Fall 12-12-2017

Nursing Students’ Knowledge and Attitudes Toward Care of the Dying

Betsy N. Ward
Kennesaw State University

Elizabeth Nora Ward
Wellstar School of Nursing

Follow this and additional works at: http://digitalcommons.kennesaw.edu/dns_etd

Part of the Educational Assessment, Evaluation, and Research Commons, Educational Methods Commons, Higher Education Commons, and the Social and Philosophical Foundations of Education Commons

Recommended Citation
Ward, Betsy N. and Ward, Elizabeth Nora, "Nursing Students' Knowledge and Attitudes Toward Care of the Dying" (2017). Doctorate of Nursing Science Dissertations. 5.
http://digitalcommons.kennesaw.edu/dns_etd/5

This Dissertation is brought to you for free and open access by the Wellstar School of Nursing at DigitalCommons@Kennesaw State University. It has been accepted for inclusion in Doctorate of Nursing Science Dissertations by an authorized administrator of DigitalCommons@Kennesaw State University. For more information, please contact digitalcommons@kennesaw.edu.
Nursing Students’ Knowledge and Attitudes Toward Care of the Dying

By

Elizabeth N. Ward

A Dissertation Submitted in Partial Fulfillment of the Requirements for the Degree of

Doctor of Nursing Science

Wellstar School of Nursing

College of Health and Human Service

Kennesaw State University

December, 2017
Acknowledgements

I am immensely grateful for my family and friends, whose faith in me were priceless. My husband’s loving care and steady support carried me when I felt inert. My son’s reassuring words affirmed me when I was doubtful. My dear friends Dr. and Mrs. James Thompkins never ceased to believe and expect the best from me; Joanne Council walked for hours with me, listening patiently about every chapter; Debbie Phillips heard me vent but never me let me give up. Dr. Tommie Nelms was gracious, patient, and meticulous with words for qualitative research. Dr. Lois Robley was generous with her wisdom and expertise in care of the dying. Dr. Linda Johnston was remarkable with her eagle eye for detail, which stretched my frame of reference for thoroughness down to the space between the period and the page numbers. Dr. Patricia Hart was kind to help me sort the data for quantitative formulas and masterful with table construction. Drs. Judith Hold and Barbara Blake were model educators who helped to facilitate my work. I am also grateful to Dr. Genie Dorman, who was there with me from the start and to the very end.

Finally, I acknowledge that this work was inspired by the life and death of many loved ones or patients and sustained by the belief in an Almighty and ineffable God, who gives meaning to earthly life and provides eternal rest for the soul in the realm of a spiritual existence. May that Spirit always guide me while still on earth until entering eternity through death.
KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING

Abstract

Most nursing students fear death or care of the dying and thus question their abilities to give compassionate and competent care to patients or families at end-of-life (EOL). Research has shown positive results when students have experiences with dying patients in environments where interdisciplinary palliative and end-of-life practices are delivered. The purpose of this mixed methods comparative group study was to assess BSN students’ knowledge and attitudes toward care of the dying guided by Bandura’s social cognitive theory, which addresses learning under difficult circumstances. Nursing students in a palliative and end-of-life care elective course were compared to students in the required senior clinical practicum course. In addition to learning about EOL nursing care, students in the elective course were required to spend ten hours “being with” dying patients without providing physical nursing care. Students in the senior practicum course may or may not have had the opportunity to care for dying patients in their 172 hours of clinical. Two instruments were administered before and after the courses: The Palliative Care Quiz for Nurses and the Frommelt Attitude Toward Care of the Dying. Focus groups were also conducted at the end of the courses with both groups of participants. Data were compared, contrasted, and interpreted in consideration of study aims. Participants in the EOL elective gained confidence “being with” dying patients and families. Participants in the practicum course had few experiences with dying patients. Requiring end-of-life content and experiences with dying patients is recommended for all nursing students.

Key Words: End-of-life, Palliative care, Education, Nursing Students, Knowledge, Attitudes
# Table of Contents

## Chapter I: 

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>The Problem</td>
<td>1</td>
</tr>
<tr>
<td>Purpose</td>
<td>2</td>
</tr>
<tr>
<td>Theoretic Basis</td>
<td>3</td>
</tr>
<tr>
<td>Aims of the Study</td>
<td>5</td>
</tr>
<tr>
<td>Research Questions</td>
<td>7</td>
</tr>
<tr>
<td>Significance of the Study</td>
<td>9</td>
</tr>
<tr>
<td>Theoretic Basis for the Study</td>
<td>9</td>
</tr>
<tr>
<td>Theoretic Assumptions</td>
<td>23</td>
</tr>
<tr>
<td>Personal Assumptions</td>
<td>25</td>
</tr>
<tr>
<td>Nursing Assumptions</td>
<td>26</td>
</tr>
<tr>
<td>Limitations</td>
<td>28</td>
</tr>
<tr>
<td>Summary</td>
<td>29</td>
</tr>
</tbody>
</table>

## Chapter II: Review of the Literature

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>History of End-of-Life Care in Nursing Education</td>
<td>34</td>
</tr>
<tr>
<td>Hospice Care</td>
<td>35</td>
</tr>
<tr>
<td>Palliative Care</td>
<td>39</td>
</tr>
<tr>
<td>Palliative and End-of-Life Care in Nursing Education</td>
<td>40</td>
</tr>
<tr>
<td>Student Experiences with Dying Patients</td>
<td>43</td>
</tr>
<tr>
<td>Guidance in EOL Education in Nursing Programs</td>
<td>45</td>
</tr>
<tr>
<td>KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Formats for Palliative and EOL Education 46</td>
<td></td>
</tr>
<tr>
<td>Separate Course Formats for Palliative and EOL Education 62</td>
<td></td>
</tr>
<tr>
<td>Theoretic Frameworks Guiding EOL Education 71</td>
<td></td>
</tr>
<tr>
<td>End-of-Life Education with Clinical Experience 79</td>
<td></td>
</tr>
</tbody>
</table>

**Chapter III: Methodology** 85

- Research Design 85
- Course Descriptions 90
- Instruments 92
- Procedures 97
- Methodologic Considerations 101
- Data Analysis 101
- Summary 104

**Chapter IV: Findings** 106

- Sample Demographic Characteristics 106
- Instrument Reliability 110
- Findings to Research Questions 111
- Qualitative Findings 113
- Focus Groups 114
- Data Analysis 115
- Elective Group Major Themes 122
- Elective Group Paradigm of End-of-Life Care 150
- Comparison Group Major Themes 160
- Comparison Group Paradigm of End of Life Care 189
KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING

Limitations 196
Summary of Findings 198

Chapter V: Conclusions and Recommendations 205

Study Overview 206
Theoretic Framework 207
Conclusions to Research Questions 213
  Question One 213
  Question Two 218
  Question Three 221
  Question Four 225
  Question Five 228
  Question Six 233
Final Study Conclusions 237
Recommendations for Nursing Student Educators 242
Recommendations for Practice 246
Recommendations for Further Research 249
Summary 252

References 254

APPENDIX A. Palliative Care Quiz for Nurses (PCQN) 288
APPENDIX B. Frommelt Attitude Toward Care of the Dying scale. 289
  (FATCOD) Side 1
APPENDIX B. Frommelt Attitude Toward Care of the Dying scale. 290
  (FATCOD) Side 2
APPENDIX C. Demographic Data Questionnaire 291
APPENDIX D. Focus Group Questions

APPENDIX E. Consent Form p. 1 of 2

APPENDIX E. Consent Form p. 2 of 2

ADDENDUM 1. Authorization for use of PCQN

ADDENDUM 2. Authorization for use of FATCOD
Chapter I

Nursing Students’ Knowledge and Attitudes Toward Care of the Dying

Impending death affects patients and their families physically, emotionally, and spiritually, requiring nurses to provide holistic end-of-life (EOL) care that includes more than knowledge of facts and physical tasks. Virginia Henderson (1964) described nursing as ‘holistic’ rather than disease-centered. Her definition of nursing included helping people whether sick or well, from birth to death, to cope with handicaps and irreversible disease, “even more important, to assist the patient toward a peaceful death by facing it with him honestly and courageously” (p. 66).

In 1997, the Institute of Medicine (IOM, 1997) and the American Association of Colleges of Nursing (AACN, 1998) acknowledged the omission of humane physical and emotional care provided to people with life threatening illnesses at EOL. Major deficiencies were found with an underlying thread, the lack of knowledge and experience specific to care of the dying. Professional education for physicians and nurses lacked content and clinical experience dedicated to palliative or EOL care (AACN, 1998; Copp, 1994). Simply summarized, “clinicians-in-training experience and learn too little of the caring that helps people to live well while dying” (IOM, 1997, p. 265). Nurses are expected to provide physical, emotional, and spiritual EOL care (EOLC) because of their holistic education (IOM, 1997). However, the AACN (1998) realized that without changes in nursing education to provide a cohesive knowledge base of palliative and EOL care, graduates would remain unprepared to provide physical, emotional, and spiritual care to patients and families experiencing life threatening diseases (Beck, 1997).
Researchers have confirmed that nursing students feel unprepared to provide EOL care and as a result avoid dying patients and their families (Ek et al., 2014; King-Okoye & Arber, 2014). Unfortunately, such responses have extended into professional practice (Bloomer, Endacott, O’Connor, & Cross, 2013) with nurses admitting their lack of EOL knowledge and skills, especially of emotional care (Cui, Shen, Ma, & Zhao, 2011; Peters et al., 2013). Regrettably, bereaved families rank emotional care as highly important yet the type most lacking from health care providers at EOL (Burge et al., 2014; Sadler et al., 2014). In order to develop the emotional or affective skills nursing students will need in practice, nurse educators need to begin early in the educational process to make this a priority so that students become more comfortable with and able to deliver EOL care desired by patients and families.

The Problem

End-of-life content has increased in nursing programs through varying formats and amounts to improve the quality of EOL care (Dickinson, Clark, & Sque, 2008; Todaro-Franceschi & Lobelo, 2014; Wilson, Goodwin, & Hewitt, 2011), yet new nurses consider themselves unprepared to cope with death and dying. Nursing students do not feel self-assured to provide EOL care (Barrere & Durkin, 2014; Cavaye & Watts, 2010) and have expressed inadequacies coping with difficult emotions, addressing practical issues of symptom relief or post mortem care, and lacking knowledge and experience for answering patients’ and families’ questions (Poultney, Berridge, Malkin, 2014). Students especially lack affective skills (Ying et al., 2011), which are comprised of attitudes, beliefs, values, and emotions (Billings & Halstead, 2009). Expressions of compassion and respect for the worth, dignity, and uniqueness of individuals (American Nurses Association (ANA), 2015, Provision #1) are ethical and non-
negotiable skills, which nursing educators need to cultivate in nursing students, especially regarding EOL care.

In systematic reviews of EOL education in nursing programs between 1984 and 2013, authors identified the lack of qualitative research assessing effective educational strategies (Bassah, Seymour, & Cox, 2014; Gillan, van der Riet, & Jeong, 2014b). Quantitative measures of students’ attitudes toward EOLC have been found to improve after receiving EOL education targeting the cognitive and affective learning domains (Barrere, Durkin, & LaCoursiere, 2008; Dobbins, 2011; Weissman, 2011). Such findings indicated positive responses to EOL education without providing evidence of actual experience with dying patients by students. Experience with dying patients has been found to improve students’ attitudes toward EOLC (Kwekkeboom, Vahl, & Eland, 2005), which adds validity to such assessments after experience with dying patients. Assessment of student attitudes after completing a comprehensive EOL course with didactic instruction, experiential activities, and experience with dying patients would be more substantial evidence of student learning and attitudes toward EOLC.

**Purpose**

The purpose of this mixed methods study was to assess Bachelor of Science in Nursing (BSN) students’ knowledge and attitudes toward care of the dying after different amounts of EOL education and experience with dying patients. A convenience sample was gathered from two intact classes at a BSN nursing program in a southeastern state university. Students were assessed for knowledge and attitudes toward care of the dying after having participated in either a palliative and EOL elective course or the required Senior Practicum course.

The fifteen-week, palliative and EOL elective course included content based on the End-of-Life Nursing Education Consortium (ELNEC, 2012) curriculum modules. Three hours of
content with experiential activities were taught in class per week in addition to ten hours of experience “being with” dying patients in a supportive role. Nursing instructors trained on didactic strategies for presenting ELNEC content taught the course with guest professionals, such as hospice nurses, in-patient palliative care providers, social workers, chaplains, and musicians who played voluntarily for dying patients and their families. Experiential class activities included videos, communication exercises, role-play, small group discussions, EOL case presentations, and weekly reflective journaling assignments. Students were also required to spend at least ten hours “being with” dying patients enrolled in a hospice service. Students were instructed to visit patients in two hour increments to “be present” with them, which may have involved sitting quietly, listening, talking, and/or empathizing with patients and family members without the responsibility of providing physical care (Haraldsdottir, 2011; Bailey, Murphy, & Porock, 2011). Time in class each week was devoted to students for sharing and discussing their patient experiences.

Students’ EOL knowledge and attitudes toward care for the dying were assessed in three ways. Knowledge was assessed before and after the course using a 20-item instrument called the Palliative Care Quiz for Nurses (PCQN) (Ross, McDonald, & McGuinness, 1996). The PCQN assesses basic knowledge and misconceptions about palliative and EOL care. Attitudes were assessed before and after the course using a 30-item instrument entitled the Frommelt Attitude Toward Care of the Dying Scale (FATCOD) (Frommelt, 1991), which assesses feelings, thoughts, behaviors, and comfort with providing nursing care specifically to dying patients and their family members. Knowledge and attitudes were assessed a third way through focus groups with no more than nine students in each and conducted toward the end of the course.
For comparison purposes, students from the senior practicum course, which requires 172 hours of clinical experience in various acute care settings under the supervision of a preceptor, were asked to participate. Student participants from the practicum course completed the same instruments as the EOL elective course group as well as participated in a focus group toward the end of the course. It was anticipated that knowledge from this study would guide and direct EOL education given the different educational strategies provided and encounters with dying patients in the context as nursing care providers.

**Theoretical Basis**

Bandura’s (1977, 1989) social cognitive theory (SCT) of learning provided the framework for this study because of the principle idea that a resilient or strong sense of self-efficacy is necessary for learning and persevering through adversities to achieve success. Bandura defined “self-efficacy” as “people’s beliefs about their capabilities to exercise control over events that affect their lives” (Bandura, 1989, p. 1175). Bandura found that improving one’s self-appraisal of personal effort could strengthen self-efficacy beliefs. Through sustained exposure to an anxiety producing circumstance, one could develop coping skills to the circumstance, thus leading to a self-appraisal of efforts as efficacious. Increased beliefs of efficacious effort tended to diminish self-doubt and anxieties in one’s ability to cope with the difficult circumstance (Bandura, 1989). People with strong self-efficacy beliefs persevered longer through difficult circumstances. In contrast, people with low self-efficacy beliefs about their abilities reduced their efforts or prematurely withdrew from the circumstance. As a result, self-doubt increased and led to avoidance behavior. Therefore, to overcome avoidance behaviors related to anxieties of inefficacy, sustained exposure to certain circumstances was proposed to strengthen self-efficacy until self-doubts were diminished or invalidated.
In addition to self-efficacy, Bandura (1989) proposed that self-awareness, social cognition, and emotions were inseparable and equally necessary for human learning, which is congruent with a holistic approach to EOL education and patient care. Reflective thinking fostered self-awareness of one’s thoughts, emotions, and social situations to affect learning (Bandura, 1989). Bandura (1989) proposed that self-reflection in these areas added meaning and value to most external influences of behavior, thus affecting self-efficacy beliefs. More explicitly, self-awareness of emotions, thoughts, and social situations influenced self-efficacy, thus altering one’s thinking and motivation to persevere or not. “The capacity to exercise control over one's own thought processes, motivation, and action is a distinctively human characteristic. Because judgments and actions are partly self-determined, people can effect change in themselves and their situations through their own efforts” (Bandura, 1989, p. 1175).

Social cognitive theory describes learning as a holistic process, which appropriately framed components of this study. Educational strategies were aimed at decreasing student anxieties of perceived inefficacies in providing EOL care. Students were provided didactic EOL content to increase knowledge or the cognitive resources for providing EOL care. Experiential exercises were included to foster students’ self-awareness of thoughts, emotions, and social situations significant at EOL. Finally, experiences “being with” dying patients allowed students to develop affective coping skills, thus leading to the self-appraisal of efforts as efficacious.

End-of-life care involves strong emotional responses because of the personal and social significance of death and dying for human beings (O’Grady, Dempsey, & Fabby, 2012). Therefore, increased exposure to knowledge of death and dying, as well as experiences with dying patients in a non-threatening environment are theoretically appropriate for improving lasting EOL learning. Facilitating reflective self-awareness by “being with” dying patients
would allow students to experience and appreciate all the emotions that influence EOL care, which in turn would foster sustained or increased efforts to assure quality EOL care.

**Aims of the Study**

There were several aims of this study. The first was to measure changes in students’ knowledge and attitudes toward care of the dying after participation in an elective course that included didactic content and experiential learning in class as well as experience “being with” dying patients. In order to enhance their comfort with EOL, students were asked to spend time with dying patients without being responsible for providing physical care. End-of-life and palliative knowledge was measured before and after the course using the PCQN (Ross et al., 1996). Attitudes were measured before and after the course using the FATCOD scale (Frommelt, 1991). Gains in both measures were expected after having received education focused on EOL and experience with dying patients.

A second aim was to measure any changes in knowledge and attitudes toward care of the dying in a “comparison” group of nursing students who have not participated in the palliative and end-of-life course, but may have had experience with dying patients. Participants for the comparison group were recruited from a senior level clinical practicum course, which required 172 hours of clinical practice. Knowledge and attitudes toward care of the dying in this group were measured before and after the practicum course using the same instruments. The comparison group would not have exposure to specific EOL education or planned experience with dying patients, but may have had experience with dying patients in clinical or in their lives. In addition, topics related to EOL care may have been learned in previous courses in the nursing program.
A third aim of this study was to compare scores of knowledge and attitudes toward care of the dying between students who took the EOL elective and the comparison group. Integrating EOL content into existing required courses is the most common way nursing programs address EOL education in the United States (U.S.) (Dickinson, 2007; Todaro-Franceschi & Lobelo, 2014). At the nursing program where the study was conducted, there was no strategic inclusion of specific EOL content within the curricula. Therefore, differences in EOL knowledge and attitude scores between groups would reflect possible effects of a 15-week EOL course that included experience “being with” dying patients coinciding with EOL instruction and experiential strategies to promote affective learning and skills for EOL care.

A fourth aim of the study was to gain insight through focus groups about the quality and depth of student learning (attitudes, beliefs, values, and emotions) related to death, dying, and end-of-life care. Quantitative data may not have fully revealed students’ previous attitudes, values, and beliefs about EOL care that would indicate affective learning. Such learning about EOL care may would be more effectively communicated in person and provide richer qualitative meanings through focus groups rather than questionnaires (Ballesteros, Centeno, & Arantzamendi, 2014; Jayasekara, 2012).

The purpose and aims of this study were accomplished using mixed-methods with a comparison group research design. A faculty member not assigned to either course recruited students from both groups. The primary investigator of the study, who also instructed in the EOL elective, did not recruit students to participate. Quantitative data were obtained at the beginning and end of the semester. As part of demographic data obtained at the outset of the study, students were asked to answer questions about previous education specific to death and dying, previous experiences with terminally ill or dying patients, previous experiences with loss,
and current experiences in anticipating a loss. Near the end of the semester, separate focus groups were conducted with each group.

