education during their Bachelor of Science in Nursing (BSN) programs.<sup>10</sup> Jensen-Seaman and Hebert<sup>11</sup> surveyed 101 nurse practitioner students from programs around the United States and found that many BSN programs provide very little instruction on end-of-life care, with only a few hours dedicated to palliative care.

Data collected in 2016 from the American Association of Colleges of Nursing showed that only 615 000 of the nearly 3 million registered nurses in the United States have completed End-of-Life Nursing Education Consortium (ELNEC) training.<sup>12</sup> From a regional perspective, the availability of end-of-life care education is mostly limited to Western Europe, North America, and Australia/New Zealand.<sup>13</sup> End-of-life care education is urgently needed within low-andmiddle-income countries where education on end-of-life care is lagging, which means that end-of-life care education desperately needs an improved dissemination plan.

Understanding end-of-life care and the placement of it within the curriculum in BSN programs is vital for improving care of the dying patient.<sup>14</sup> Whether students should be exposed to end-of-life content at an earlier or later stage of their nursing programs and into which course palliative care content should be integrated remain unclear. It has been suggested that this content be taught at a later/advanced stage, such as senior level courses where students may have background knowledge that facilitates their learning about end-of-life care.<sup>14</sup> On the other hand, earlier exposure to end-of-life care education might enhance students' understanding of the principles of palliative care and prevent them from developing misconceptions during early clinical exposure.<sup>15</sup> In addition to the different stages for placement, various offerings are related to the integration of end-of-life content into different courses, especially simulation content. Studies on this issue are based on the educator's perspective, with limited studies from the student's perspective. The student's perspective can provide a unique insight into their perception of the most appropriate placement for EOL care education.

Although the placement of end-of-life care education is important, the evaluation of teaching also becomes part of the teaching-learning process. Most of the studies used researcher-

generated instruments to evaluate certain aspects of learning, such as the Frommelt Attitude Toward Care of the Dying to evaluate students' attitudes<sup>16</sup> and the Palliative Care Quiz for Nursing to assess students' palliative care knowledge.<sup>17,18</sup> However, seldom has in-depth qualitative research been used for evaluation. The limited number of qualitative studies means that little is known about the education experiences of BSN students. The purpose of this study was to (1) report students' perception of the best placement for an online series of ELNEC modules specifically designed for undergraduate nursing students and (2) evaluate the students' experience and perception of their current education on end-of-life care, using qualitative methods to set the stage for future evaluation studies.

## METHODS

### ELNEC Integration Across the Curriculum

West Virginia University School of Nursing began to integrate the ELNEC Core curriculum into undergraduate nursing courses in 2010, with a module presented in 8 different courses throughout the program. The ELNEC Core curriculum includes 8 learning modules covering the following content: (1) overview of palliative care, (2) pain management, (3) symptom management, (4) ethical consideration, (5) cultural considerations, (6) communication, (7) grief, and (8) final hours. The modules were broken down with module 1 (overview of palliative care) being presented at the sophomore level, modules 2 and 3 (pain and symptom management) being presented at the junior level, and modules 4 to 8 (ethical considerations, cultural considerations, communication, grief, and final hours) being presented at the senior level. In addition, an elective course was developed, which allowed students who wanted to learn more about palliative care to gain additional knowledge. The elective course provided 2 credits for students to obtain knowledge of their role as a nurse working with palliative care. The course was completed online, which allowed students from other campuses to complete the elective course. The elective course was available for any level of nursing student. During the ELNEC integration, students were provided with the ELNEC notes in advance of the class meeting and were given time to listen and take notes during the education. Furthermore, ELNEC-trained faculty, who had experience in palliative care and were educated as ELNEC trainers, provided the education that used the ELNEC Core curriculum.

Nursing students who received all 8 modules of ELNEC Core training throughout their curriculum were asked for their opinions of the placement for the new online series of modules. Students were also asked about their perception of their education and for suggestions regarding other end-of-life care education. This study is a teaching evaluation that used mixed research strategies incorporating both quantitative and qualitative measures.

### Ethical Considerations

The study was approved by the institutional review board. Participation was voluntary. The survey process was anonymous, with all senior level students invited to participate. Student participation in completing the survey did not impact their course grade.

## Instruments

A 12-question survey was developed by nursing faculty who provided education using the ELNEC curriculum; the survey was also reviewed by a member of the ELNEC leadership team. The first part of the survey consisted of 6 questions regarding sociodemographic information (age, nursing program, program starting and finishing years) and 6 questions regarding experience in end-of-life care education (Table). The 5-point Likert scale responses were recoded into 3 categories describing the comfort levels ranging from “average” to “excellent” and 5 categories describing how useful integrating an end-of-life care simulation experience into the prelicensure program would be ranging from “definitely useless” to “definitely useful.” The second part of the survey consisted of 3 open-ended questions regarding students’ perspectives on end-of-life care education.

## Data Analysis

SPSS 22.0 was used to analyze the quantitative data. Because of a small sample size, nonparametric Mann-Whitney *U* test was used to compare the comfort level between 2 groups. Content analysis was used to analyze the quantitative data. Investigators first read through the data to gain an overall sense of the perceptions and identify initial categories. Two investigators independently coded each transcript using NVivo software (QSR International Pty Ltd, 2008) with initial priori codes defined. Additional codes were added as they emerged. The coders agreed in more than 90% of cases; any discrepancies were resolved through consensus. The research team determined and agreed upon final themes and subthemes through an iterative process.

## FINDINGS

### Demographics

Thirty-seven students participated in the survey (response rate, 46.3%) (Table). Of those who participated in the survey, 23 responded to the open-ended question related to students’ suggestion (response rate, 62.2%). Participants ranged in age from 18 to 25 years, with a mean (SD) age of 20.77 (5.9) years. Of all the participants, 11 students started nursing school before 2015, 12 students started from 2015, and 7 students started from 2016. Most of the students will graduate from nursing school in 2018 (86.5%), and 13.5% of them had graduated in 2017. All students were seniors at the time of survey completion and from BSN programs.

### Participants’ Opinion of Placement

Regarding opinion of placement, 92% of students heard of the ELNEC curriculum before completing the survey and 100% reported that they gained valuable knowledge from the integration of end-of-life care education in the curriculum (Table). Furthermore, 43.2% of students have not witnessed a death, and no students reported that they felt “bad” or “terrible” with providing palliative care for patients after graduation; all students felt excellent, good, or at least average. More than half of the students (54.1%) supported integrating a simulation focused on end-of-life care into the curriculum. Given the small sample size, Mann-Whitney *U* test was used to compare students’ comfort level with

providing palliative care by having witnessed a death or not; because *P* value was greater than .05, no statistically significant difference was found, which may be partly attributed to the small sample size. The students had received the ELNEC Core modules integrated throughout the 4 years of education. Students were asked their opinions on the placement of the new ELNEC for undergraduate nursing students' curriculum. Their responses for placement of this online curriculum were nearly evenly distributed regarding preference for sophomore, junior, and senior. In students' opinions, every level is suitable for the ELNEC curriculum placement from junior to senior level.

**Students' Suggestions for Integration of Palliative Care Simulation**—The open-ended questions were analyzed by content analysis. Twenty-six students responded to the question regarding into which course a palliative care simulation should be integrated. Students suggested a variety of 7 different courses; 61.5% recommended that palliative care simulation be integrated into the medical-surgical course, 15.4% suggested pediatrics, 7.7% suggested the community course, and 15.4% recommended the geriatric and other courses. Students make suggestions based on their learning experience, and the courses proposed by students are closely related to palliative care in terms of core content.

**Students' Suggestions for Improving Palliative Care Education**—Three themes were extracted from 23 students' suggestions on improving palliative care education: (1) The quality of instruction techniques needs to be improved, (2) the palliative care education should be delivered in various ways from different perspectives, and (3) methods to assess student learning on palliative care should be enhanced. Students valued the quality of instruction and suggested that different teaching methods and delivery for the content be implemented.

**Students' Suggestions Regarding Quality of Instruction**—Four subthemes were extracted from open-ended question answers under this theme, including (1) real-world experience; (2) elaboration; (3) being interactive and flexible; and different, timely education on relevant topics. Simulation laboratory and real clinic exposure is recommended by students as the optimal method to obtain experience in real-life palliative care struggles. In addition to clinic exposure, students suggested using interactive teaching methods to supplement the lecture, "such as a case study or group work as a good addition to just lecture" (S12) and "use some methods to make the lecture more interactive and more flexible and interesting" (S18). Some students hope to get some different knowledge through this course, such as "get some different and timely mannered knowledge as soon as patients with diseases such as Chronic Obstructive Pulmonary Disease (COPD) are diagnosed" (S21). From this theme, students expressed their desire for interactive, flexible, and practical knowledge, especially through clinical exposure experience.

**Students' Suggestions for Delivery of Palliative Care Education**—Within this theme, suggestions focused on 2 subthemes: teaching format and curriculum pattern. Some students suggested the course be implemented online: "An online class for palliative care would be great" (S19). Others prefer face-to-face teaching: "Face-to-Face lecture on palliative care modules rather than modules uploaded to SOLE, would make students to take

palliative care more seriously” (S07). On curriculum pattern, some students suggested the ELNEC be a unique course. However, more of them think the content of palliative care should be incorporated into other courses: “I think it is important for the faculty to incorporate palliative care into each lesson that they teach instead of making it a separate lesson” (S3). Although the opinions are not necessarily the same, it can be seen that the students desire to see enhanced teaching delivery paths.