**Research Questions**

1. To what extent does participation in structured EOL education based on the ELNEC curriculum and planned experiences “being with” dying patients affect students’ knowledge and attitudes toward EOL care?

2. To what extent does 172 hours of clinical experience without a didactic component or ELNEC content affect students’ knowledge and attitudes toward EOL care?

3. Is there a difference in knowledge and attitudes toward EOL care between the EOL elective group (students who did participate in a structured EOL course) and the comparison group (those who did not receive structured EOL education but were enrolled in a clinical practicum course)?

4. From focus group discussions, what attitudes, beliefs, values, and emotions about EOL care did students from the elective group express?

5. From focus group discussions, what attitudes, beliefs, values, and emotions about EOL care did students from the comparison group express?

6. Do students who participate in a structured EOL course express different attitudes, beliefs, values, and emotions about EOL care from students who do not participate in a structured EOL course but who participate in 172 hours of clinical experience?

**Significance of the Study**

*Care of patients with life-threatening illness.* An increase in patients suffering from life-threatening illnesses has warranted demands for palliative treatment. As a result, palliative care education has increased within schools of medicine and nursing since 1997 (Center to
Advance Palliative Care [CAPC], 2015; Weissman & Meier, 2011). Yet in a follow up report by the IOM (2015) on EOL education, two key findings were that there was insufficient palliative care education in discipline specific school curricula. The second was that “Health professionals are not always adequately prepared to deliver ‘basic’ or ‘primary’ palliative care to patients who are not currently hospitalized or do not require specialty palliative care” (p. 2). It was anticipated findings from this study would improve nursing students’ basic palliative and EOL care knowledge and attitudes toward death and dying. If students’ knowledge of palliative care and attitudes toward death and dying are firmly established and improved during nursing education, as nurses they may be better able to provide comfort for dying patients and families, regardless of health care setting. As indicated by the IOM (2015), providing sufficient palliative care education through discipline-specific curricula has the potential to decrease suffering for patients not enrolled in hospice by increasing the EOL knowledge and experience base of all health care providers (Meier, 2011).

**Communication about end-of-life.** Many nurses are uncomfortable communicating about EOL care and fear saying the ‘wrong thing’ due to lack of education, lack of experience with the dying, and little confidence in providing EOL care (Barrere & Durkin, 2014; Dahlin, 2010; Peterson et al., 2013). From a survey of 717 registered nurses from four states in the U.S., Reinke et al., (2010) found that nurses ranked communication as the highest yet most underutilized skill among 19 other skills important in EOL care. Nurses reported that knowledge and practical experience to improve communication at EOL were the greatest needs. Providing EOL knowledge and experiential opportunities to practice communication with dying patients and family may improve students’ abilities to talk comfortably about EOL. Students more assured in their knowledge base and experience with dying patients may as nurses help facilitate
Patients and family members report inadequate communication as consistently lacking from care providers at the end-of-life, especially communication related to emotional and spiritual support, (Brazil et al., 2013; Burge et al., 2014). Students may not be aware of how supportive it is to patients and family members to communicate with them openly, honestly, and compassionately about death and dying (Lundberg, Olsson, & Fürst, 2013; Sutton & Coast, 2014; Seymour, Bellamy, Gott, Ahmedzai, & Clark, 2002). Besides knowledge about EOL care, a common source of nurses’ discomfort with communication at EOL is not knowing how much the patient and/or family have been told about their terminal condition (Reinke et al., 2010). The amount of information about a terminal condition divulged to patients and/or families is only one aspect of supportive communication that varies across situations. However, Clukey (2007) asserted that “being present with” patients was more helpful than providing information to patients. According to 22 bereaved family members who were asked what was most helpful to them during the anticipatory grief experience, “the importance of being present with the dying person was noted by all informants and was most often their first and most spontaneous reply” (Clukey, 2007, p. 152).

In the EOL elective, students received three hours weekly of palliative/EOL education in class and ten hours of experience “being with” dying patients without the expectation of providing physical care. Students spent time with dying patients who were aware of their terminal condition. In two-hour increments per visit, students had the opportunity to communicate, listen actively, and empathize with patients who knew they were dying. During such visits, students recognized and experienced the supportive effects of communicating with
patients and families. It was anticipated that with specific knowledge and practice of supportive communication skills, students would be more likely to practice these skills in professional practice. Therefore, knowledge from this study had the potential to improve the psychosocial care that dying patients and families receive from nurses who had practiced providing therapeutic communication.

**Attitudes toward care of the dying.** In studies of nursing students who received didactic EOL education, researchers reported that students had less discomfort and more positive attitudes toward care of the dying (Barrere et al., 2008; Bush & Shahwan-Akl, 2013; Brien, Legault, & Tremblay, 2008; Frommelt, 2003; Hurtig & Stewin, 1990). However, these studies were based on classroom EOL content alone and provided little to no assessment of students’ actual experience with dying patients. Knowledge and attitudes toward care of the dying have not been studied in conjunction with scheduled experience with dying patients. This study involved providing students with didactic EOL education and ten hours of experience required for “being with” dying patients to obtain more reliable measures of students’ attitudes toward care of the dying. Measuring student attitudes before and after structured EOL education and experience provided more accurate assessments of their attitudes toward EOL care. Knowledge from this study substantiated effective EOL educational strategies that may lead to more positive attitudes toward care of the dying and better practice of EOL care.

**Practice.** In a qualitative study examining the influence of ELNEC education on nursing care of dying patients and their families, Barrere and Durkin (2014) interviewed 12 nurses with approximately one year of practice after graduating from a BSN program in which ELNEC content was integrated throughout the curriculum. Each participant was asked to describe in as much detail as possible, the first experience as a new nurse caring for a terminally ill patient and
any available resources and/or barriers encountered. Analysis of interviews revealed major themes from ELNEC content threaded throughout descriptions by all nurses, such as the importance of nurses in facilitating a good death. Despite feelings of discomfort from their first terminally ill patient care experience, nurses described how they comforted patients. Nurses reported active listening and providing mental, physical, and emotional presence. These are all critical affective skills needed in EOL care. Another ELNEC concept all nurses described was maintaining a healthy balance between emotional involvement expressed as compassionate care and emotional over-involvement leading to burnout. Nurses described EOL education in nursing school and from the employing hospital as ‘helpful for learning.’ However, in comparison to the classroom education, all described a memorable patient and/or family experience at EOL that made a lasting impression that enhanced their knowledge and understanding of EOL care. As one nurse stated “I don't think there's any class that can teach you how to deal with it...I think you just need to just experience it” (Barrere & Durkin, 2014, p. 41).

Knowledge from this study may shed light on whether or not an experience of “being with” dying patients for 10 hours in two hour increments without expectations to provide physical care provides a sufficient learning experience about EOL care for nursing students. Also important to know is what impressions the “being with” experience creates for students. Qualitative data from students revealed the impressions that occurred during visits and how they may have changed their understanding of EOL care. Findings may reveal the benefits of hospice care environments as potential clinical placements for supplementing EOL education. Knowledge from this study may improve the challenges educators have in finding adequate clinical placements to ensure that nursing students receive experience with dying patients.
In a survey study including eight university nursing schools in Buenos Aires, Argentina, where EOL education was not part of the curricula, Mutto, Errázquin, Rabhansl, and Villar, (2010) found that a majority of first year nursing students (freshmen) reported more satisfying relationships with dying patients and a greater desire to engage with them emotionally than fifth year students (seniors). Seniors averaged more time in direct contact with terminally ill patients (10 pts. per year) than freshmen (6 pts. per year). However, more seniors (45.1%) than freshmen (31.2%) wished to avoid emotional involvement or affection with patients to avert personal pain. Such findings suggest that without increasing knowledge or understanding about EOL, cumulative experience with terminally ill patients during the course of five years did not improve students’ attitudes toward emotional involvement in the care of the terminally ill. The authors concluded that seniors were more likely to withdraw from care of dying patients emotionally as well as physically.

Knowledge from this study where students were provided didactic and experiential EOL learning had the potential to improve students’ attitudes toward EOL care. Increasing students’ knowledge base along with exposure to dying patients had the potential to improve students’ attitudes toward EOL care as they progressed through nursing school. If students are supported with EOL knowledge and experience, they may feel more self-assured to provide EOL care.

**Educational research.** One of the research priorities for 2012-2015 cited by the National League for Nursing (NLN, 2012) was advancing the science of nursing education. The NLN calls for determining the quality of education that achieves desired learning outcomes and measuring the link between education and practice outcomes were noted. There is quantitative evidence that didactic and experiential strategies of EOL education improve nursing student attitudes toward care of the dying (Bailey & Hewison, 2014; Ballesteros et al., 2014; Dobbins,
This study provided a type of EOL patient experience that may improve students’ abilities to communicate and interact with dying patients. Qualitative data from this study revealed knowledge of student learning about palliative/EOL care. Of particular concern was evidence of students’ practice of affective competencies in EOL care (Nicholl & Price, 2012). Such evidence is needed for linking EOL educational experience to positive EOL practice.

More experience with dying patients in undergraduate nursing programs was a recommendation from several researchers who studied student knowledge and attitudes toward care of the dying (Brien et al., 2008; Charalambous & Kaite, 2013; Dickinson et al., 2008; Wallace et al., 2009). In a study of nursing students given planned experience with dying patients but no classroom content on EOL (Kwekkeboom, Vahl, & Eland, 2006), measures of knowledge and attitudes toward care of the dying were not significantly different from students in traditional clinical experiences. More research is needed to learn the effects of experience with dying patients as a strategy for learning about EOL care among undergraduate students. Given that the course being examined in this study had both classroom content and planned clinical experience with dying patients, knowledge from this study ascertained the value of actual classroom and clinical experience with dying patients as a strategy to improve depth of EOL learning among undergraduate nurses. Knowledge from this study contributes to the body of research on effective EOL education strategies.

**Education.** What is known from the literature is that student discomfort about care of the dying stems from fears of harming the patient. Students lack knowledge of what to say or do in the presence of dying patients. Students often lack self-awareness of their own emotional responses to death and dying, and even less about how to deal with physical care at EOL (Edo-Gual, Tomas-Sabado, Bardallo-Porras, & Monforte-Royo, 2014; Ek et al., 2014; Parry, 2011).
What is unknown is the extent or amount of knowledge and experience specifically with dying patients that students need in order to enhance their self-confidence when caring for dying patients and their families (Bassah et al., 2014; Schlairet, 2009). End-of-life (EOL) content in nursing programs has been offered predominantly in the classroom (Todaro-Franceschi & Lobelo, 2014). Little is known about the number of hours students actually spend with dying patients and their families because it is difficult to assess (Ballesteros et al., 2014; Bush & Shahwan-Akl, 2013; Mallory, 2003).

This study addressed common student anxieties, which are fears of the unknown when facing dying patients. Providing a systematic knowledge base and experience with dying patients may decrease student fears of the unknown and enable them to discern common human needs at EOL. Suliman and Halabi (2007) found that increased anxiety was associated with decreased self-esteem and critical thinking skills among nursing students. Chesser-Smyth and Long (2013) found that knowledge acquisition decreased nursing students’ anxiety. If student anxieties about EOL are diminished, learning and critical thinking about care of the dying may be enhanced. Therefore, knowledge from this study had the potential to improve students’ critical thinking skills, decrease their anxieties, and improve over-all learning about EOL while in nursing school.

Knowledge from this study had the potential to illustrate methods designed to strengthen students’ self-efficacy in EOL care and subsequent ability to perform necessary EOL care competencies developed by the AACN (1998). Palliative and EOL care competencies have been developed by the American Association of Colleges of Nursing (AACN, 1998) to guide educators in preparing undergraduates who can provide basic EOL care in practice. Examples of the core competencies include effective communication with the patient and family (competency
3), recognition of one's attitudes, feelings, values, and expectations about death (competency 4), and provision of current therapies for symptom management (competency 8). Knowledge from this study addressed nursing students’ specific fears of inadequacy due to lack of EOL knowledge and experience associated with care of the dying (Allchin, 2006; Parry, 2011) prior to professional practice. If the strategy of providing systematic knowledge and planned experience with dying patients decreases students’ fears of inadequacy, they may be more confident as new nurses to provide quality EOL care to the dying.

**Learning from “being with” dying patients.** Given that undergraduate nursing students desire more knowledge and experience with dying patients (Birkholtz et al., 2004), it is imperative to know how much and to what extent experience “being with” hospice patients can influence students’ comfort levels in providing EOL care. Knowledge from this study provided both objective and subjective assessments of students’ EOL learning based on 15 weeks of didactic education and ten hours of time spent “being with” dying patients.

Experiential learning has long been associated with positive student attitudes toward EOL care (Hurtig & Stewin, 1990). The types of ‘experiential learning’ utilized in EOL education have varied. Methods labeled ‘experiential learning’ have occurred within the classroom and include role-play, case study analysis, discussion, reflective writing exercises, and video viewing (Adriaansen & van Achterberg, 2008; Crookes, Crookes, & Walsh, 2013). The goals of these experiences were to promote affective learning by evoking emotions and raising awareness of solutions indicated for common EOL situations that students could expect in practice. Chesser-Smyth and Long (2013) found that a positive clinical experience had stronger effects on increased self-confidence than classroom education. Researchers found that self-confidence was positively correlated with adjustment to college and positive academic performance (Brady-
Amoon & Fuertes, 2011; Chesser-Smyth & Long, 2013). Although highly recommended, few studies have been done to examine the effects of educational experience with dying patients as an experiential method combined with didactic EOL content to improve knowledge and attitudes toward care of the dying (Hurtig & Stewin, 1990; Wilson et al., 2011).

The experiential method of ‘being with’ dying patients provides opportunities to change how students think, feel, interact with, and value psychosocial and emotional care when the requirement to provide physical care is removed. Knowledge from this study provides insight into EOL education that involves learning from “being with” dying patients.

Providing EOL care education addresses an area of discomfort for nursing students and new graduates, caring for dying patients and family. According to Casey et al., (2011), the difficulties of transition into practice often force graduate nurses out of the profession with 30% to 60% changing or leaving nursing altogether during their first year of practice. Reasons nurses cited for leaving were that they felt “inadequately prepared for the pace of acute care, the challenge of high-acuity patients, disempowerment, and understaffed work environments” (p. 646). Senior practicum clinical courses requiring hours of practice with a preceptor have been implemented in nursing programs to increase student readiness for professional practice. In a survey study of 429 seniors from three nursing schools who had completed senior practicum courses ranging from 144 to 280 hours of practice with a preceptor in a clinical setting, students reported feeling more confident in communicating with patients and families, collaborating with other disciplines, prioritizing and completing tasks, recognizing changes in patient conditions, and problem solving. The only item that students felt uncomfortable with was what to do for a dying patient (Casey et al., 2011).
Research indicates that providing emotional care is the most difficult aspect of EOLC among nurses (Cui, Shen, Ma, & Zhao, 2011; Peters et al., 2013) and students (Ying et al., 2011). This study addressed nursing students’ discomfort with care of the dying by providing specific EOL knowledge. Since students have difficulty coping with emotions commonly expressed at EOL (Barrere & Durkin, 2014; Cavaye & Watts, 2010), planned experiences of “being with” dying patients allowed students to learn about the emotional aspects of EOL from dying patients. Knowledge about emotional needs of dying patients prepared students for what to expect about providing psychosocial care, which addressed the lack of affective skills needed to cope with dying patients (Ying et al., 2011). Therefore, knowledge from this study had the potential to enhance students’ sense of preparation for providing psychosocial care of the dying, a commonly feared area.

Providing students with theoretic principles and knowledge of technical skills for EOL care is often insufficient for developing affective skills to address emotional responses by dying patients and their family members (Peterson et al., 2013). For many nursing students, ‘identifying with’ and ‘sharing with’ the suffering of dying patients are not comfortable thoughts (Ek et al., 2014). However, avoidance only delays the development of necessary skills to persevere despite discomfort (Bandura, 1989). By providing experience “being with” dying patients and families, students can recognize commonly expressed emotions, whether negative or positive, and begin to develop the skills needed to deal with emotional suffering at EOL. As a result of spending time with dying patients, students may experience a sense of satisfaction, rewarding feelings, personal accomplishment, and professional enrichment from observing or contributing to the well-being of patients and families at the end-of-life (Ek et al., 2014; Muñoz-Pino, 2014; Sinclair, 2013). Based on the influence from negative experiences, positive
experiences would be expected to extend into professional practice as new nurses. Improved coping skills and rewarding experiences early in a nursing career may potentially decrease attrition in the first year of nursing practice.

**Affective skills.** The affective skills necessary for nursing care are not easily measured by written tests, lab check-offs, or clinical performance tasks (Benner & Sutphen, 2007; Mann, Gordon, & MacLeod, 2009; Neumann & Forsyth, 2008; Savickiene, 2010), but are important in providing EOL care. End-of-life care requires nurses to have a much deeper understanding of psychosocial and emotional needs of the patient, the family, and oneself. Providing students with EOL education and opportunities to “be present with” dying patients without the requirement to perform tasks is suggested as a means to develop knowledge and affective skills especially needed in EOL care (Braitman, Fothergill-Bourbonnais, Casey, Alain, & Fiset, 2007; Charalambous & Kaite, 2013; Todaro-Franceschi, 2011). Educators must ensure that affective components of learning occur among students as they begin forming ideals of holistic care. Knowledge from this study may help students internalize the ideals of nursing care and thus maintain the holistic essence of nursing. In an age of constant technical and mechanical advances in health care (Brown, 2011), knowledge from this study may improve the holistic quality of nursing care for patients, especially at EOL.

**New nurses.** Too often, the inability to recognize signs or symptoms at EOL results in unnecessary aggressive or futile care that prolongs patient and family suffering while incurring greater health care costs (Center to Advance Palliative Care [CAPC], 2012; IOM, 1997; Penrod et al., 2010). New nurses are often not able to recognize when palliative care is warranted for patients in a hospital setting (Weissman & Meier, 2011). Nearly 85% of new nursing graduates under the age of 30 are employed by hospitals (U.S. Department of Health and Human Services,
KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING

[HHS], 2014), where a majority of deaths still occur (Price, Dornan, & Quail, 2013; Zhao & Encinosa, 2007). Palliative care is associated with improved symptom control, better quality of life, and prolonged life (Arthur & Bruera, 2013; CAPC, 2012; IOM, 1997, 2015). Improving EOL assessment skills of new nurses may influence the efficiency of EOLC in a hospital setting (Meier, 2011; Penrod et al., 2010). Knowledge from this study may potentially increase quality and timely access to appropriate palliative care for hospitalized patients with progressive life-threatening diseases.

Hospitals are the most common places of employment for all nurses (62%) and 82% of those nurses will work in a community hospital setting (HHS, 2014). Palliative care in U.S. hospitals continues to improve as the prevalence of hospitals (50 or more beds) with palliative care teams increased from 658 to 1,734, a steady 163.5% increase from 2000-2012 (CAPC, 2015). Nurses working in smaller community hospitals are less likely to have a complete interdisciplinary palliative care team for referral. Therefore, preparing nurses with basic palliative concepts and practice skills will potentially benefit patients in smaller community hospital settings, where access to palliative care is less developed. Knowledge from this study has the potential to expand the reach of quality EOL care to patients in smaller community hospital settings.

Other patient populations. All nurses must have basic palliative and EOL education in order to provide care that leads to a good death. Although palliative and EOL care are historically associated with cancer patients in hospice, less than half (36.9%) of all hospice admissions are cancer related (National Center for Health Statistics [NCHS], 2011; National Hospice and Palliative Care Organization [NHPCO] (2015). Statistics support older adults with non-cancer diagnoses as benefitting from such care, with the majority of hospice admissions
being for diagnoses such as debility with an unspecific source, dementia, heart disease, and lung disease (NCHS, 2011; Tinetti et al., 2012). Such chronic diseases increase the mortality rates for older adults (Vig, Davenport, & Pearlman, 2002; Woo, Lo, Cheng, Wong, & Mak, 2011) who may suffer from similar physical and psychosocial burdens as cancer patients, but for longer periods (Gott et al. 2009; Hayle, Coventry, Gomm, & Caress, 2013). Yet, these adults are often excluded from consideration for palliative care because of unpredictable prognoses with non-malignant conditions that fall outside of the six-month life expectancy requirement associated with U.S. hospice care and reimbursement (Lau & O’Connor, 2012).

The ELNEC modules, which were used in the EOL and palliative elective, address death, dying, and related nursing care for all populations regardless of diagnosis (ELNEC, 2012). Therefore, students who are knowledgeable about palliative or EOL principles can extend the benefits of such care to patients in various settings outside the context of hospice or oncology. Students with a palliative and EOL knowledge base and experience with dying patients have the potential to benefit all populations for whom such principles are applicable, no matter where they are being cared for, especially those suffering from end-stage symptoms of chronic and irreversible disease. Knowledge from this study may improve the quality of life for all patient populations who do not qualify for hospice admission but could benefit from basic palliative care.

The educational strategy of “being with” patients can help students learn to cope with and provide quality EOL care to other patient populations not normally associated with dying. For example, pediatric patients with end-stage disease can evoke strong emotions that make pediatric nurses feel helpless, thus interfering with EOL care that is needed (Nicholl & Price, 2012). Sensitive and complex issues involving the parents of dying infants and children make nursing
care of this population difficult (Carson, 2010). Since death is more prevalent among older populations, there is little research done on preparing students for care of dying children (Nicholl & Price, 2012). Knowledge from this study may be useful for nursing educators to apply in teaching about EOL care of all patient populations, including children.

**Theoretical Basis for the Study**

Bandura’s (1977, 1989, 1999) social cognitive theory of learning as the basis for the expression “success breeds success” is a simple view of how learning takes place when positive experience leads to successful behavior. Bandura proposed that for humans, many factors interact to influence learning and subsequent behavior, including factors such as individual abilities, motivations, thoughts, feelings, expectations, actions, and feedback. All interact simultaneously to shape and regulate behavior whether actual outcomes are successful or not.

Bandura’s theory emphasizes self-efficacy and cognitive self-appraisal as critical components for learning. Self-efficacy is defined as one’s perceived ability to change or produce a desired effect. Cognitive self-appraisal is defined as what one thinks, judges, and believes about one’s ability to change or produce a desired effect. Bandura (1989) emphasized the importance of self-efficacy and self-appraisal of personal actions and consequences rather than actual outcomes. Although successful effort reinforces self-efficacy, how one experiences less successful effort also influences self-efficacy depending on cognitive self-appraise of personal effort involved.

**Encountering adversity.** When facing adversity, Bandura emphasized prolonged intentional exposure as a way to strengthen self-efficacy for lasting behavioral change despite the adversity. “Real encounters with threats produce results decidedly superior to imagined exposure, which has weak, variable effects. Prolonged encounters that ensure behavioral
improvements are more effective than distributed brief encounters that are likely to end before successful performance of the activity is achieved” (Bandura, 1977, p. 196). Based on this supposition, intentional exposure to dying patients is theoretically likely to influence students’ self-efficacy in care of the dying as long as the exposure does not cause a continued state of emotional discomfort or agitation for a student.

Multiple methods of exposure to dying patients may be necessary to increase students’ sense of self-efficacy before being required to care for dying patients in an acute care hospital setting. As applied to students learning about EOL care, how students appraise their abilities (self-appraisal) to produce a desired effect with dying patients will influence whether or not they continue such efforts in the future. Negative appraisal decreases self-efficacy. Positive appraisal increases self-efficacy, which enhances learning and perseverance. Therefore, positive experiences with dying patients facilitated by educators can help nursing students overcome any initial discomfort they may associate with care of the dying.

In addition, the experience of “being with” a dying patient should last long enough for students to discount it as a threat and/or see personal improvement or progress during the experience. Time spent “being with” dying patients without having to provide physical care may reduce students’ fears of harming patients, which may diminish perceptions of the situation as threatening. Allowing students to focus on skills such as communication and active listening through “being with” dying patients may expedite their awareness of emotional responses by dying patients as well as their own. Recognition of personal emotions and coping is especially helpful to students who have never experienced a death.

Bandura (1977) also proposed that human learning was not a mechanistic or isolated process. Several factors interact to provide feedback so people can learn to judge and develop a
stronger sense of self-efficacy. Feedback on efficacy information can come from “performance
commitments, vicarious experience, verbal persuasion, and emotional arousal” (Bandura,
1977, p. 195). For example, students can learn by performing skills in a simulated lab or from
instruction in a classroom. They can also learn vicariously from observing and modeling in
clinical settings. Emotional discomfort from exposure to a stressful situation, such as the
responsibility to comfort a dying patient without any prior knowledge of or experience with EOL
care, might naturally evoke fears of inefficacy. Avoiding stressful situations that elicit emotional
discomfort impedes development of a sense of self-efficacy when faced with the same situation
again. If not exposed long enough to identify fears or heightened emotional responses from
which to learn, a student’s self-appraisal of emotional or psychosocial coping abilities may
remain negative toward dying patients and hinder further learning, or worse, lead to avoidance of
dying patients.

Bandura (1977) postulated that prolonged encounters rather than brief exposure to
threatening situations were more effective for ensuring behavioral improvements. It would
logically follow that intentional exposure to dying patients that leads to positive appraisal of self-
efficacy, would also lead to improved psychosocial coping in the face of future situations with
death and dying. The alternative is that sporadic exposure to dying patients and families may not
allow enough time for the development of positive self-appraisal. On the contrary, sporadic
exposure might perpetuate negative self-appraisal of coping with death and dying, and if not
addressed, students may continue to feel anxious and inadequate in care of the dying.

Theoretic Assumptions

1. As adult learners, students are genuinely interested in learning how to provide quality
care to dying patients. For this reason, they “do things that give them self-satisfaction
and a sense of pride and self-worth, and refrain from behaving in ways that give rise to self-dissatisfaction, self-devaluation, and self-censure” (Bandura, 2001, p. 8).

2. Increased exposure to an anxiety producing circumstance must be within an expected range of students’ abilities for their educational level, which supports the need to provide appropriate educational support through didactic instruction on EOL care (Bandura, 1989; Ozer & Bandura, 1990).

3. Increasing students’ self-efficacy beliefs to face emotional fears and anxieties during difficult circumstances will involve spending time with dying patients in a non-stressful environment.

4. To achieve lasting change of positive attitudes and behaviors toward care of the dying, personal awareness, cognition, and emotion are necessary and inseparable in the learning process.

5. Actual experiences of improvement or mastery in stressful situations (interacting with and providing psychosocial care to dying patients) take less time to extinguish uncomfortable feelings about the situation than merely symbolic or imagined representations of the stressful situation (Bandura, 1977), such as classroom case studies without an experiential component.

6. Human caring is intentional because the professional goals of nursing are rooted in a value system and a sense of personal identity, which leads one to invest in activities with meaning and purpose (Bandura, 2001).

**Personal Assumptions**

1. Advances in nursing knowledge and practice expand constantly, making it difficult to know exactly what content educators should include in preparing students for the practice
knowledge and attitudes toward care of the dying

environment. Saving life is not the ultimate success, nor is death the ultimate tragedy. Not caring for humans compassionately as they approach death is the ultimate tragedy for nursing as a paradigm for caring professions, no matter how advanced or complex practice environments become.

2. At the end-of-life, there are common concepts of a desirable death among humans both physically and emotionally. All humans want to die peacefully, which encompasses being physically free of pain, suffering, and the discomforts of breathlessness, nausea, or weakness. Equally important is the desire for emotional peace, which includes being free of depression or emotional anguish and being close to loved ones, or people who genuinely care about them as individuals. Family members want their dying loved ones to be treated with respect, compassion, and dignity.

3. Advances in technology have not changed universal human values at the end-of-life. On the contrary, medical advances have added to the complexity of decision-making for EOL care preferences.

4. Alongside the many advances in sustaining life, a holistic approach to EOL nursing care is desirable and requires special emphasis to maintain human values in caring.

5. Quality EOL nursing care requires affective learning to grasp the impact of death and/or dying on patients and families. Increasing knowledge about dying and EOL care using textbooks, high fidelity manikins, and virtual sources are valuable for nursing education. However, such resources may not have the same affective impact on students as “being with” dying patients may have in evoking a wide range of emotional responses.
Nursing Assumptions

1. Death and dying are stressful events, which nurses encounter and nursing students have to be prepared to face.

2. Suffering is thoroughly individual, intensely personal (Ferrell & Coyle, 2008), and experienced by persons, not merely bodies (Cassell, 1999).

3. Students want to be knowledgeable and properly prepared to address death and dying within the health care setting. Although education and experience will not prevent the reality of death, nurses must be equipped emotionally to address EOL care with confidence and support in order to make death and dying experiences better for patients and families.

4. Alleviating pain and suffering are common goals for health care professions and are significant for nurses who routinely care for patients and interact with families.

5. Although not all nurses routinely experience care of dying patients, they must be accountable for alleviating pain and suffering, which will require physical, psychosocial, emotional, and spiritual care.

6. The demographics of an aging population make preparation for EOL care more relevant for all nurses. Nurse educators want to prepare future nurses for the reality of EOL care in all patient populations.

7. Expecting all EOL care to be delivered by expert specialists is unrealistic. End-of-life care requires an interdisciplinary approach. However, nurses are often the first point of contact in many health care delivery systems. Therefore, preparation of all nurses must include EOL concepts that are transferable to any health care system and communicated by nurses who understand holistic care.
Limitations

Bias. The principle investigator (PI) of this study was an instructor in the palliative-EOL elective course taught in the nursing program, which may have introduced some form of bias to students and/or the PI. Students may have perceived that grades from the PI would be negative if they did not participate in the study and conversely that grades would be more favorable if they participated. Any revelation of instrument scores by participants to the PI, particularly areas of weakness, may have resulted in subconscious bias by the PI to emphasize EOL content based on instrument score results. Bias from students may have unduly influenced study participation. Bias by students or the PI may have influenced the validity of study results. Therefore, a facilitator, who was a faculty member not involved with the research study or instruction in either of the courses, introduced the study to students with the PI absent. The facilitator then distributed and obtained informed consents from participating students, administered and collected the study instruments, placed all completed study forms into a sealed envelope, and provided a master schedule of times for participants to sign up for a focus group near the end of the semester. All signed consent forms obtained were sealed in envelopes, separate from completed data instruments, and inaccessible to the PI until after the study.

Preexisting motivations. Since the palliative and EOL elective was an optional course, those who chose it might have had pre-existing motivations for enrolling different from those who did not enroll. Motivation and interest are always possible factors in education where elective courses are offered to students. For example, students with a previous degree or background in psychology may be partial to psychosocial skills. To account for possible motivations and descriptive purposes, demographic data including level of education was obtained from participants of both groups.
**Prior education and experience.** Prior EOL education and/or experiences before participating in the study could not be controlled among students in both groups but may have affected study outcomes. If participants had prior education and experience with death and dying, they may not have seen the need for enrolling in the elective. Participants who had EOL education and/or positive experience with dying patients may have been inclined to enroll in the elective course. Conversely, the opposite may be true for those in the comparison group. Those who had negative experiences from prior EOL experience or education may have been averse to enrolling in the EOL elective.

Students in the practicum course may have encountered dying patients in their clinical practicum, which they could not avoid. Such experience could not be prevented or discounted but could have affected attitudes toward care of the dying as an experiential factor. However, participants in the practicum course who encountered a dying patient would not have the benefit of focused classroom education and a “being with” experience that allowed them to forego expected physical care requirements and all other clinical responsibilities at the same time. A focus group with participants from the comparison group was conducted using the same semi-guided questionnaire to assess depths of learning from such experiences with dying patients. Prior experience with EOL education and/or experience with death or dying patients was assessed of all participants as part of the demographic data.

Prior end-of-life content taught within the nursing curriculum in previous courses could not be controlled for or prevented within the comparison group, which was also true for the elective group. Inclusion of any previous EOL content within the nursing curricula of both groups may have affected knowledge and attitude measures. However, students in the practicum
group who had previously taken the palliative and EOL elective course were excluded from study participation.

Demographic factors such as age, sex, work experience, and highest level of education could not be controlled among any participants. Such information was obtained from both groups through a single demographic questionnaire.

**Schedules.** Individual student schedules could not be controlled for, but may have affected sample sizes. Student attrition was possible in both groups due to personal issues or academic schedule. The type of nursing program may have prevented enrollment in an EOL elective due to lack of time, such as in an accelerated program.

**Setting.** One university setting was included for this study, which limited generalizability of quantitative data. This study involved one university in the southeastern U.S. Results are not generalizable to nursing student populations in different regions of the U.S. In addition, the elective course was optional while the practicum course was mandatory for students. Absence of a non-probability sample makes quantitative data not generalizable to the nursing student population at large. Throughout the U.S. a majority of structured EOL courses are offered as nursing electives (Todaro-Franceschi & Lobelo, 2014) as well as a mandatory senior clinical course, which makes non-probability sampling less of a concern. Qualitative results from this study may be transferable if data from focus groups are trustworthy and credible (Jayasekara, 2012; Morgan, 1996). Focus groups were conducted similarly in both groups.

**Quantitative instruments.** Self-rating instruments have been questioned as reliable tools for adequately assessing students’ abilities, which is why qualitative focus groups were conducted to obtain further data directly from students about their experiences with dying patients.
The FATCOD instrument has demonstrated reliability for measuring attitudes toward care of the dying among U.S. nursing students. Frommelt (1991, 2003) reported Chronbach’s Alpha values of 0.94 using the FATCOD with nurses and 0.90 with use among nursing students. Weissman (2011) reported values between 0.87 and 0.82, indicating adequate reliability for internal consistency of the instrument with nursing students. It was reasonable to expect the English version to be reliable and consistent for students in this study.

**Summary**

A goal for EOL nursing education is that students transfer principles from palliative and EOL education into practice. Current evidence suggests that psychosocial or emotional patient care is an area needing improvement, especially at EOL. Although current EOL education has been predominantly integrated into curriculum, assessment of EOL care knowledge, particularly affective skills, needed further study to assure that competent and compassionate EOL care is implemented into clinical practice.

Based on social cognitive theory of learning (Bandura, 1977, 1989), overcoming a difficult situation requires cognitive resources along with repeated exposure to reinforce efforts and improving abilities to provide affective EOL care. Improving students’ self-appraisal of personal efforts during actual encounters with dying patients should lead to positive changes in thoughts, emotions, and abilities resulting in a greater sense of self-efficacy. According to Bandura:

People must have a robust sense of personal efficacy to sustain the perseverant effort needed to succeed. Self-doubts can set in quickly after some failures or reverses. The important matter is not that difficulties arouse self-doubt, which is a natural immediate reaction, but the speed of recovery of perceived self-efficacy from difficulties. Some
people quickly recover their self-assurance; others lose faith in their capabilities.

Because the acquisition of knowledge and competencies usually requires sustained effort in the face of difficulties and setbacks, it is resiliency of self-belief that counts. (1989, p. 1176)

Death and dying are emotionally filled situations, which nurses cannot avoid. Education supplemented by exposure to dying patients in a less stressful manner is theoretically warranted to diminish students’ self-doubts and improve their self-efficacy in approaching patients at EOL.

This study involved two groups of nursing students for comparison of knowledge and attitudes toward care of the dying. A purposeful sample from the practicum course was compared to a purposeful sample of students from the palliative and EOL elective course that included didactic content and clinical experience “being with” dying patients. A mixed methods, comparison group approach for studying students’ knowledge and attitudes toward EOL care provided evidence educators need to devise curricula that efficiently enhance students’ thoughts, emotions, and behaviors toward EOL care. Comparative data analysis between two groups of BSN students provided the basis for addressing EOL education to improve the quality of EOL care for patients and families. Data from students who participated in a palliative and EOL course were compared to students who did not participate in the course but received standard nursing education with a corresponding clinical component. Comparing the two types of data from this study corroborated findings from other studies that focused separately on either quantitative or qualitative results independently, thus contributing to the body of evidence on best practices of EOL nursing education.
CHAPTER II

Review of the Literature

History of End-of-Life Care in Nursing Education

Nursing has a rich history of holistic care for the dying based on the work in England by Dame Cicely Saunders (Saunders, 2000, 2001). Trained as a nurse, social worker, and physician, she addressed the physical, emotional, and social needs of dying patients. Saunders also addressed patients’ spiritual needs for security, self-worth, and finding meaning and purpose in life, thus establishing holistic foundations for modern hospice (Campion, 2011; Saunders, 2001). From observing and caring for thousands of dying patients, Saunders simply stated, “Care of the dying demands all that we can do to enable patients to live until they die. It includes care of the mind, spirit, body, and family of the patient. All these are so interwoven that it is hard to consider them separately” (Saunders, 1965, p. 71).

The “nature of nursing” described by Virginia Henderson (1964, 1980) reflects a holistic framework for nursing care from birth to death. She believed that the concept of holistic care was applicable for patients at all ages suffering physically, psychosocially, and spiritually. Henderson (1964) acknowledged that “even more important, in my concept of nursing, is the nurse’s effort to assist the patient toward a ‘peaceful death’ by facing it with him honestly and courageously” (p. 66). Because of this ‘holistic’ framework, Henderson (1978) suggested a broad-based education in a variety of clinical settings for students. Besides a variety of practice settings, Henderson (1978) emphasized that the most successful nursing preparation included opportunities for students “to have the satisfaction of seeing the care they themselves give hasten a person’s recovery, help a person cope with a handicap, or die in peace when death is inevitable” (p. 30).
Hospice Care

The concept of “total pain” was espoused by Dame Cicely Saunders while caring for hospice patients and conducting research on pain control in terminal illness between 1958 and 1965 (Clark, 1999; Saunders, 2000). Saunders discovered that constant physical pain could be controlled by regular doses of opioids, a regimen not common at the time. Regular dosing enabled patients to be free of pain and more communicative with family members. Saunders also discovered other dimensions of suffering, such as mental distress, social problems, emotional difficulties, and spiritual distress. Saunders found that “Mental distress may be perhaps the most intractable pain of all,” requiring other skills such as attentive listening or hearing to discover root causes (Saunders, 1963, p. 197). By addressing suffering in all these dimensions, terminally ill patients could achieve relief of “total pain” (Clark, 1999). This approach to EOL care became a defining feature of hospice care.

Through her work at St. Christopher’s and St. Joseph’s Hospice in London, where dying patients were cared for separately from hospitalized patients, Saunders observed how “being with” as opposed to “doing to” affected patients (Buck, 2007; Clark, 1999, 2007; Saunders, 1965). She watched the Irish Sisters of Charity stay by patients’ bedsides to listen to them. Saunders noticed the effects of their silent presence on patients and families. The effects of someone “being with” or “being there” for patients and families resulted in patients having a decreased sense of anxiety and increased sense of safety and security (Saunders, 1965).