**Methods to Assess Education on Palliative Care**—Students also thought that evaluation of learning was an important component of successful delivery of the content. Codes to construct this theme included “test,” “assignment,” and “bonus points.” Students’ suggestions on teaching evaluation include “be tested on the material” (S22), “including the palliative care on a class assignment” (S18), and “extra points for assignments completed to get bonus points” (S14). Suggestions showed that students value teaching evaluation of learning.

### **Palliative Care Points Remembered by Students**

Three themes were extracted from students’ experiences from their program: (1) get the key elements in palliative care, (2) understand the difference between palliative care and hospice, and (3) understand nurses’ role in palliative care and hospice.

The most frequent theme is “get the key elements of palliative care;” mentioned by 68.2% of the students. Four subthemes emerged as ingredients of “key elements” of palliative care, including comfort, support and accompaniment, symptom management, and sympathy. These key elements relate to the main content of the 8 core modules. In all the answers, the word “comfort” was mentioned most, by 65.2% of the respondents. Students mentioned misconceptions between the terms “palliative care” and “hospice,” which existed before receiving education; however, after the ELNEC course, 43.5% of the students’ narratives show they understand the difference between the terminologies. They mentioned the ability to distinguish between concepts at the beginning moment of diagnosis (S21), in the treatment of symptoms (S19), and in understanding myths and facts of both (S8).

Cases and experiences of faculty were presented often during in-person education on end-of-life care, which brought students numerous opportunities to experience the responsibility and role of a nurse in palliative care. For example, “It is a nurse’s responsibility to contact hospice on behalf of patients who are terminal and do not want to die in the hospital” (S12).

“Unlike other healthcare professionals, nurses have the unique opportunity to spend time at the patient’s bedside and be able to know the patient and family’s goals of care, so nursing care in palliative care is important” (S4). Students believe what they gained most was knowledge, as well as the recognition of the nurse’s role. What impressed the students most was the ability to distinguish the difference between the terminologies.

## **DISCUSSION**

Studies have shown that students’ attitude toward death and dying can be improved through education.<sup>19,20</sup> Without pretest data, it cannot be claimed that students’ comfort for



providing palliative care came primarily from students' learning within the nursing program. Given the potential hidden value of students' clinical encounters and of the interaction with faculty, this is a reasonable hypothesis. Additional studies are needed to explore this further, and the only way to do this conclusively would be through a randomized controlled trial. Analysis of quantitative data indicated that the improvement can also be linked to knowledge and understanding the role of the nurse in palliative care, which is consistent with other studies.<sup>21,22</sup>

Students also mentioned that a key issue addressed through their education is the need to learn clear terminology and clarified the difference between "palliative care" and "hospice." Unclear terminology is often used interchangeably within practice and literature, even within policy and service developments.<sup>22</sup> Lack of clear terminology and the inconsistent interchangeable use of terms can pose challenges to nurse educators and students and therefore have an impact on service delivery.<sup>15</sup> For curriculum developers and students, ambiguity in terminology requires attention.

Although variations may exist between students in different stages of their programs,<sup>14</sup> this does not mean earlier levels are not suitable for end-of-life education. Students in this study believed that every stage is suitable for learning, with the exception for the freshman level. Students believed that freshmen have not yet started the actual nursing courses and this could lead to poor understanding of their role as future nurses in palliative care. Because of the heavy work burden of advanced level nursing courses, some students recommend placement of this course in the earlier stage. Many of the studies reviewed for this project involved nursing students in an advanced stage of their programs,<sup>14,23–25</sup> with a small number at an earlier stage.<sup>26</sup> However, positive changes in attitude and experience were shown in both earlier and advanced stages.<sup>14,23–26</sup> This positive change across levels may occur because general nursing principles have something in common with palliative/end-of-life care, a commonality that could help students in earlier stages understand the nursing measures for palliative care.<sup>24</sup>

Studies suggest that decisions about which stage to include end-of-life education at the BSN level should be informed by students' previous knowledge, preparation, and clinical practice exposure.<sup>14</sup> A constructivist educational model and reflective teaching methods were recommended for earlier-stage students.<sup>26</sup> Additional studies are needed to determine rationale for placement of the ELNEC content at the different levels of nursing programs.

Students suggested in this study that clinical exposure was an important part of their learning process with end-of-life care education. Clinical exposure can enhance students' understanding of their future work and enable them to care more effectively for dying patients.<sup>27</sup> However, limited clinical placement on specialist units, large numbers of students, and short lengths of stay may negatively impact the opportunities for clinical experiences in real patient care situations.<sup>28</sup> Literature revealed that clinical simulation is a suitable pedagogical method to replace or supplement real clinical encounters, with positive effects on awareness, knowledge acquisition, communication skills, self-confidence, and level of engagement, as well as student reliability and satisfaction.<sup>29–33</sup> Therefore,

incorporating simulation into the nursing curriculum is better than classroom instruction only, especially when clinical resources are sparse.