“Being with.” Saunders described the idea of “being with” as an interaction requiring emotional involvement through awareness of another’s experience (Haraldsdottir, 2011). According to Saunders, a “being with” interaction includes honest discussion, affirmation, and a mutual acceptance of thoughts, feelings, and responses to death or dying (as cited by
Haraldsdottir, 2011). Yet, “being with” interactions are often difficult for nursing students because of the lack of insight into another’s suffering, fears of sharing in the suffering, or fears of the emotional work required to cope with another’s suffering.

Eifried (2003) studied affective learning among nursing students after allowing them to listen to one another tell stories of encounters with suffering patients. She found through thematic analysis of interviews that students could “see, hear, and feel suffering” as if bearing witness to the suffering themselves (p. 60). Recurring themes from students’ bearing witness to suffering indicated an awareness of their own vulnerabilities. Major themes centered around: a) grappling with suffering, b) struggling with the ineffable, c) getting through it, d) being with suffering patients, e) embodying the experience of suffering, and f) seeing possibilities in suffering. Increased awareness of their own and another’s suffering expanded their internal frame of reference to empathize with suffering patients (Eifried, 2003; Williams & Stickley, 2010). Increased awareness of one’s attitudes, feelings, values, and expectations about death was considered a requisite for “being with” dying patients in a way that could bring comfort, support, and relief of loneliness (Halldorsdottir, 2007; Haraldsdottir, 2011; Saunders, 2000; Williams & Stickley, 2010). Saunders was accurate in realizing how skills of “being with” could meet the emotional and psychosocial needs of patients and families at EOL (Clark, 2007).

There is substantial evidence on the effects of nursing care that includes “being with” patients. Several authors have found that patients and families felt supported, a sense of security and relief, emanating from nurses’ physical, cognitive, and emotional presence (Clukey, 2007; Halldorsdottir, 2007; Smith, 2001). Clukey (2007) found that hospice nurses’ “being there” or “being with” the patient and/or family members stood out as the most helpful service provided before death. From the perspectives of bereaved family members, the physical act of ‘being
with’ or ‘being there’ communicated empathy, concern, respect, and strength to patients and family members.

Before the growth and specialization of palliative care, EOL education was primarily guided by the hospice philosophy of Cicely Saunders, founder of modern hospice (Ferrell & Coyle, 2010). In the United Kingdom (U.K.), hospices provided EOL materials to be taught in nursing schools (Kenny, 2001). The U.K. Department of Health developed and provided palliative care materials taught through modules within a nursing program (Arber, 2001; Bush & Shahwan-Akl, 2013). Each module separately addressed the physical, emotional, social, and spiritual aspects of care to assure that a holistic approach was underscored. The patient and family were emphasized as the unit of care in EOL (Egan-City & Labyak, 2010). Hospice presents a holistic model of care and remains a paradigm for EOL nursing care and education (Cassell, 1999; Purnell, Walsh, & Milone, 2004).

Recognizing hospice as a valuable service for providing patients and families quality EOL care outside the confines of a hospital setting, the U.S. established the Medicare Hospice Benefit (MHB) in 1983 (Connor, 2007; Lutz, 2011). Hospice care is still recognized as “a comprehensive, holistic approach to treatment that recognizes when impending death necessitates a change from curative to palliative care” (U. S. Department of Health and Human Services [HHS]. Center for Medicare & Medicaid Services [CMS], 2014). Without the need for extensive curative treatments found in hospital settings, hospice care could be provided in a personal residence, a care home, or hospice facility rather than in a hospital.

Currently 94% of hospice care is provided at a patient’s place of residence or an inpatient hospice facility (National Hospice and Palliative Care Organization (NHPCO), 2015). Twentieth century ‘Hospice care’ is comprised of interdisciplinary services including nurses, nursing
assistants, physicians, counselors, therapists, social workers, clergy, and volunteers who extend holistic EOL care into personal residences, nursing homes, hospice centers, or hospitals for all patients facing incurable, life limiting illness (Meier, 2011; NHPCO, 2015).

The U.S. Medicare Hospice Benefit enacted in 1983 was originally designed to cover hospice care for a finite period of time, roughly corresponding to a life expectancy of six months or less (Connor, 2007; HHS, CMS, 2014). Under the U.S. MHB, ‘terminally ill’ is defined as being medically certified to have a life expectancy of six months or less. To receive hospice care under the MHB, individuals who are terminally ill must revoke curative treatment and elect palliative care through a Medicare-certified hospice organization. Palliative care originated out of hospice and was commonly associated with MHB guidelines for a life expectancy of six months or less and the revocation of traditional curative treatment. General guidelines remain the same with medical recertification required if individuals survive past six months (HHS, CMS, 2014). Projected life expectancy determines level of palliative care for hospice admission or discharge status, which affects the EOL services patients have access to.

Palliative care has been found to be beneficial for patients whose conditions are unresponsive to curative treatment but for whom suffering could be palliated sooner rather than in the last six months of life (Hess et al., 2014; Irwin, Greer, Khatib, Temel, & Pirl, 2013; Irwin et al., 2013). Although the hospice model has long been associated with palliative care for patients with cancer diagnoses, a majority of patients currently enrolled in hospice have chronic, incurable diseases unrelated to cancer (NHPCO, 2015). Research and education on palliative care has extended to all patients approaching death, regardless of diagnosis (CAPC, 2015). As a result, palliative care has expanded into a specialty with an interdisciplinary approach to deliver holistic EOL care outside of hospice restrictions imposed by the MHB.
Palliative Care

A current view is that “palliative care outside hospice is offered independent of the patient’s prognosis and simultaneously with life-prolonging and curative therapies for persons living with serious, complex, and life-threatening illness” (Meier, 2011, p. 345). The palliative approach has had similar physical symptom relief and psychological benefits for those with incurable diseases such as Alzheimer’s, dementia (Ferrell & Coyle, 2002), end-stage kidney disease, heart failure, stroke (Fitzsimons et al., 2007; Mazzocato, Michel-Nemitz, Anwar, & Michel, 2010), and end-stage chronic obstructive pulmonary disease (COPD) (Irwin et al., 2013; Janssen et al., 2010; Ryan et al., 2013; Temel et al., 2010). There are greater needs for palliative care by patients with chronic diseases that are non-cancer related (NHPCO, 2015; Ryan et al., 2013; Wittenberg-Lyles, Goldsmith, & Ragan, 2011). Because many patient populations suffer from symptoms similar to patients with cancer, palliative care is appropriate sooner than at the last six months of life if providers can recognize deteriorating symptoms and initiate earlier access in the course of life limiting illness, regardless of diagnosis (Meier, 2011).

The World Health Organization (WHO, 2002) defined palliative care as an “approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (p. 84). This broadened view of palliative care outside the traditional restrictions of hospice has warranted distinct EOL and palliative care education, especially for nurses who make up the largest segment of health care providers in the U.S. (U.S. Department of Health and Human Services, Health Resources and Services Administration [HRSA], 2014).
Palliative and End-of-Life Care in Nursing Education

According to Henderson (1964, 1978), EOL care exemplified the essence of nursing, which was a holistic view that is maintained throughout nursing education. Some of her major recommendations for successful nursing education included a broad knowledge base of natural sciences (biology, anatomy, and physiology), as well as psychology, sociology, and humanities for understanding human needs and responses within the environment. Henderson firmly believed that the ability to recognize patient needs and develop clinical judgment would come with protracted time rather than brief encounters with patients (Henderson, 1978). Therefore, she strongly advocated for providing students with enough opportunities to practice so that they could experience the satisfaction from seeing the results of their own efforts with patients.

Currently, the time devoted to EOL education within those recommendations has varied across nursing programs, leading to questions about which combinations are best for improving students’ knowledge and attitudes toward care of the dying that become reflected in practice.

To help educators incorporate EOL content into nursing curricula, the AACN (1998) developed 15 EOL competencies specific to EOL care that all undergraduate nursing students should achieve before entering professional practice. The competencies were based on holistic principles of hospice. The AACN (1998) suggested several areas within existing nursing courses where competencies could be integrated. For example, competencies for assessment and treatment of pain and other symptoms of dying could be addressed in Health Assessment and Pharmacology courses. Communication and psychosocial assessment competencies could be addressed in Psychiatric and Mental Health courses. Patient care experiences for demonstrating competencies were not specified but are assumed dependent on individual program resources, clinical placements, and faculty.
Various formats have been used to incorporate EOL content into nursing curricula making it difficult to assess where EOL competencies have been addressed (Adesina, DeBellis, & Zannettino, 2014; Brajtman et al., 2007). One format is integration of EOL content throughout an entire nursing curriculum (Adesina et al., 2014; Brajtman et al., 2007). With integration, EOL topics are included in various courses taught throughout the program. Another format is a shortened time frame over days or weeks for concentrating on specific content, such as affective components of EOL care (Brien et al., 2008; Jackson & Motley, 2014). A third format is offering EOL content as a separate, semester-long elective (Arber, 2001; Ballesteros et al., 2014; Dobbins, 2011). Various formats have had positive effects on attitudes toward EOL care and increased knowledge, but are inconclusive for determining effects on practice (Bassah et al., 2014; Cavaye & Watts, 2010). Although much has been done to improve EOL care through education, results of the most effective formats and strategies have been inconsistent.

Evaluating research studies for effective EOL education has been challenging because of different outcomes used to measure success. The most common and reliable outcome measures for assessing and evaluating EOL education have been knowledge (Arber, 2001; Brajtman et al., 2007; Wallace et al. 2009; Kwekkeboom et al, 2005, 2006) and attitudes toward care of the dying (Barrere et al., 2008; Brajtman et al., 2007; Dobbins, 2011; Gillan et al., 2013; Mallory, 2003; Weissman, 2011). Measures of EOL knowledge have not been consistently reported to evaluate EOL education. Improved student attitudes toward care of the dying have been demonstrated after receiving EOL education. However, both knowledge and attitudes toward care of the dying have not been studied together in relation to experience with dying patients.

A common metric for evaluating EOL care has been satisfaction with the care received by a patient as ranked by their bereaved family members (Meier, 2011; National Quality Forum
Satisfaction scores have been obtained through surveys after discharge. Families have also been asked to rank various aspects of EOL care in priority from ‘most to least important’ (Cavaye & Watts, 2010; Hales, Zimmerman, & Rodin, 2010; Meier, 2011; Sadler et al., 2014). Psychosocial and emotional support during EOL have consistently been ranked as important contributors to satisfaction with care, yet provided the least by nurses and doctors (Brazil et al., 2013; Burge et al., 2014; Shiozaki et al., 2005). Quality EOL care for patients and families is the goal of EOL education. Low satisfaction scores among families indicate the need to improve affective skills of providers so that they can address psychosocial and emotional aspects of EOL care (Sadler et al., 2014).

Nurses from various practice settings have admitted that emotional aspects of EOL care have been the most difficult to provide (Arantzamendi, Addington-Hall, Saracibar, & Richardson, 2012; Cui et al., 2011; Mak, Chiang, & Chui, 2013). Yet, the need for EOL education has often been overlooked for nurses not regularly exposed to terminally ill patients (Bloomer et al., 2013). In several studies, nurses reported that lack of EOL education or experience during undergraduate preparation was a factor that negatively affected their attitudes toward EOL care (Cui et al., 2011; Kent, Anderson, & Owens, 2012; Peterson, Johnson, Scherr, & Halvorsen, 2013; Thompson, Austin, & Profetto-McGrath, 2010). Mutto et al. (2010) reported similar findings among students from a nursing program where no EOL education was provided. The authors found that students became more fearful about providing EOL care as their exposure to dying patients increased. By their senior year, students resorted to avoiding terminally ill patients in clinical settings. Thus, a fundamental approach suggested to improve quality EOL care is through EOL education early in the nursing education program as students build their knowledge base and attitudes toward professional patient care (IOM, 2015).
Student Experiences with Dying Patients

Students enter nursing with various backgrounds, experience, abilities, and motivation for becoming nurses, yet common fears are of harming a patient and/or experiencing the death of a patient (Beck, 1997; Hurtig & Stewin, 1990; Kav, Citak, Akman, & Erdemir, 2013). These fears are intensified by expectations to provide physical and emotional EOL care before acquiring the knowledge or skills to provide such care (Beck, 1997; Cavaye & Watts, 2010; Charalambous & Kaite, 2013; Strang et al., 2014). In a seminal study examining student concerns with EOL care as measured quantitatively, Milton (1984) found that students with emotionally upsetting experiences involving death in their personal lives had significantly higher anxieties and worries about having to provide EOL care, especially in the areas of emotional support and maintaining emotional composure. Such findings have led to more emphasis on experiential EOL education focusing on emotions in death, loss, and grief (Brien et al., 2008; Frommelt, 2003; Ying et al., 2011).

In a qualitative study of 26 nursing students, Beck (1997) found that nursing student death anxieties stemmed predominantly from feelings of inadequacy in knowledge and experience with EOL care rather than anxieties about their own death (Lehto & Stein, 2009). A student’s first experience of having to care for a dying patient often occurs in undergraduate education (61%) or within the first year after graduation (23%) (Kent et al., 2012). Nursing students have reported negative emotions that have affected their attitudes toward EOL care (Charalambous & Kaite, 2013; Cooper & Barnett, 2005; King-Okoye & Arber, 2014; Parry, 2011). An important finding was that students felt encouraged and relieved if they had supportive nurses to mentor them (Cooper & Barnett, 2005). Unfortunately, shortages in nurses
to mentor students in busy hospital settings make such support difficult to guarantee for students (Tanner, 2006).

In a qualitative study of 38 nursing students without specific EOL education, Cooper and Barnett (2005) found that early or first experiences with dying patients left students feeling emotionally anxious, “helpless, useless, inept,” (p. 429) and shocked from seeing the magnitude of patient suffering. Students coped with strong emotions by busying themselves with tasks or avoiding contact with patients. Some students suppressed their anxieties by talking about ‘happy subjects’ around dying patients and family members. Based on 25 reflective diaries and a focus group with 11 students, fears and anxieties were found to be due to feeling inadequate in how to manage their own feelings as well as what to say to help patients.

A consistent finding was that lack of familiarity with death, dying, or EOL care while being required to provide such care resulted in students avoiding patients physically or emotionally (Allchin, 2006; Charalambous & Kaite, 2013; King-Okoye & Arber, 2014). In addition, overwhelming emotions further compounded students’ doubts of how to act or respond around patients. The inability to provide physical or emotional care left some students feeling like ‘total failures’ (Ek et al., 2014). Without EOL education in nursing curricula, students felt uncomfortable and unprepared to provide EOL care, especially emotional or psychosocial care (Kav et al., 2013; Mutto et al., 2010; Strang et al., 2014). Such responses by students confirm the need for more specific EOL care education to prepare them for practice.

Barrere and Durkin (2014) conducted qualitative interviews and found that new nursing graduates who had participated in an EOL course as students were able to provide quality EOL care in their first experience with a dying patient, despite their initial fears. New nurses focused on facilitating a good death and balancing their own emotions to provide EOL care. Nurses
commonly practiced important strategies such as ‘holistic presence’ to listen actively while assessing and reassessing the needs of EOL patients and distraught families (Barrere & Durkin, 2014). Despite initial fears in their first encounter with EOL care, nurses were able to provide quality EOL care strategies recalled from an EOL course as an undergraduate.

The emotional labor required for care of the dying can be intense and exhausting, yet underestimated (Peters et al, 2013). Bailey et al. (2011) found that nurses in an emergency room setting were able to manage emotions in care of the dying by investing more time in the nurse–patient relationship mentally and emotionally. As a result, nurses found EOL care rewarding. Allchin (2006) found similar experiences with nursing students. Initial hesitancy and discomfort with dying patients subsided when students spent more time being involved with and getting to know their patients. A challenge for educators has been about where in the curriculum to provide both EOL education and clinical opportunities for students to develop affective skills needed to cope with the emotional labor in supporting patients and families at the end-of-life (Todaro-Franceschi & Lobelo, 2014).

**Guidance in EOL Education in Nursing Programs**

To provide more consistency in providing EOL education, the AACN and the City of Hope Medical Center in California initiated an End-of-Life Nursing Education Consortium (ELNEC), (AACN, 2015) to help nurses and students achieve the required competencies for providing quality EOL care. As a result, ELNEC created a modular curriculum to assist educators in teaching palliative and EOL care to nurses and students. The ‘Train the Trainer’ curriculum contains eight to nine modules that cover knowledge, attitudes, beliefs, and skills requisite to provision of holistic EOL care. Each module contains specific content with teaching exercises for educators to duplicate with students or nurses in their respective institutions. Single
modules can be taught depending on learning needs of students or nurses. The entire ELNEC curriculum can also be incorporated into curricula for a comprehensive knowledge base of palliative and EOL care.

The entire curriculum addresses competencies for holistic EOL care. Core principles of hospice and palliative care common in EOL education are included (Arber, 2001; Brajtman, Higuchi, & Murray, 2009; Kenny, 2001). Each module has thorough content on: (1) EOL nursing care, (2) pain management, (3) symptom management, (4) ethical/legal issues, (5) cultural considerations, (6) communication, (7) loss, grief, and bereavement, (8) achieving quality EOL care, and (9) preparation for care at the time of death. With the competencies systematically supported by ELNEC for core content, teaching strategies, materials (syllabus, books, CDs), and educator training, EOL education and evaluation has become less ambiguous and more standardized.

With identified competencies and structured content for EOL education, core principles have been easier to identify and measure in terms of student knowledge and attitudes toward care of dying patients. The most common indicators examined for determining successful EOL education have been improved knowledge and attitudes toward EOL care (Frommelt, 1991, 2003; Lange, Shea, Grossman, Wallace, & Ferrell, 2009; Mallory, 2003).

**Formats for Palliative and EOL Education**

Of the various formats studied for providing successful EOL education, the most common formats used to teach and evaluate EOL knowledge and attitudes are described in this literature review.

**Integrated format.** Integrating palliative and EOL care content into existing nursing curricula is the most common educational format used in the U.S. (Dickinson et al., 2008;
Todaro-Franceschi & Lobelo, 2014), Canada (Wilson et al., 2011), and in the U.K. (Cavaye & Watts, 2010). Specific EOL content is ‘threaded’ (Adesina et al, 2014) or ‘embedded’ (Brajtman et al., 2007; Ramjan, Costa, Hickman, Kearns, & Phillips, 2010) into existing courses as described by the AACN for integration. Typically, one or two lectures from existing courses are devoted to specific EOL topics, either from ELNEC modules or other sources (Frommelt, 2003; Todaro-Franceschi & Lobelo, 2014). Educators teach topics appropriate for their existing courses and expertise, therefore integrated EOL content is taught by various instructors and across various courses throughout the curriculum.

Palliative and EOL knowledge. Measures of palliative and EOL knowledge have been obtained for two major purposes. The first has been to assess the state of palliative and EOL content in nursing curricula (Al Qadire, 2013; Wallace et al., 2009). The second purpose has been to evaluate and quantify the success of implemented EOL education strategies (Brajtman et al., 2007; Loftus & Thompson, 2002). A common instrument used for measuring palliative and EOL knowledge is the Palliative Care Quiz for Nurses (PCQN) (Ross et al., 1996). The PCQN has demonstrated strong reliability with students and nurses to assess knowledge or misconceptions in three main areas of palliative care: 1) major principles of palliative care, 2) symptom management, and 3) psychosocial and spiritual care (Adriaansen & van Achterberg, 2004; Brazil, Brink, Kaasalainen, Kelly, & McAiney, 2012). Another instrument used for measuring knowledge is the Knowledge Assessment Test (ELNEC-KAT) (Lange et al., 2009). This 50-item instrument has demonstrated strong internal consistency (KR-20=0.84) and is specific for assessing knowledge from all the ELNEC modules among English-speaking undergraduate nursing students (Lange et al., 2009).
Knowledge has not been consistently reported among studies evaluating integrated EOL content. In one study, all nine ELNEC modules were strategically integrated throughout the curriculum (Barrere et al., 2008), but knowledge was not specifically assessed. In another study, a few core EOL topics were threaded into existing nursing courses (Adesina et al., 2014), but knowledge was assessed using qualitative feedback to open-ended questions. Evidence of improved knowledge about palliative and EOL care resulting from integrated content has been inconclusive due to differences in reporting and instruments used to measure knowledge.

**Palliative and EOL knowledge without focused EOL education.** To assess the state of students’ EOL knowledge in curricula, Wallace et al. (2009) found that seniors had higher palliative and EOL knowledge scores than sophomores in a nursing program without any integrated EOL content. Knowledge was measured once with the ELNEC-KAT (Lange et al., 2009), which represents content from all nine ELNEC modules. The senior mean score (83.2%) was statistically higher than the sophomore mean score (60.9%), indicating improvement with maturation through the program without any integrated EOL content. A majority of the students (95-96%) reported not having received any palliative or hospice education (Wallace et al., 2009). Although not extensive, experience with dying patients increased incrementally over time as 15% of sophomores reported experience compared to 37.5% of seniors. In written feedback from students, they desired more EOL knowledge and experience with dying patients.

**Palliative and EOL knowledge with integrated content.** Brajtman et al., (2007) assessed palliative care knowledge among 58 nursing students from two nursing programs in Canada where similar palliative and EOL topics were integrated into existing courses of both programs. After a one-time completion of the PCQN and written feedback to open-ended questions, the overall average score of correct answers on the 20-item quiz was 61%, or 12
correct answers. Although values were not reported, authors found that seniors scored higher than freshmen, indicating improved palliative and EOL knowledge over time with integrated content. From demographic data, 26% of freshmen reported having had experience with care of the dying compared to 91% of seniors reporting experience. It is unclear whether improved scores were influenced most by integrated content, increased experience with dying patients over time, or both.

Brajtman et al., (2007) also interviewed key educators about the integrated content. Clinical educators expressed noticeable deficiencies in students’ knowledge of what to do or say in actual clinical settings around dying patients. Although palliative and EOL knowledge improved between the freshmen and senior year, clinical educators did not observe the effects on EOL practice. With EOL content integrated and increased exposure to dying patients over time in the nursing program, students revealed that they desired more knowledge of EOL care and mentoring by nurses with EOL care experience (Brajtman et al., 2007).

End-of-life knowledge scores increased over time with and without integrated content, which does not suggest a strong influence by integrated EOL content (Brajtman et al., 2007; Wallace et al., 2009). But results were incomparable since different instruments were used to measure knowledge. The 20-item PCQN instrument was developed to assess basic understanding and misconceptions of palliative care (Ross et al., 1996). The 50-item ELNEC-KAT instrument was specifically developed to assess knowledge of content from all ELNEC modules (Lange et al., 2009). Increased experience with dying patients was a common factor noted in both nursing schools, which suggests the influence of experience with dying patients on EOL knowledge.
Current state of palliative and EOL knowledge. In assessing nursing students’ baseline knowledge of palliative and EOL care as measured by the PCQN, several researchers have found that knowledge was very limited or altogether deficient (Adesina et al., 2014; Pope, 2013; Sadhu, Salins, & Kamath, 2010; Watts, 2014). Karkada, Nayak, and Malathi (2011) found that over half of students were unaware of the term ‘palliative care’ and others were unclear about the difference between palliative and EOL care.

In a descriptive study, Al-Qadire (2014) assessed baseline palliative and EOL knowledge in 220 nursing students from five schools in Jordan. Concerning previous EOL education, 63% of respondents reported not having received any formal palliative education and 26% reported having received some education. Based on item analysis of the PCQN, a majority of students had misperceptions of palliative care. Students believed palliative care required emotional detachment (69%). They believed drug addiction was a major problem with long-term morphine use (67%), and that suffering was synonymous with physical pain (71%). The total mean of correct responses on the PCQN was 40%. Authors concluded that palliative and EOL education was clearly insufficient for preparing students to provide basic EOL care.

Adesina et al. (2014) surveyed third year (senior) nursing students from a school without any integrated EOL content to survey attitudes, experiences, knowledge, and educational preparation for care of the dying. The aims of the study were to explore factors that influenced their EOL care and find out if students felt that nursing education prepared them to provide EOL care. Researchers analyzed students’ written responses to 12 open-ended questions about personal values, beliefs, and thoughts about death and dying. Students were also asked to describe their experiences with care of the dying and if any specific ethical issues or legislation influenced their EOL care.
Based on 87 surveys, authors identified five themes: 1. *Personal beliefs*. Students with an identified personal belief system, whether religious, scientific, or spiritual, reported feeling more secure and less fearful about death. 2. *Experience in care of a dying person*. Students with more experience had more positive attitudes and confidence to provide EOL care. 3. *Concept of a good or bad death*. Concepts of a good death involved not being in pain while a bad death involved pain and suffering. 4. *Legal and moral responsibilities*. Students felt that EOL care was based on legal and moral responsibilities, particularly with the issue of euthanasia. 5. The need for *adequate knowledge about EOL care*. Most students felt that they were not knowledgeable enough about EOL and palliative care and (63%) felt inadequately prepared to care for a dying patient. However, all students felt that EOL and palliative care should be a core subject because dying patients will be encountered in multiple areas of acute and intensive care, not just in hospice or palliative care areas.

Students from the Adesina et al. (2014) study could identify factors that influenced their EOL care but described a cursory understanding of EOL care. Their concept of a good or bad death centered on the presence or absence of pain without mention of emotional factors. Rather than knowledge or experience from the nursing program, students mentioned experience with a dying family member or patient from previous work experience as having positively influenced their EOL practice. The authors concluded that students had insufficient EOL preparation. They further recommended qualitative interviews or focus groups to obtain richer data on student experiences of EOL practice.

**Providers.** A general lack of knowledge is a known barrier to quality EOL care (Arthur & Bruera, 2013; IOM, 1997, 2015; Meier, 2011). Part of the knowledge deficit is lack of clarity about when and how to discuss the best options for EOL care (Arthur & Bruera, 2013; Meier,
Lack of clarity about palliative or hospice care has been correlated to communication difficulties with patients and families (Hui et al., 2014). Confusion between palliative and hospice care has resulted in misunderstanding by patients, delays arranging terminal care, and inconsistencies transitioning to EOL care (Hui et al., 2014). Lack of knowledge or clarity about the options for EOL care, even if unintentional, results in unnecessary suffering for terminally ill patients, which is unacceptable (IOM, 1997, 2015). Therefore, knowledge of palliative, hospice, and EOL care must be included as measures of successful EOL education.

**Effects of integration on attitudes toward care of the dying.** Emotions about death and care of the dying are reflected in attitudes, which encompass feelings, values, and beliefs. Negative emotions have clearly demonstrated an effect on EOL care among students (Cooper & Barnett, 2005; Ek et al., 2014; King-Okoye & Arber, 2014). Attitudes, as measured by the Frommelt Attitudes Toward Care of the Dying scale (FATCOD) (Frommelt, 1991), have shown improvement among students from programs with integrated ELNEC content (Barrere et al., 2008; Weissman, 2011). The FATCOD scale has frequently been used to measure attitudes among nurses and students because of its emphasis on affect towards dying patients and their families (Frommelt, 1991, 2003).

Barrere et al. (2008) examined demographics and attitudes toward care of the dying in 103 nursing students from a Baccalaureate nursing program with strategically integrated ELNEC modules throughout the curricula. Along with demographic data, student attitudes were measured by the FATCOD at the start of their junior year and again at the end of their senior year. Accelerated students were included and took the FATCOD before and after their yearlong program. As part of the demographic data, students were asked their level of education and if they had any education and experience with individuals who were dying. Researchers found that
attitudes had significantly improved from pre to posttest. Another finding was that younger age of the student and having had no previous experience with terminally ill individuals were the most statistically significant predictors for changes in improved attitude. Students between ages 22 to 25 who had no prior experience with terminally ill individuals before entering the program showed the most significant improvement in FATCOD scores. Such findings support integrated content for improving student attitudes toward care of the dying, especially those between ages 22-25 and with no prior experience with the dying.

**Effects of integration with no clinical experience.** Of the studies evaluating integrated palliative and EOL content, none provided a clinical component specific for EOL care experience to evaluate improvements on student practice. Historically, opportunities to apply palliative and EOL care concepts have depended on clinical experiences from other courses for exposure to terminally ill patients. From one study, 41% of students who participated had no experience with care of a dying patient (Adesina et al., 2014) and in another, 76% had no experience (Weissman, 2011). In Barrere et al.’s (2008) study, by the time of completion from their respective nursing programs, 26% of traditional students and 41% of accelerated students reported having had no experience in care of the dying. In Wallace et al.’s study (2009), 84.6% of sophomores and 62.5% of the seniors had no hospice or palliative care experience. Results from such studies on the effects of EOL education are incomplete in that students’ responses on measures have reflected theory with limited or no actual experience with care of dying patients.

Self-reported evaluations of knowledge and attitudes toward care of the dying have been suggested as proxy measures for estimating how students would practice EOL care (Barrere et al, 2008). From the studies discussed, knowledge and attitudes toward care of the dying have been the primary measures used to assess effectiveness of EOL education. The effect of integrated
EOL content on knowledge was inconclusive yet positive for improving attitudes toward care of the dying. Whether content was integrated or not, most students desired more knowledge and experience with EOL care. Self-reported evaluations of attitudes toward care of the dying would be more accurate if students were assured experience with dying patients from which to base their responses.

**Debates on integrating EOL content.** Although the AACN suggested ways to integrate EOL competencies and ELNEC initiatives have made integrating EOL content more comprehensive and systematic, research on knowledge and subsequent practice is lacking. One argument in support of integration is the flexibility to spread teaching responsibilities across several instructors and courses (Ramjan et al., 2010). Others argue against EOL education by various instructors because of their different areas of expertise and levels of preparation for teaching EOL care (Adesina et al., 2014; Arber, 2001; Bassah et al, 2014; Todaro-Franceschi & Lobelo, 2014). Some authors argue that EOL education taught in discontinuous courses may fragment learning and be forgotten if not strategically coordinated with clinical experiences (Carman, 2014; Komprood, 2013; Mallory, 2003). However, other educators contend that EOL integration across the entire curriculum allows for palliative and EOL concepts to be reiterated as students increase their knowledge base (Barrere et al., 2008; Ramjan, et al. 2010). Integrating palliative and EOL content into curricula has had questionable effects on knowledge, but positive effects on improving attitudes toward care of the dying.

A concern about an integrated approach is that not enough time is given to EOL content, thereby diminishing the importance of palliative principles necessary for holistic EOL care in many settings (Coenen, Doorenbos, & Wilson, 2007; Todaro-Franceschi, 2011). In a qualitative study, Watts, (2014) found that senior nursing students’ initial understanding of palliative care
was superficial, being associated mostly with cancer. Only one student recounted a more inclusive definition of palliative care because of a palliative module in class and a palliative care clinical experience. Improvements in knowledge and attitudes toward care of the dying have been inconsistent using an integrated approach to education.

**Shortened formats.** Rather than discontinuous EOL lectures integrated throughout a nursing program, shortened formats (less than a semester long) have been designed to target specific affective EOL competencies, such as recognizing one's attitudes, feelings, values, and expectations about death. Individual cultural beliefs and spiritual customs have also been included (Competency #4, AACN, 1998). The thought of physical death or caring for a dying person can produce highly emotional concerns and preconceived ideas that affect care (O’Grady et al., 2012; Sanford, Townsend-Richiccioli, Quiett, & Trimm, 2011; Wardhere, 2014). Emotional aspects of EOL care are especially difficult for students (Ek et al., 2014; King-Okoye & Arber, 2014). Shortened formats consisting of didactic content and experiential exercises have been successful in promoting self-reflection of personal feelings and attitudes toward death, dying, and EOL care (Bailey & Hewison, 2014; Weissman, 2011). However, when caring for the dying in a clinical experience, students were unsure of how to handle their own feelings of helplessness. During such vulnerable moments, the presence of sensitive staff, instructors, or fellow students has been found supportive. Authors advocate for clinical experience in care of the dying, but under supportive circumstances (Allchin, 2006; Brien et al., 2008; Pederson & Sivonen, 2012; Poultney et al., 2014).

Brien et al. (2008) studied students’ social and affective learning after participating in experiential exercises in class over four weeks. The authors held four, weekly sessions (three hours each week) for second year, Canadian nursing students. The mandatory course included
In this study, students were engaged in a variety of activities including lectures, case studies, and documentary film viewing. The entire class of 197 students was divided into smaller groups led by faculty members, each group facilitated experiential activities to promote introspection about death and dying. Activities included interactive role-play, personal presentations on meanings of death, and reflective journaling. Before the course began and at its completion, students were asked to journal their responses to several questions from the FATCOC scale. Faculty facilitators evaluated social competencies by observing students in different role-play scenarios. Affective competencies were assessed from a sample of 45 student journals out of 137 submitted.

Brien et al. (2008) found differences between student and facilitator evaluations of ‘meaningful learning.’ For facilitators, minimal student participation indicated minimal affective or social learning. Facilitators had difficulty interpreting student reactions in small groups. Student responses such as crying, recoil, reluctance, aggression, or passivity were difficult for facilitators to interpret as meaningful learning. Journals revealed a reverse response by students who found the emotional nature of reflective exercises in small groups as the most meaningful learning experiences. Students also expressed a greater awareness and understanding of empathy, compassion, and the nurse’s responsibility for relieving patient suffering and providing emotional support to families.

Although not outwardly evident to facilitators, the course was effective in evoking emotions students recognized as difficult. Therefore, Brien et al. (2008), concluded that the course promoted affective learning and improved attitudes toward care of the dying.

Ying et al. (2011) conducted a similar study in two half-day classes (three hours each) among first and second year students from Taipei, Taiwan, focusing on responses to their own
KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING

death. Reflective exercises were used to evoke emotional responses from students. They were asked to imagine their lives ending in 30 minutes and to write a letter to those left behind. They were also asked to write their own epitaph and journal any reflections. After the exercises, students were divided into smaller groups with a teaching assistant present to encourage them to share their responses. The purpose of the study was to describe students’ responses after imagining and preparing for their own death.

Based on responses in small groups and written journals, students were surprised by the wide range of emotions experienced. They felt shock, sadness, and reluctance to ‘let go’ of life. Most of the students cried as they wrote the letters. However, students also expressed gratitude, appreciation for friends and family, heightened awareness of cherishing the present, and greater admiration for the nursing profession. They identified similar feelings and beliefs about death shared by others (Ying et al., 2011). Some expressed relief after realizing they were not alone in their responses to death. The authors concluded that the two-day course helped students experience contrasting emotions that occur at EOL.

**Shortened formats with broad content.** Lockard (1989) found that participation in a seven-hour death education unit covering broad topics about death and dying decreased the level of death anxiety in nursing students. In an experimental group, students volunteered to participate in a death education unit taught over two weeks. Students not enrolled in the death education unit but from standard nursing courses volunteered to participate in a control group. Death anxiety was measured by the Death Anxiety Scale (DAS) (Templer et al., 2006), which is a ‘true/false,’ 15-item questionnaire that asks if students fear: discussing death, life after death, seeing a dead body, getting cancer, or dying a painful death themselves. Death anxiety in the experimental group decreased immediately after the seven-hour course and remained decreased
when measured four weeks after the course and then again one year later. In the control group, death anxiety remained unchanged when measured at the same intervals. The author concluded that the material provided an awareness of personal death and dying enough to decrease anxiety over one year.

Lockard’s (1989) study focused on personal death anxiety as a factor that can potentially influence patient care. However, research indicates that student anxieties are related to lack of EOL knowledge, lack of practical experience with terminally ill patients, and lack of understanding affective responses at EOL (Ek et al., 2014; Mutto et al., 2010; Parry, 2011). Although death anxiety diminished, a broad course on death education did not address anxieties related to patient care. Seven hours to cover such a broad scope of information may have been sufficient for increasing personal awareness of death, but insufficient for application beyond self-understanding.

Jackson and Motley (2014) presented selected topics from eight ELNEC modules in one 4.5-hour workshop with 106 senior nursing students. At the end of the mandatory workshop, 106 students completed a course evaluation rating each module from 1=poor to 5=excellent in clarity, content, and strategy used to present information. Students also listed information they considered most helpful for nursing practice. A majority listed signs and symptoms of imminent death, communicating about death, the holistic aspect of care, and self-care. Yet, when asked to list topics that should have been covered, students listed: dealing with anger and denial of family members, types of ‘Do Not Resuscitate’ (DNR) orders, self-care strategies, and ‘how’ to communicate with non-verbal patients, all of which are topics included in ELNEC modules. Given the brief amount of time to cover all eight modules, depth of coverage was undoubtedly limited.
The researchers noted contrasting responses from students’ reflective papers written about the course (Jackson & Motley, 2014). One student questioned her ability to successfully communicate about EOL after learning that body language could show her own discomfort with death and dying. Another student realized that dealing with the emotional needs of dying patients and family was more challenging than learning technical skills. In contrast, one student felt more confident about future EOL care after learning how sensitive and empathetic care can facilitate a peaceful death. Another student learned that being present with dying patients and listening were effective interventions that could have more ‘meaning’ than technical tasks at EOL. Repeated themes included holistic care of the patient and family, meeting emotional needs, and effective communication. Although some key concepts were identified, it was not clear how many of the students were able to identify them. Students provided feedback immediately after the workshop, making it uncertain if students understood how to apply concepts in practice. Jackson and Motley (2014) recommended further research on the amount and types of education effective for preparing students with the reality of patient death.

Mallory (2003) studied the effects of a six-week ELNEC educational component on nursing students’ attitudes toward care of the dying and compared them to a control group of students who were not exposed to the ELNEC educational component. The ELNEC component involved weekly didactic education and experiential exercises provided within each ELNEC module. Other experiential activities included visiting a cadaver lab, a funeral home, and spending one day observing palliative patients receiving care from an interdisciplinary team. The author found that posttest attitudes were significantly improved in the ELNEC group but not in the control group.
The author concluded that student attitudes toward care of the dying were positively affected by systematic ELNEC content and experiences to reinforce EOL content. However, the author recommended extending the course to a full semester in order to allow time for students to implement content into clinical experiences.

Bailey and Hewison (2014) conducted a single day, workshop called ‘Critical Moments’ with experiential exercises allowing nursing students to explore their own emotions about death and dying before attending six weeks of critical care clinical experience. The purpose of the workshop was to enable students to explore emotional components of care and work through the emotional labor required to manage their intense feelings in care of the dying. Exercises included real case scenarios for discussion, small group sharing, and presentations from each small group on the scenario study assigned. Students were also informed of resources for seeking support if needed during clinical experiences. Attitudes toward care of the dying using the FATCOD were measured before and after the workshop.

Open-ended questions for students’ written comments about the course were also included with the FATCOD. Posttest attitudes were significantly improved. Qualitative comments from students about the workshop revealed three themes: 1) preparation for practice in critical care, 2) peer support within the workshop to express thoughts, and 3) theories about death and dying. With real case scenarios discussed and worked through in smaller groups, students felt that the workshop gave them confidence enabling them to break bad news. Students felt supported by peers who identified with similar emotional responses to death. Small group discussions made students feel comfortable with sharing their experiences. Students also related theoretic EOL concepts to past experiences. The timing of the workshop prior to a six-week critical care experience was appropriate for preparing students to work through and cope with
emotionally difficult situations. Focus groups with students after their six-week clinical experiences could have provided richer detail about their recall or application of EOL concepts in practice.