Studies identified a need for improved end-of-life care education throughout the nursing curricula, which may best be accomplished through program integration because it incorporates essential content without adding to already extensive nursing curricula.<sup>14,34</sup> The simulation experience can also be integrated into standard nursing curricula. Palliative care simulation is suggested to be integrated into courses related to the core content of palliative care, such as symptom management, medication, and the target groups of palliative care, including the elderly and long-term chronic disease patients.<sup>35</sup> This may support the rationale for students suggesting medical-surgical, community health and geriatric courses in this study. As other studies demonstrate, most research regarding palliative care teaching focuses on the adult population. More research is needed for age-specific palliative care education, specifically related to the pediatric population.<sup>15,36</sup> Placement of pediatric-specific ELNEC content into the curriculum is also a recommendation from students in this study. It is suggested that the integration of end-of-life care content require focused curriculum planning to ensure that there is clarity and cohesion in the delivery of content and to minimize gaps and overlaps.<sup>23</sup>

Besides clinic exposure, students made note of the importance of having a content delivery method that is interactive and flexible and that involves the application of different teaching strategies. Film observation, simulation experiences, companion programs, specific assigned readings, role playing, and journaling/writing for reflection provide students with opportunities to integrate knowledge and promote meaningful palliative care learning experiences.<sup>14</sup> Findings suggest that teaching strategies, whether independently or in combination, regarding palliative/end-of-life care seem to have a positive effect on student attitudes, knowledge, self-confidence, and awareness/appreciation.<sup>14,19,23,24,37</sup> However, there was no clear indication of which strategy is most effective; more research on teaching strategies is valuable to provide more clues to future teaching.

Students also offered ideas about the combination of formative assessment and summative assessment and the development of evaluation instruments. Lippe et al<sup>38</sup> suggest that teaching evaluation extends to educational outcomes of self-efficacy, comfort level, and knowledge related to therapeutic communication with the dying patient and caregivers and among the interprofessional teams. Within the literature, there is an increasing emphasis on service user and career involvement in learning and teaching<sup>38</sup>; patients and their family, the interdisciplinary teaching team, and students should be empowered to have access to evaluation of end-of-life care education.

## LIMITATIONS

The limited sample size and the homogeneity of the sample (sample all came from the same academic institution) may preclude generalization of the findings to all baccalaureate nursing students. Participating in the teaching evaluation was also voluntary; although there were 80 students in the class, only 37 students participated in the closed-ended question assessment and 23 completed the open-ended question assessment.



Information from the qualitative material is limited, and in-depth research is needed to explain the reason for placement. Because this study was descriptive in design without long-term follow-up, it is not known whether the knowledge gained from the ELNEC integration across the curriculum will be retained as nurses graduate and move into their professional roles.

## IMPLICATIONS

This study adds to the current literature regarding student perceptions of end-of-life care education placement within the BSN program. This study supports the use of the ELNEC curriculum as an effective way to educate nursing students. The study does not clearly support one level over another for the placement of the content within the BSN curriculum. The study also supports the use of an online, consistent, and interactive method for delivery of the ELNEC content. The use of the new ELNEC for undergraduate nursing students online program through Relias, which is an online platform for education delivery, can help to streamline education on end-of-life care while also opening areas within the curriculum to place simulation experiences and other clinical engagement opportunities. Future research is needed whereby students from different schools of nursing are compared to each other to identify transferability of the findings. Furthermore, additional studies will need to be conducted assessing students' perceptions before and after taking the online ELNEC modules for undergraduate nursing.

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**TABLE**

## 37 Students' Experience in End-of-Life Care Education

Question		Count	%
1. Have heard of the ELNEC curriculum before class?	Yes	34	91.9
	No	3	8.1
2. Did you gain valuable knowledge from receiving ELNEC throughout your curriculum?	Yes	37	100.0
	No	0	0
3. Comfort level with providing palliative care for patients after graduation	Excellent	5	13.5
	Good	23	62.2
	Average	9	24.3
4. What are your feelings regarding integrating an end-of-life care simulation experience into the prelicensure program?	Definitely useful	10	27.0
	Probably useful	10	27.0
	Might or might no	11	29.7
	Probably useless	5	13.5
	Definitely useless	1	2.7
5. Which level do you recommend ELNEC be placed?	Sophomore	12	32.4
	Junior	12	32.4
	Senior	13	35.1
6. Have witnessed a death	Yes	21	56.8
	No	16	43.2

Abbreviation: ELNEC, End-of-Life Nursing Education Consortium.