**Disadvantages of shortened formats.** Although shortened formats made students more aware of emotional responses in EOL, authors admitted that it was difficult to predict how such awareness would impact future practice (Brien et al., 2008). Greater emotional awareness and recognition of abstract concepts such as respect, empathy, and dignity in a classroom setting does not assure that students can appropriately apply such concepts in clinical. Other authors were concerned that EOL concepts learned in short courses would lack reinforcement through clinical application because experience with dying patients could not be guaranteed in clinical settings (Gillan et al., 2013, Gillan, Jeong, & van der Riet, 2014b; Lockard, 1989; Mallory, 2003).

McKenna and Rolls (2011) found that students experienced shock, fear, abandonment, and helplessness, after witnessing an unexpected death for the first time in a clinical setting. To make sense of the experience, students sought support from peers, family, friends, and clinical educators for several days or months after the death. The authors suggested preparing students with EOL knowledge and clearly identified support strategies before encountering a death in the clinical setting. Poultney et al. (2014) argued that students needed time in a supportive environment, such as a classroom among peers, to reflect on their own values and emotional responses to death before facing dying patients. Consequently, longer formats for EOL education have been implemented to reinforce content and give students time to assimilate the concepts into their other course clinical experiences if applicable.
Separate Course for EOL Education

Effects of palliative and EOL education on attitudes toward care. Student attitudes toward death and care of the dying have been significantly improved after attending EOL education offered as a distinct course, for at least 12 weeks or more (1 semester), (Dobbins, 2011; Frommelt, 2003; Hwang, Lin, & Chen, 2005). A longer format allowed time for providing didactic content and experiential strategies for students to explore their thoughts and emotions about death while receiving support from faculty and peers (Ballesteros et al., 2014; Dobbins, 2011). More time has allowed for comprehensive coverage of the physical and psychosocial aspects of death, dying, grief, and loss (Frommelt, 2003; Poulney et al, 2014). Despite various teaching strategies described across several studies, student attitudes have improved after a semester-long, EOL or death elective course.

Based on Knowles’ (1984) Adult Learning theory, Frommelt (2003) conducted a quantitative study and found that a semester-long (15-week) elective on death education improved attitudes toward care of the dying among college students. Attitudes were measured using the FATCOC scale (Frommelt, 1991). Students voluntarily enrolled in the death education elective. A control group of students who attended other classes volunteered to participate by completing the FATCOC at intervals. The elective included didactic and experiential teaching strategies using active role-play and case study discussions. The course covered broad topics related to loss, grief, death, dying, and bereavement. Although specific EOL knowledge was not assessed, attitudes from pretests to posttests were significantly improved in the death education group but remained unchanged in the control group.

According to Adult Learning theory by Knowles (1984), adults are characterized as independent and self-directed learners. They seek out resources and orient their learning toward
practical application for social or work roles (Knowles, 1984; Smith & Bar, 2002). Self-selection into the elective group may have indicated pre-existing biases or motivations not present in students from the control group. Demographics from Frommelt’s (2003) study revealed that students in the death education group majored in ‘Nursing’ (42%) and ‘Psychology’ (24%). Students in the control group majored in ‘Physical therapy’ (85%) or ‘other’ (15%). In keeping with Adult Learning theory, nursing and psychology students may have been more motivated to learn about death education as applicable to their majors than physical therapy majors and other students. Notwithstanding self-selection, the death education course significantly improved attitudes toward EOL care among college students majoring in nursing and psychology.

In a similar study, Dobbins (2011) examined attitudes toward care of the dying between an experimental and control group of Associate Degree Nursing (ADN) students. End-of-life knowledge and previous experience with dying patients were not assessed. Students in the experimental group were enrolled in a semester-long (14 weeks) elective incorporating all nine ELNEC modules taught by ELNEC-trained instructors. Teaching strategies for this group included dialectic discussion, viewing of the film *Wit* (Edson, Thompson, & Nichols, 2001), and visits to a hospice and funeral home. Students not in the elective but enrolled in a required, senior-level, medical-surgical (Med/Surg) course agreed to participate as the control group. This group received one, three-hour EOL lecture by an ELNEC trained instructor. The lecture was integrated into one Med/Surg class. Using the FATCOD scale, attitudes were measured in both groups before and after the semester. Posttest attitude scores in the elective group were significantly improved, whereas, scores in the control group remained unchanged. Results
indicated that a semester long EOL elective with ELNEC modules and experiential strategies were more effective than one three-hour lecture for improving attitudes toward care of the dying.

Dobbins’ study was based on Mezirow’s (1997) Transformative Learning theory, which is based on characteristics of adult learners. Adult learners have presumptions, beliefs, or judgments from previously acquired experiences that have shaped their frames of reference for learning (Kitchenham, 2008; Mezirow, 1997). According to the theory, learning occurs through critical self-reflection of beliefs and assumptions, primarily through experiences that foster dialectic discourse with others to find new meaning.

This theoretic background is appropriate for Associate degree nursing students, who often are older than traditional students and have had prior work experiences in a non-health related field (National Center for Health Statistics, 2011; Kovner, Brewer, Katigbak, Djukic, & Fatehi, 2012). Based on this theory, experiences are central sources for challenging old beliefs and stimulating critical self-reflection and judgment (Kitchenham, 2008; Mezirow, 1997, 2003). Thus, Dobbins’ teaching strategies included dialectic discussion and experiences that allowed students to examine and analyze EOL concepts and critically judge previous assumptions or old beliefs about EOL for new meaning. Such strategies were successful in transforming ADN students’ attitudes toward care of the dying. However, EOL knowledge was not assessed. The lack of EOL knowledge has been found to significantly affect students’ feelings of inadequacy (Beck, 1997; Cavaye & Watts, 2010; Charalambous & Kaite, 2013).

**Effects of palliative and EOL education on practice.** An important goal in EOL education is to enable nursing students to provide palliative and EOL care, which benefits patients and families while positively reinforcing students’ competence in practice. Researchers have used qualitative approaches to explore the impact of an EOL course on students personally
and on their nursing practice. For example, qualitative surveys have been used with nursing
students. Students were asked to write their thoughts to specific questions on a survey form
(Ballesteros et al., 2014; Bush & Shahwan-Akl, 2013; Muñoz-Pino, 2014). Results of two
studies using qualitative surveys suggested positive effects of EOL education on practice
(Ballesteros et al., 2014; Bush & Shahwan-Akl, 2013).

Bush and Shahwan-Akl (2013) conducted a study to determine if an oncology/palliative
care elective helped third year nursing students provide palliative care in a clinical setting. Using
a questionnaire with Likert-scale responses, students who had completed the course were asked
“To what degree the elective influenced their perceived abilities to care for terminally ill
patients, their understanding of palliative care practices, and the likelihood of choosing to work
in palliative care in the future.” Students were also asked to write responses for each question.
From 51 surveys, researchers found that the elective influenced students’ perceived abilities to
give palliative care to some degree, with 57% of students answering “large degree” and 43%
answering “moderate degree.” Twenty-five students (50%) reported desiring an
oncology/palliative position in the future. Many students commented on how applicable the
course content would be for ‘future palliative care.’ Several others commented in past tense that
the course gave them confidence to practice palliative care. It was not clear whether students
had applied the content already or not.

The authors did not assess how much experience students had with terminally ill patients
or examples of how they applied the course content. Therefore, it was difficult to determine how
the course influenced EOL care. Fixed responses such as “moderate degree” or “large degree,”
did not provide details about what students applied in practice. Written comments were not
specific regarding communication, assessment, physical care, or psychosocial support of dying
patients and families. Students generally addressed the fixed categories from the questionnaire. Although not the focus of this study, EOL knowledge was not assessed, which previous researchers have determined is a deficiency contributing to student anxiety when faced with care of the dying (Ek et al, 2014; King-Okoye & Arber, 2014). From Bush and Shahwan-Akl’s (2013) study, it is unclear whether or not students applied the content in experiences with terminally ill patients.

Ballesteros et al. (2013) conducted an exploratory study to determine how an optional Palliative Care (PC) course contributed to nursing preparation of second and third year nursing students from two schools in Spain. Both schools provided the same PC course. Data were obtained from participants who had completed the elective. The course included lecture, small group discussion, and audio-visuals. Additional clinical experiences were not offered with the course nor were students asked about prior experience with dying patients. Students were asked to write responses to one question: ‘What was the contribution of the PC course to your nursing training?’ Data were collected between 2006 and 2010 at one school and between 2005 and 2011 at another school for a total of 236 responses from students who had completed the course.

Four major themes emerged from Ballesteros et al.’s (2013) study as contributing most to students’ training. The first two themes centered on patient care. The first was realization of the comprehensive scope of nursing as a discipline. Students realized the priority of ‘humanizing care’ at the end of life by focusing on other dimensions of the whole person, such as social and emotional needs. Until taking the palliative course, students expressed the technical focus of care from other courses. The second theme expressed was greater confidence in knowing what to do and say around dying patients and families. Because the course made them aware of what
patients’ and families’ experience at EOL, students felt ‘better trained’ to anticipate care and empathize with patients and families by ‘maintaining emotional communication.’

The third theme expressed was personal growth and development gained from reflecting on their own mortality and spiritual beliefs regarding death. Many students expressed personal growth after learning how to work through their own grief responses or unresolved fears from the past. Spiritual growth as a result of palliative or EOL education has not been reported in previous studies.

The last theme expressed was the belief that the EOL course reinforced important concepts learned in other courses, such as pain relief. In addition to pharmalogical treatments, students learned how to alleviate pain through holistic measures to enhance quality of life in all dimensions. Many students felt that the PC course completed nursing education by addressing care for patients and their families through the end of life.

One open-ended question generated themes revealing greater depth of affective learning than a questionnaire with several fixed responses (Bush & Shahwan-Akl, 2013). Although EOL knowledge was not measured, students provided insight on how concepts were helpful in resolving personal and professional situations recalled from the past, indicating some level of application in hindsight. Retrospective reflection helped students ‘feel better prepared’ for future practice. However, the authors recommended further research using focus groups to obtain more insight into whether a PC/EOL course really improves EOL care behavior, which is a major concern by other authors (Gillan et al., 2014b; Barrere & Durkin, 2014). The authors recommended future research using interviews or focus groups to gain insight into more specific application of palliative and EOL concepts with patients.
**Practical application of palliative and EOL education.** It is difficult to draw conclusions about practical application of palliative and EOL education due to inconsistent EOL care opportunities for students in the clinical setting and the self-report nature of the studies. A limitation cited in many studies is that self-report instruments have made it impossible to determine if the EOL education actually improved skills in caring for a dying patient and family or only improved students’ perceptions of their skills (Ballesteros et al., 2014; Bassah et al., 2014; Fluharty et al., 2012). Qualitative research methods have provided more insight into students’ application of EOL content with dying patients. However, the amount of experience students have had with dying patients has not been consistently reported in such studies. Therefore, it is uncertain if improved attitudes toward care of the dying have reflected actual practice enough to predict further application.

Students admit that providing emotional and psychosocial support are greater challenges than providing technical or physical care to dying patients (Ballesteros et al., 2014; King-Okoye & Arber, 2014). Yet, students desire experience with dying patients to gain confidence providing effective EOL care (Birkholz, Clements, Cox, & Gaume, 2004; Brajtman et al., 2007; Wallace et al., 2009). The paradox in students’ desire for experience is that they fear being unprepared, which they know could cause harm (Ek et al., 2014; Parry, 2011). Various experiential teaching strategies have been studied for allaying student fears about EOL care (Ballesteros et al., 2014; Barrere et al., 2008; Dobbins, 2011; Frommelt, 2003; Poultney et al., 2014).

**Enhanced experiential learning in palliative and EOL education.** Multiple experiential strategies have been used for introducing students to EOL content in a non-threatening environment. For example, ‘cinemeducation’ with movies, video clips,
documentaries (DiBartolo & Seldomridge, 2009; Dobbins, 2011) have been successful in helping students recognize complex emotions that dying patients and families experience at the EOL. Interactive role-play, communication exercises, and self-reflective journals have also been effective in helping students recognize and express their emotions, attitudes, and thoughts verbally and in written form (Brien et al., 2008; Ying et al., 2011; Kwekkeboom et al., 2006). Visits to a funeral home, hospice, and a palliative care unit have been incorporated in EOL courses to improve knowledge, emotional awareness, empathy for others’ suffering, and attitudes toward care of the dying (Mallory, 2003; Pimple, Schmidt, & Tidwell, 2003; Price et al., 2013).

Experiential strategies have improved knowledge and emotional awareness about EOL care, but there are few studies on the effects of such improvements on students’ care of dying patients (Ballesteros et al., 2014; Bassah et al., 2014). The amount of experience students have had with dying patients has not been assessed or consistently reported across studies (Bush & Shahwan-Akl, 2013; Pimple, et al., 2003; Price et al., 2013). In many studies evaluating an EOL course, planned experience with dying patients was not provided through the course. However, authors have referred to students’ exposure to dying patients from other courses with a clinical component (Bush-Shahwan-Akl, 2013). For greater evidence of best practices, studies examining the effects of an EOL course on student abilities to provide EOL care must include care-giving opportunities involving patients at EOL to be valid.

Hold, Blake, and Ward (2015) conducted a qualitative study using focus groups to assess learning from 19 BSN students after completing a palliative and EOL elective course. As part of the elective, students spent ten hours as ‘volunteers’ with hospice patients in conjunction with didactic and experiential ELNEC content in class each week for a full semester (15 weeks). Students were not allowed to provide physical care to patients, but spent time listening and
talking with their patients. At the end of the semester, focus groups were conducted and audio-recorded with a convenience sample of participants from the course. Each researcher independently conducted a thematic analysis of the qualitative data and then the group met to verify themes that emerged. Three themes emerged about how students learned: 1) from stories, 2) from being with the dying patient, and 3) from caring for the patients.

The quality of students’ sharing in focus groups provided insight into how and what students learned about EOL care. Students reported how attentive they were to stories told by patients and professional speakers who shared their expertise in class. One student admitted that she was attentive to speakers who were engaging but “would doze off” when a speaker taught from a slide projector/lecture format (Hold et al., 2015, p. 3). Different professionals came each week to share their experiences from practice, including a hospice nurse, a chaplain, a social worker, a palliative care nurse, and a professional harpist. Stories captured students’ attention.

Students also learned from their experience of being with dying patients. Through ten hours as hospice volunteers rather than physical caregivers, students learned how to know more about patients. Students recognized patient needs from listening and communicating in different ways. Students communicated without words but with smiles and being present. However, some students did not specify ‘other needs by patients’ and ‘other ways of communicating’, which made it difficult to know what needs were identified, whether psychosocial or physical. Students appreciated each experience describing it as “one on one, hands on, very personal,” compared to learning about it from sitting in a classroom. One student commented, “The true teachers in this course were the patients you saw” (Hold, et al., 2015, p. 3). A clear preference was made for learning through a personal encounter with a dying patient rather than listening to class content.
Finally, from planned visits with dying patients, students learned about caring for patients in the affective sense. A comment from one student was “I think I realized we make such a big impact, especially when people are dying. I think every little thing, they just grab it and they hold on to it. So we need to be more compassionate, and be more, I don't know, watch our actions and how we speak to them and show them that we care. I don't feel like I have to run out the door, you know, when they start crying or having all these emotions. I can actually sit there and talk to them” (Hold et al., 2015, p. 3). Such comments illustrate affective responses to the personal encounter and realizations of compassionate care needed at EOL.

Students did not mention fear or anxiety from any encounters. Perhaps the lack of fear and anxieties was due to the limited responsibilities students had as volunteers, which were to listen and interact instead of providing physical care. Focus groups were effective for eliciting students’ affective responses from personal encounters with dying patients.

**Theoretic Frameworks Guiding EOL Education**

**Bandura’s social cognitive theory of learning.** Bandura’s social cognitive theory of learning ([SCT], 1989) has been the basis for guiding several studies assessing behaviors or attitudes among health care providers. The underlying principle of improving one’s sense of self-efficacy or confidence through increased exposure and subsequent self-appraisal has been the basis for: expanding the knowledge and skill base for choosing appropriate interventions among nursing students (Burke & Mancuso, 2012), improving communication skills among medical students (Mason & Ellershaw, 2010), and exploring knowledge, attitudes, and self-efficacy in relation to pediatric pain management among pediatric nurses (Stanley & Pollard, 2013). The tenant of self-efficacy as proposed by Bandura involves self-reflection or appraisal of knowledge, affect, social situations, and personal efforts to assure lasting change (1989).
Increasing knowledge of EOL care and improving attitudes toward the care of the dying are proposed for creating lasting changes among nursing students. Adequate knowledge and attitudes are necessary to ensure that nursing students can deliver quality EOL care necessary in professional practice. Self-efficacy, which is the perceived ability to change or produce a desired effect, and self-appraisal, which is what one believes about self-efficacy, are needed in a profession where constant advances increase the complexity of providing care.

**Experiential Learning and simulated EOL experiences.** Based on SCT, (Bandura, 1989), Moreland, Lemieux, and Myers (2012) hypothesized that experience with high-fidelity simulation of a dying patient would increase students’ knowledge of EOL signs/symptoms and self-efficacy in caring for a dying patient. In a mixed methods study, 14 students were asked to complete questionnaires measuring their knowledge of signs and symptoms of dying and self-efficacy before and after a 15-minute simulation experience in which a manikin shows signs of imminent death and then expires. Self-efficacy was measured using a six level, Likert scale for eight statements about professional care, emotional reaction, and physiological knowledge related to EOL care. End-of-life knowledge was measured with a seven item, multiple-choice quiz on EOL care adapted from *The Textbook of Palliative Care Nursing* (Ferrell & Coyle, 2010). Results of the posttest on signs and symptoms of dying were significantly increased. Results of the posttest for self-efficacy were also significantly improved.

After the simulation, students participated in a focus group to discuss questions designed by investigators to elicit emotions, feelings, and thoughts about their personal performance, care of the dying patient, things that went well, things that did not go well, their confidence, and simulation as an effective teaching experience. Major themes from the focus group revealed that students had difficulty changing their perspectives from cure to care oriented goals, from doing
tasks to just being there for the patient. Students reported feeling uneasy, having doubts about their expected role, and being conflicted by expectations to perform when nothing else could be done. The authors noted that despite students’ reported uneasiness and doubts in performance during the simulation, scores revealed improved self-efficacy to care for a dying patient.

Based on Experiential Learning theory (Kolb, 1984), human patient simulators (HPSs), or high-tech manikins, have been used to provide a more realistic experience for learning about EOL care without risking harm to patients (Adamson, 2012; Fabro, Schaffer, & Scharton, 2014). According to Kolb (1984), learning is a process requiring active experience for changing knowledge and beliefs. Therefore, adapting to new knowledge and beliefs marks success. With adults, challenging old beliefs can involve tension. Engaging in active and concrete experiences promotes understanding of new beliefs and knowledge, thereby resolving the tension required to adapt (Kolb, 1984). Based on these tenets, HPSs have been used to provide realism in a controlled environment. Manikins are intended to allow active engagement by students to dispel the tension in providing EOL care (Fabro et al., 2014; Smith-Stoner, 2009).

Results have been mixed on the effects of HPSs on dispelling fears of providing care to dying patients while improving knowledge. Using researcher-constructed instruments, some have reported improvements in knowledge, self-confidence, and self-reported communication skills in care after simulation experiences (Fluharty et al., 2012; Gillan et al., 2014a; Moreland et al., 2012). Other researchers have reported no significant improvements in knowledge resulting from simulation experiences (Adamson, 2012; Twigg, Donovan, & Lynn, 2012). Twigg et al. (2012) found that after a simulated experience, students reportedly felt more anxious about their abilities to provide EOL care, which has been similar with clinical experiences.
Limited realism has been a drawback to human patient simulators. Negative comments by students about HPSs were that ‘they are still dummies’ that can’t talk or respond spontaneously, or that ‘they’re just creepy looking’ (Bremner, Aduddell, Bennett, & VanGeest, 2006; Smith-Stoner, 2009). Instead of relieving student anxieties about EOL care, Smith-Stoner (2009) found that students were just as overwhelmed and anxious during a simulated EOL experience as students who were in an actual clinical setting (Allchin, 2006).

Costly requirements to maintain human patient simulators are other drawbacks cited. The manikins were time-intensive to set up, required plenty of storage space when not in use, and when in use could only accommodate 8 to 10 students at most for supervision and evaluation (Childs & Seppsles, 2006). In 2006, the cost for some manikins ranged from $30,000 to $200,000 (Bremner et al, 2006), which educators have cited as a major limitation for use (Bassah et al., 2014; Gillan et al., 2014a). In Australia, Lapkin and Levett-Jones (2011) found that the cost to maintain of a high-fidelity manikin (≈ US $102,522) was five times more than the cost to maintain a medium-fidelity manikin (≈ US $16,111.54). Yet, both manikins produced similar results on student measures of knowledge acquisition and satisfaction. In a systematic review of applicable EOL educational approaches worldwide, Bassah et al. (2014) concluded that more research was needed on educational strategies that consider the barriers in resource-poor countries.

**Experiential learning by direct contact with dying patients.** Based on the premise that learning is grounded in experience (Kolb, 1984), Kwekkeboom et al. (2005) evaluated the effects of an experiential EOL elective on quantitative measures of knowledge, attitudes, and concerns about care in 19 nursing students. The primary experience for learning was spending time with a dying patient as a palliative companion. No didactic teaching was provided. However, other
educational experiences through the course were available to students. A cohort of 15 students who did not participate in the elective served as a control group and completed the same instruments before and after the semester. Knowledge was measured using the PCQN. Attitudes were measured using a 12-item instrument measuring three constructs: 1) professional responsibilities in EOL care, 2) the efficacy of EOL care, and 3) the role and importance of patient-clinician communication. Bradley et al. (2000) reported moderate reliability of this instrument by obtaining a Chronbach’s $\alpha = 0.60$. The authors found significant improvements in all measures from pretest to posttest among the palliative companion group and none in the control group.

**Experiential course description.** In Kwekkeboom et al.’s (2005) study, students spent time with dying patients without requirements to provide physical care. Spending time with hospice patients as volunteer companions allowed for direct patient experience without the stress imposed by a hospital environment (Blomberg et al., 2014) or fears of having to complete physical tasks of EOL care (Ek et al., 2014). At the start of the elective course, participating students were given palliative and EOL education by a palliative coordinator during an orientation to the palliative companion program. The coordinator provided students with a two-hour discussion covering death, loss, bereavement, palliative care philosophy, and the physical, psychosocial, and spiritual needs of patients and families. Students were then debriefed about limits and physical restrictions as palliative companions. Students could interact, play music, read, hold hands, rub lotion on hands, or accompany a patient for a walk if independently capable. Finally, students shadowed the coordinator while touring a cancer center, a cancer unit, and a palliative care unit. Optional opportunities included: attending a hospital-based oncology orientation, palliative care team meetings, oncology grand rounds, hospice support groups, or
grief workshops. Although not required, students could also view one video of a television series called *On Our Own Terms* (Moyers & Ablow, 2000) or make bereavement follow up phone calls to family members to supplement their experience. Students were required to spend at least 15 hours of participation to receive independent study credit.

Students were asked to rate their responses from 1 = *strongly disagree* to 5 = *strongly agree* about their attitudes toward EOL care in three main areas: roles and responsibilities of health providers, belief in palliative care as a benefit, and views about provider-patient communication (Kwekkeboom et al. 2005). Concerns were measured with a questionnaire asking how ‘worried’ they were about providing emotional support to dying patients or families and about their own emotions and psychological composure while providing physical or postmortem care. Students rated their responses with 0 = *not at all* to 4 = *very much so*.

Researchers speculated that spending time with dying patients without being required to perform physical tasks would diminish student fears, and thus allow them to listen and interact, thus focusing on the act of “being with” patients (Kwekkeboom et al., 2006). Most students from the elective in that study chose spending time as palliative companions for 16 weeks and attending a grief workshop for eight weeks. Such findings suggest the influence of direct contact with patients and select didactic education on grief for improving EOL knowledge, attitudes, and concerns about providing EOL care.

**Contrasting results after replication.** In 2006, Kwekkeboom et al. repeated the 2005 study but collected data over four semesters to obtain a larger sample of 28 nursing students who had completed the palliative care companion elective and twenty matched cohorts who agreed to participate as a control group. To obtain qualitative data, students in the companion group were asked to keep journals describing their weekly experiences. The same measures for knowledge
and concerns from the 2005 study were used. The attitude instrument was modified for nursing students instead of nurses, but showed poor retest reliability ($\alpha = 0.38$ at both administrations with this sample). The authors found no significant effects of the elective course companion program on knowledge (Kwekkeboom et al., 2006), which refutes results from the previous study. Attitudes were not reported due to poor instrument reliability. In contrast to the previous study, most students (69%) did not choose the companion experience. Qualitative data from journals provided insight into companion visits that were made. Authors concluded that limiting students to direct contact through companion visits might have yielded stronger quantitative data (Kwekkeboom et al., 2006).

**Qualitative insight on students’ direct patient experiences.** Although a majority of students (69%) did not choose palliative companionship to complete the required 15 hours, journal data revealed affective insight on students’ direct patient experiences. Other experiences chosen each week were palliative lectures, hospital program orientations, hospice continuing education, video viewing, journal readings, and bereavement follow-up calls to family members. Thus, the most common or effective method for learning was not clearly identified (Kwekkeboom et al., 2006).

However, qualitative data from students’ journals indicated an affective impact from spending time with dying patients. For example, some students expressed ‘privilege’ in being present at a significant life event for patients and family. Many described a ‘sense of reward’ in appreciating life from the perspective of dying patients and families. Students were also ‘surprised to see how simply listening’ and ‘being there’ positively affected patients and families. Students reported a great sense of satisfaction from hearing patients and families thank
them for ‘being there.’ Qualitative data provided insight into students’ experiences during actual patient visits.

Until studies by Kwekkeboom et al. (2005, 2006), no systematic research had been conducted to determine if a specific amount of experience with dying patients contributed to nursing student knowledge and attitudes toward EOL care. Lack of clinical placements with dying patients along with qualified faculty for student supervision have been barriers for increasing experience with dying patients (Bassah et al., 2014; Gillan et al., 2013).

In 2001, Arber assessed palliative care knowledge, as measured by the PCQN, among nursing students before and after four months of didactic EOL education followed by one week of hospice observation. Knowledge scores as measured by the PCQN were significantly improved from pretest to posttest, particularly in the areas of palliative care philosophy and symptom management. However, students’ attitudes and patient care experiences were not explored further for depth of application in practice. Arber suggested further research with a comparison or control group and on student emotions related to EOL care. Subsequently studies have been conducted examining students’ attitudes specific to EOL care (Barrere et al., 2008; Dobbins, 2011; Frommelt, 2003; Mallory, 2003).

Since 2001, results from research on the most common formats and components of EOL education have provided a better understanding of the benefits and limits of didactic and experiential strategies. Improved knowledge and attitudes toward care of the dying have been important benefits of EOL education. However, a limitation has been the lack of evidence clearly correlating such benefits to actual skills with dying patients and their families (Gillan et al., 2013; National League for Nursing [NLN], 2012; IOM, 2015).
Kwekkeboom et al. (2005) found positive effects of direct patient experience on student knowledge and attitudes toward care. Complementing quantitative findings from exclusive patient encounters, Hold et al. (2015) found positive affective responses from students to patient encounters. However, students and hospital managers have reported that new graduates, especially from BSN programs, still lack the ‘readiness’ to provide care (Oermann, Poole-Dawkins, Alvarez, Foster, & O’Sullivan, 2010). Given that student and new graduate readiness to provide EOL care is affected by lack of knowledge, lack of affective awareness, and lack of practical experience, EOL educational research should systematically examine all three areas, particularly practice skills to improve EOL practice.

End-of-Life Education with Clinical Experience

Authors have long asserted that EOL education should ideally include didactic instruction, experiential learning, and corresponding practical experience with dying patients for a significant impact on student learning (Arber, 2001; Bassah et al., 2014; Hold et al., 2015; Mallory, 2003; Muñoz-Pino, 2014). Yet, no studies have examined the effects of didactic EOL education and a specific amount of direct experience with dying patients on all three measures of EOL knowledge, attitudes, and practice skills, which collectively influence students’ ability to provide EOL care. Researchers have found that the presence of supportive nursing staff or faculty with students facing care of the dying has been vital for developing positive impressions while mediating negative emotions (Mallory, 2003; Pederson & Sivonen, 2012). However, shortages in qualified faculty, limited clinical opportunities for consistent palliative care, and faculty resistance in adopting distinct EOL content have been barriers to providing EOL education with concurrent experience (Bassah et al., 2014; Komproof, 2013; Todaro-Franceschi
& Lobelo, 2014). Therefore, evidence of experience with dying patients as a contributing factor to student EOL knowledge, attitudes, and EOL practice has been difficult to achieve.

Muñoz-Pino (2014) described positive first encounters with terminally ill patients of nursing students from a school where all students received EOL education in class before encountering dying patients in a palliative care facility. Students had no direct experience with dying patients until their third and fourth year. Students rotated through a palliative care institution for one morning (5 hours) assisting interdisciplinary staff with patient-care. In addition, the palliative care staff oriented students about the institution’s comprehensive-care philosophy prior to the palliative care experience. After completing their rotation, students were asked to provide written feedback to a single survey question: “What did this experience mean to you?” A thematic analysis was done until saturation was reached with 31 surveys. Students described the overall experience as positively ‘enriching.’

From the surveys, major themes emerged encompassing concepts of holistic or ‘comprehensive’ EOL care, which students interpreted as personally and professionally enriching (Muñoz-Pino, 2014). Similar to results from other studies describing first encounters with dying patients (Ek et al., 2014; King-Okoye & Arber, 2014), students anticipated anxiety when seeing patients suffer. They initially felt inadequate in their ability to comfort patients emotionally or physically and were overwhelmed by mixed emotions of sadness, anguish, gratification, and affection. In contrast to other studies in which students had no previous EOL education (Ek et al., 2014; Mutto et al., 2010; Parry, 2011), student anxieties dissipated soon after engaging with patients, observing staff, and helping patients with simple care such as helping with oral hygiene, combing hair, feeding, accompanying patients in an outing, and listening.
Students commented specifically on the significance of seeing how important family members were in EOL care and communicating in simple ways. Students reported feeling comfortable being present and interacting with dying patients and their family members. Students were especially gratified by patients’ kind words or smiles affirming the value of their presence. Overall, students described their first experience with dying patients as personally ‘heartwarming’ and professionally ‘enriching,’ overcoming such emotional vulnerability within themselves and with patients. Muñoz-Pino’s (2014) qualitative findings suggested a positive effect of didactic EOL education and experience with dying patients for preparing students to learn and grow from those encounters instead of becoming more anxious.

Chow, Wong, Chan, and Chung (2014) studied nursing students from a university in Hong Kong to identify and compare groups of nursing students based on demographics and four variables: clinical experience, knowledge, perceived competency, and attitude toward end-of-life care. The sample was composed of third and fourth year nursing students who had completed an EOL course and clinical experiences in EOL care. Using a cross-sectional survey method, a single, 40-item questionnaire was used to obtain demographic data and measures for each variable. From a cluster analysis of the data, students were grouped based on shared characteristics. Major shared characteristics were program type and gender. Groups were then compared based on the main variables of interest. The authors found significant differences in experience, perceived competence, and attitudes across the groups but no significant differences in knowledge.

Experience with dying patients seemed to be the greatest factor contributing to increased attitudes and perceived competency across all groups. In the group with all bachelor program students, all were female and had the least amount of clinical experience and perceived
competency. Students in the diploma program group were also all female, but had the most experience; the highest perceived competency, and highest attitudes. Students in a mixed group were composed of males and females from a mixture of the programs. This group had attitude scores similar to the bachelor group but lower than the diploma group. The mixed group also had perceived competency scores higher than the bachelor group but lower than the diploma group.

In an effort to clarify specific amounts of experience with dying patients, Chow et al. (2014) clarified ‘clinical EOL experience’ in more detail. Students were asked to recall the number of times they were involved with: observing nurses provide EOL care, providing direct care as a student, receiving feedback on EOL care by an instructor, or experiencing the death of a loved one. Responses were quantified as: ‘0 (never), 1-2 times, 3-4 times, >5 times.’ Knowledge was assessed with 10 questions from the American Association of Critical Care Nurses’ (2015) website on palliative education. Perceived competency providing EOL care was assessed by questions regarding specific activities such as giving bad news, providing nutritional support, or pain management. Attitudes were assessed by questions regarding their feelings toward terminal illness, talking about death, suffering, grief, or depression in terminal illness. Authors found that experience was the most significant factor affecting attitudes and competency leading to the conclusion that experience was imperative for improving perceived competency and attitudes in providing EOL care among nursing students.

One critique by Chow et al. (2014) was that previous studies of student knowledge and attitudes toward care of the dying have been collected evaluating for effectiveness of an EOL course without further validation of application to practice. Assumptions were that improved EOL knowledge and attitudes would positively affect patient care. Bereaved families noting the
lack of supportive psychosocial care have not verified this assumption (Sadler et al, 2014). Although retrospective, Chow et al. (2014) provided strong evidence supporting clinical experience as contributing to attitudes and competence in providing EOL care based specifically on quantified aspects of EOL care.

Attitudes involve feelings, values, and beliefs, which are emotional qualities that can be measured by psychometrically strong instruments (Frommelt, 1991; Savickiene, 2010). However, from studies reporting quantitative measures of attitudes, external validity of such measures are weakened by the fact that those studies were based on sporadic or no experience with dying patients. Thus, many educators have suggested further research including qualitative data for assessing the depth of student learning about EOL care based on actual experience with dying patients (Ballesteros et al., 2014; Bassah et al., 2014; Chow et al., 2014; Hold et al., 2015; Mallory, 2003).

Research on the quantitative and qualitative effects of EOL education has not moved beyond the recommendation to include experience with dying patients while receiving didactic and experiential EOL education. Therefore, this study was proposed in order to assess knowledge and attitudes toward care of the dying in students after receiving regular classroom instruction about EOLC and a specific amount of time spent exclusively with dying patients. The nursing program selected for the study setting periodically offered a semester-long palliative and EOL elective course to students. The elective provided weekly didactic and experiential education in class and required students to spend a specific amount of time exclusively with dying patients in a hospice volunteer role. Limiting student exposure to dying patients without having to provide physical care allowed students to focus on affective skills such as ‘being present’ or ‘being with’ dying patients in the way that Dame Cicely Saunders described as a skill
for comforting dying patients and their family members. Exposure to dying patients through a “being with” experience was expected to make students less fearful of experiencing the suffering of another and enhance their ability to recognize psychosocial needs of the patient. For relatively younger students who had no previous experience with death, dying, or care of the dying, weekly time in class with peers and faculty for open discussion of such experiences provided the ongoing support needed from faculty and peers.
CHAPTER III

Methodology

A mixed method comparative group design study was conducted using quantitative methods to assess student knowledge and attitudes toward care of the dying and qualitative methods to further explore beliefs, values, and emotions, which make up attitudes about care of the dying. For comparison purposes, two groups of baccalaureate nursing students at the same school were examined. One group of students was enrolled in the palliative and EOL elective course and the other group was enrolled in the required senior practicum course. The same quantitative and qualitative data were obtained from both groups.

This chapter describes the rationale for a mixed method, comparative group design. The population, sample, and setting of the school are described, along with the palliative and EOL elective course and the senior practicum course. For obtaining quantitative data, two instruments were used, the Palliative Care Quiz for Nurses (PCQN) and the Frommelt Attitude Toward Care of the Dying Scale (FATCOD). Descriptions of and rationale for using the instruments are presented along with their reliability and validity. Focus groups, which were used for obtaining qualitative data, are discussed along with the rationale for their use. The demographic questionnaire is described, which includes questions assessing previous EOL education along with previous experience with EOL care and personal loss. Procedures for conducting the study are described as are assumptions, limitations, data analysis methods, and presentation of results.

Research Design

Since lack of knowledge and experience with EOL care contribute to student fears and avoidant behaviors when faced with an EOL clinical experience, quantitative measures of student knowledge and attitudes toward care of the dying were obtained to assess effectiveness
of a palliative and EOL elective course that provided content as well as direct experience with
dying patients. Since quantitative methods have provided a limited picture of desirable outcomes
from EOL education, focus groups were used to obtain qualitative data about student learning
regarding dying and EOL care. Given that experience with dying patients can elicit a variety of
emotions among nursing students, focus groups were conducted in order to gain better
understanding of student learning not captured by questionnaires. Student interaction in focus
groups revealed nuances of learning that provided greater insight into what students learned after
time spent with dying patients.

Because all nursing graduates are expected to provide quality EOL care regardless of age,
education, or background experience with death and dying, a group of nursing students not
enrolled in the elective, but enrolled in a required senior practicum course were also assessed for
knowledge and attitudes toward EOL care. With this group, neither EOL content nor experience
with dying patients was guaranteed. Therefore, this group served as the control group for
comparison purposes. Data from the comparison group were obtained using the same
instruments and focus groups.

The mixed methods comparison group design of this study incorporated pretest and
posttest measures of knowledge and attitudes toward care of the dying from a non-randomized
sample of third and fourth year baccalaureate students from two intact courses as independent
participant groups. One group was enrolled in the palliative and EOL elective course and is
referred to as the ‘elective’ group. The other group was enrolled in the senior nursing practicum
course and is referred to as the ‘comparison’ group. In addition to the pretest, all participants
completed a demographic questionnaire that included questions assessing any previous education
about death and dying, previous experience with the care of a terminally ill person, experience
with personal loss, and experience with anticipated loss. At the completion of the semester, semi-structured focus groups were conducted with both groups to obtain qualitative data. A set of open-ended questions were used during focus groups to probe students about attitudes, beliefs, values, and emotions during their experience with terminally ill patients and what they learned about death and dying through their experiences.

**Data collection.** The following instruments were administered as pretests and posttests to obtain quantitative data from both groups: 1) The Palliative Care Quiz for Nurses (PCQN) (See APPENDIX-A), 2) the Frommelt Attitude Toward Care of the Dying Scale (FATCOD) Form- B (See APPENDIX-B), and 3) a single demographic data questionnaire. Students were asked to provide demographic data such as age, gender, and highest level of education completed. To assess EOL education and experience, addition questions after demographic data included 1) previous education on death and dying, 2) previous experience with caring for a terminally ill person, 3) previous loss of someone close and relationship to the person within the last 10 years, and 4) any anticipated losses. The demographic data questionnaire was administered twice. Once was before the semester prior to course content or experiences in clinical or with hospice patients. The second was at the end of the semester after completion of course content and clinical or hospice patient experiences. The first was to capture amount of education and experience prior to the course. The second at the end of the semester was to capture amount of education and experience gained during the semester (See APPENDIX-C).

After completing pretest instruments, students signed up for one of several scheduled focus groups conducted by the primary investigator (PI) to obtain qualitative data near the end of the semester. Focus groups were conducted on campus and limited to a maximum of nine students. Focus groups were scheduled at different times to accommodate all participants. The
primary investigator (PI) conducted focus groups using the same set of open-ended questions to keep discussion semi-structured and the format consistent across groups (See APPENDIX-D). Since the primary investigator (PI) co-instructed the EOL elective course, she was not present at pretest and posttest times. A faculty member who did not instruct in the EOL elective obtained informed consent and administered quantitative instruments from elective group participants at pretest. At posttest, quantitative instruments were left in the elective course class room for participants to complete voluntarily while the primary investigator left the classroom.

**Rationale for design.** Since quantitative measures alone do not fully explain complex human phenomena, such as learning about death and dying (Heyvaert, Maes, & Onghena, 2013; Johnson & Onwuegbuzie, 2004), mixed methods were appropriate to obtain qualitative data as well. Student learning about death, dying, and EOL care is multifaceted and not easily understood or captured by a single source of data. Learning about care of the dying requires knowledge of facts or practice skills. Such care also includes affective qualities that may vary based on individual degree or depth of understanding about EOL (Foss & Ellefsen, 2002). Depth of learning about EOL and care of dying patients is not easily measured within the context of a classroom or by written instruments at a single moment in time (Albright, Gechter, & Kempe, 2013).

In the context of nursing education, evaluating EOL learning often requires triangulation of data sources to confirm that students know how to provide quality EOL care (Joshi, 2013; Stavropoulou, & Kelesi, 2012). Therefore, quantitative measures of knowledge and attitudes toward the care of dying patient were obtained using written instruments and qualitative data were obtained through focus groups to assess depth of affective learning.

Death, dying, and care of the dying evoke affective responses less amenable to
quantitative measurement. For example, empathy, helplessness, and emotional vulnerability as responses to witnessing suffering are better understood in the context of real encounters with suffering patients (Eifried, 2003). Understanding what students learn from real encounters however requires more discussion and elaboration by students. Thus, conducting focus groups was suitable for assessing the depth of affective learning in the context of EOL education and actual experience with dying patients. A mixed methods approach was appropriate for examining the quantitative and qualitative effects of participation in an EOL course requiring experience ‘being with’ dying patients.

**Theoretic framework.** Based on Bandura’s (1989) social cognitive theory of learning, when confronting a threatening situation, knowledge by itself will not change a learner’s behavior in the situation. Learning requires increasing exposure to the threatening situation that is commensurate with a learner’s perceived abilities to engage and/or improve in the situation. It was anticipated that as students’ sense of self-efficacy increased with more exposure to dying patients, they would become more comfortable engaging in the EOL situation. Focus groups were a better approach for obtaining students’ insights and feelings about their experiences ‘being with’ dying patients. Gaining such information from students provided greater insight into student learning than quantitative findings of EOL knowledge and attitudes toward care of the dying.

**Population and sample.** The population for this study was Bachelor of Science in Nursing (BSN) students enrolled in a program at a public university in a southeastern state. A convenience sample was assessed from two groups of students, those enrolled in a palliative and EOL elective, and those enrolled in the senior practicum course. Inclusion criteria for the elective group were: students enrolled in the palliative and EOL care elective, voluntary consent
to complete pretests and posttests, and participation in a focus group after the posttest. Inclusion criteria for the comparison group were: enrollment in the senior practicum course, no previous enrollment or completion of the palliative and EOL elective, voluntary consent to complete pretests and posttests, and participation in a focus group after the posttest. Students in the comparison group completed 172 hours of patient care experience in various clinical settings, which may or may not have included EOLC for dying patients.

Setting. The setting was on the university campus of a state-supported BSN school of nursing located near a large metropolitan city of the Southeastern United States. The university enrolls approximately 240 undergraduate nursing students per year, with roughly 60-80 traditional students and 40-60 accelerated students each semester. The nursing program offers a palliative and end-of-life course as one of the electives required at least once per year. The required senior practicum course is offered every semester. End-of-life content was “threaded” or included within various but appropriate required nursing courses of the curriculum resembling an integrated format suggested by the AACN (1998) for meeting EOLC competencies. Therefore, the comparison group served as a control group representing the integrated method of EOL education and most common format used within nursing programs throughout the U.S.

Course Descriptions

The palliative and EOL course. The palliative and EOL elective course in this study setting is typically taught over one semester, or 15 weeks, for three hours per week. Didactic content was provided through nursing faculty and guest speaker lectures to cover the following content based on ELNEC modules: nursing care at the end of life, pain management, symptom management, ethical issues, communication, cultural considerations, loss, grief, bereavement, achieving quality palliative care, and preparation for the time of death. Experiential content
included interactive role-play by faculty and students, video/film viewing, and case studies for small group discussion. Each student also engaged in weekly written reflective exercises and conducted a final presentation in class about their experience with dying patients.

The course required students to spend a total of 10 hours “being with” an assigned hospice patient. The hours with patients were extended over the course of the semester with no more than two hours per visit, or less depending on the patient’s condition. Students visited patients at their home, assisted care facility, or hospice facility. For assigned patients that died during the semester, the case manager assigned another hospice patient to the student. Each week in class, time was devoted for students to discuss their experiences with the dying, especially emotional encounters or remarkable reflections from their experiences.

Students enrolled in the EOL elective course were oriented to the role of hospice volunteers and trained by the volunteer coordinator of a collaborating hospice agency prior to starting their experience with patients. An agency volunteer coordinator and the hospice case manager provided the orientation to students during one class period. At the orientation, the coordinator discussed hospice agency policies and explained what volunteers could and could not do. As volunteers, students could not provide physical care, although assistance with grooming was allowed such as painting nails, applying make-up, or combing hair. After the training, the hospice case manager contacted students directly by email to assign individual hospice patients. Students were permitted to contact their respective patients directly or through the care facility to schedule each visit. During visits “being with” patients, students were expected to practice affective skills learned in class such as listening, being attentive, observing, talking, reading, singing, listening to music, watching television, or holding hands. Students could stroll patients in a wheelchair outside of their facility pending patient conditions.
The senior practicum course. The comparison group participated in a required senior practicum course, which required 172 hours of clinical experience in various placements with a nurse preceptor. Each student was required to attend the first day of class for course and clinical orientation. As the primary clinical capstone course before graduating from the nursing program, the practicum did not include didactic instruction. During the practicum, students were responsible for submitting weekly journals about their clinical experience to their clinical instructor. In addition to completing 172 clinical hours, students completed teaching projects pertinent to their clinical practice settings and presented their projects to classmates at the end of the semester. Students may or may not have had experiences with dying patients during the clinical practicum.

Instruments

Palliative Care Quiz for Nurses (PCQN). Knowledge was measured using the 20-item Palliative Care Quiz for Nurses (PCQN). The tool was developed to assess knowledge or education about basic palliative and end-of-life care principles (Ross et al., 1996). The tool also discriminates for common misconceptions about palliative care nursing (Arber, 2001). Items on the tool cover three main categories of content: four items on philosophy and principles of palliative care, 13 items on management of pain and other symptoms, and three items on psychosocial aspects of EOL care. Each item can be answered: TRUE, FALSE, or I DON’T KNOW (See Appendix A).

Knowledge of basic palliative and EOL care is necessary for providing quality care to dying patients in all settings. Previous research has shown the PCQN to be reliable in assessing basic principles and EOL facts among nurses and students. Results of didactic education on student knowledge using the PCQN have been helpful for evaluating EOL courses and integrated
Reliability of the PCQN. Although the PCQN quiz was originally developed to assess entry-level nurses, it has demonstrated reliability in discriminating knowledge deficits and gains related to educational interventions used with nursing students (Ross et al., 1996). The instrument has demonstrated internal consistency (IC) of 0.78 based on a Kuder-Richardson formula 20 (KR-20), (Ross et al., 1996). The instrument has also been used widely to assess palliative knowledge as an outcome measure for evaluating the effectiveness of EOL educational (Adriaansen & van Achterberg, 2004; Arber, 2001; Loftus & Thompson, 2002).

The PCQN has been translated into Dutch yielding 36 items on the quiz to match the concepts and intent of the original 20-item English version of the PCQN (Adriaansen & van Achterberg, 2004). The Dutch version was tested on three groups: fourth year nursing students, nurses with palliative care experience, and licensed practical nurses with palliative care experience. Scores from all three groups were merged (n=157), yielding an internal consistency (KR-20) of 0.71, which matched the original version. A French version of the PCQN yielded only a moderate internal consistency of 0.60 (KR-20) among 189 combined RNs, LPNs, and nursing students (Carroll, Prud'Homme Brisson, Ross, & Labbé, 2005). However, a split half technique for determining IC using half the test items obtained a Guttman Coefficient of 0.67 (Carroll et al., 2005).

Validity of the PCQN. In developing the PCQN instrument, multiple focus groups consisting of palliative care coordinators, nurses in palliative service or education, and supervisors of community and hospital-based palliative care agencies identified multiple areas of knowledge necessary for delivering quality palliative care until three final categories emerged
KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING

(Ross et al, 1996). The three categories are: 1) the philosophy and principles of palliative care, 2) the management and control of pain and other symptoms, and 3) the provision of psychosocial and spiritual care.

Items for each category on the instrument were determined to discriminate different levels of palliative care knowledge based on educational background and nursing care experience of the test taker, especially regarding common misconceptions about palliative care (Ross et al., 1996). Adriaansen and van Achterberg (2004) obtained further validation of the instrument with a randomized, stratified sample of Canadian palliative care nurses who were surveyed for feedback on the items in each category. To test discriminative properties of the instrument, these authors compared means of 200 nursing students and 196 nurses from various health settings in Canada. Participants also indicated their education level. Adriaansen & van Achterberg, (2004) found that registered nurses scored the highest. Nurses with additional education and experience scored higher than traditional students and registered practical nurses. Other researchers have found the tool valid in detecting misconceptions about palliative care knowledge based on different educational backgrounds and experience in long-term care workers (Brazil et al., 2012).

Frommelt Attitude Toward Care of the Dying Scale (FATCOD). Attitudes toward care of the dying were measured using the Frommelt Attitude Toward Care of the Dying Scale, Form A (FATCOD), which was designed for assessing nurses (Frommelt, 1991). Another form of the FATCOD, Form B, was created from Form A but altered for use among students of different disciplines by removing the words “nurse” or “nursing” from Form A (Frommelt, 2003; Tait et al., 2015). This 30-item questionnaire assesses feelings, thoughts, attitudes, and comfort levels about care of the dying. All questions are answered using a Likert scale rating with “1-strongly disagree” to “5-strongly agree”. Fifteen items on the scale are positively worded.
Another fifteen items are negatively worded with reversed scoring. Possible scores can range from 30 to 150 with higher scores reflecting more positive attitudes toward care of the dying. Twenty items on the scale assess attitudes toward the patient and ten items assess attitudes toward family members. Nine questions reflect attitudes of avoidance, which is of great concern to patients, families, and educators. The scale assesses a wide range of emotional and behavioral responses toward care of the dying.

The scale was justified for use in this study because of its content specific to nursing care of the dying. The scale measures positive and negative emotions, attitudes, and actions toward care of the dying patient and family members. It addresses possible fears and anxieties related to personal abilities to care for the dying. The tool addresses psychological, emotional, and physical responses students might have toward care of the dying. Therefore, students were expected to identify various emotions addressed by the instrument from experience with dying patients and their family members.

**Reliability and validity of the FATCOD.** The scale has demonstrated good reliability and validity among students and nurses in a variety of settings. Test/retest reliability of the FATCOD has demonstrated a Pearson’s correlation coefficient of 0.93 among nursing students (Frommelt, 2003). The FATCOD has also demonstrated validity with an inter-rater agreement of 1.0 (Frommelt, 2003). Wessel and Rutledge (2005) obtained a Cronbach’s alpha score of 0.89 for internal consistency. With a group of 95 Australian nurses, the FATCOD instrument demonstrated strong internal consistency with a Cronbach’s alpha coefficient of 0.80 (Tait et al., 2015).

Mastroianni et al. (2015) reported strong psychometric properties of an Italian version of Form B among nursing students. The Italian version was back translated into English by two
professional translators and sent to the original author to verify accuracies in conceptual meanings. The English version from the original author was then back translated into Italian by three bilingual, Italian nurses with palliative experience and a methodologist for the final Italian version. The Italian version was given to a convenience sample of 442 nursing students from various nursing schools within a single region of Italy. Internal consistency was demonstrated by a Cronbach’s alpha coefficient of 0.81. The Pearson’s correlation coefficient for test-retest reliability was 0.87. The scale has been widely used to assess attitudes specific to nursing care of the dying (Barrere et al., 2008; Brazil et al., 2012; Mastroianni et al., 2015; Mallory, 2003; Tait et al., 2015; Wessell & Rutledge, 2005).

Demographic questionnaire. The demographic questionnaire was one-page used to obtain data such as age, gender, and highest level of education completed. Additional questions were included to assess 1) individual EOL education on death and dying, 2) amount of experience with care of a terminally ill family member, close friend, or patient, 3) previous experience with loss of someone close, and 4) any anticipated losses. Students were asked about their relationship to each loss, how long ago the loss occurred up to 10 years, and if they were experiencing or anticipating the loss of someone close at the time of the study. Age, education, and previous experience with death and dying have been found to affect attitudes toward care of the dying (Barrere et al., 2008; Mallory, 2003). Therefore, the demographic data questionnaire was administered twice, at the beginning and end of the semester to cover two periods in which students could have gained EOL education or experiences that influenced their knowledge and attitudes toward care of the dying.

Focus groups. Focus groups are valuable not only for evaluating services and programs (Stavropoulou & Kelesi, 2012), but also for seeking opinions, values, and beliefs in a collective
Focus groups provided a means for learning from students about their experiences of providing psychosocial care to dying patients and families. “Focus groups are particularly useful when current knowledge about a phenomenon is inadequate and expansion is important. The focus group method is important when the issue being investigated is complex and when concurrent use of additional data is necessary for validity” (Jayasekara, 2012, p. 412). One strength of focus groups is the ability to observe the extent and nature of participants’ agreement and disagreement during interactions (Morgan, 1996). Such interactions were noted on field notes by the author of this study for verifying students’ emotions.

Several methodologic rationales for using focus groups are supported in the literature. Focus groups allow students the freedom to talk about their experiences “being with” dying patients with the support of peers (Brien et al., 2008; Ying et al, 2011). Students may feel more comfortable among peers to express feelings, values, and beliefs about death and dying, thus allowing more reflective, intuitive, and affective traits to be revealed (Albright et al., 2013). Focus groups are subjective and contextual approaches for gaining qualitative data, particularly for eliciting emotions that support a respondent’s perspectives, values, and opinions about the learning experience (Albright et al., 2013). Qualitative methods are well suited for addressing aspects of learning that may be abstract such as learning, emotional support, or expressing empathy with dying patients and families (Foss & Ellefsen, 2002).

Procedures

Protection of participants. Institutional Review Board (IRB) approval of the study and consent forms were obtained from the participating university. The (PI) used the IRB approved form for explaining the study and obtaining consent from all participants. The consent briefly
explained the purpose of the study, requirements for participating, estimated time of participation, and possible benefits and risks of participation (See APPENDIX E). To avoid the perception of coercion from the PI who co-instructed in the elective course, another faculty member facilitated study procedures with participants in the elective group. This faculty member was not associated with the study nor instruction in either the EOL elective (N4440) or the Senior Practicum course (N4417). With elective group participants, the facilitator explained the study, obtained informed consents at pretest, administered the instruments, and collected completed consents and instruments. Students were asked to sign up for one of several focus group discussions scheduled toward the end of the semester. It was emphasized that the study was voluntary and would not affect students’ course grades, regardless of their participation. Full disclosure of benefits and risks were explained to all potential participants at the beginning of the study. Benefits for students included gaining greater insight and knowledge about EOL care and/or self-awareness of personal attitudes toward care of the dying. The possible risk of participation included the potential for processing unpleasant experiences with dying patients and/or memories of the loss of a patient, family member, or friend that could make them sad. The consent form provided the name, phone number, and email of the PI for any questions, or if further follow up was needed for referral to a counselor. Students who agreed to participate returned signed consent forms and kept an unsigned copy for themselves.

Confidentiality. Complete anonymity of participants during the focus groups at the end of the semester within each group was not possible. Focus groups were audio-recorded for transcription purposes. Students were assured that their identities in written materials related to the study would remain confidential. All results would be presented as aggregate data. Students were asked to label all forms with the last four digits of a cell phone number as identifiers known
KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING

only to them at pretest and at posttest. A cell phone number was suggested as an identifier students might find easiest to remember and that would be unlikely to reveal personal identities. Numbers were also easier to decipher than letters, which potentially could have been illegible or misread. The PI was not present in the elective group classroom when the facilitating faculty member explained study procedures. All signed consents from the elective group were sealed in an envelope and inaccessible to the PI until after the study was completed.

Initiation of study. At the beginning of the semester, the facilitating faculty member introduced the study to students enrolled in the EOL elective and the PI introduced the study to students enrolled in the senior practicum. Two copies of the consent form were distributed to students. The facilitator and/or PI read the consent aloud to students. Students who volunteered to participate in the study returned signed consent forms to the facilitator and/or PI and the participants kept a copy of the consent form. Signed consents collected from each group were kept in separate envelopes, apart from instruments and demographic questionnaire so that participants could not be identified. The PI and/or the facilitator passed out instruments and demographic questionnaire to consenting participants. Directions for completing all forms and labeling them with cell phone identifiers were clarified verbally before students completed the forms. Returned instruments were checked for completeness and identifying numbers by the facilitator and/or the PI before placing forms into marked envelopes indicating participants from the elective or practicum course. Envelopes containing forms from each group were kept separate. Consent forms from the EOL elective group remained inaccessible to the PI until the study was completed.

After submitting completed forms to the facilitator or the PI, each participant was asked to sign up for a one-hour focus group scheduled toward the end of the semester. Pizza and
drinks were served in each focus group. For convenience to participants, focus groups were conducted on campus in a private room reserved at times following required class attendance on campus. Voluntary participation was emphasized as was the fact that participation would not affect student grades for the course in which they were enrolled.

End of the semester. The same procedures for administering study instruments and obtaining data forms from participants were repeated toward the end of the semester with minor changes in location for the practicum group. Because the senior practicum course is comprised of 172 hours in various clinical sites, there are no classes on campus. For the senior practicum group, the PI administered posttests and the demographic questionnaire toward the end of the semester in another required course with mandatory class attendance on campus. However, all students were asked at the end of the semester to label instruments and the demographic questionnaire with the same four-digit identifier used on the pretest. Completed posttests and demographic questionnaires were checked for completeness and four digit identifiers and placed in a sealed envelope. Students were reminded of the scheduled times, dates, and the locations for focus groups they chose to attend. Directional signs were posted on the days of the scheduled focus groups.

The primary investigator (PI) in collaboration with course coordinators, made a master schedule of focus groups available to students throughout the semester. Several focus groups were scheduled toward the end of the semester for the convenience of participants. Although each focus group was limited to nine participants, no more than five participants attended any focus group. Focus groups lasted approximately 60 to 90 minutes and were led by the study PI.

Participant confidentiality. Consent forms were distributed again in each focus group and participants were verbally reminded that participation was voluntary. The benefits and risks
of participating were also reiterated. Focus group discussions were audio-recorded and transcribed verbatim by the PI. Participants were identified on transcripts by a pseudonym. Since anonymity was not possible within focus groups, participants were reminded to maintain the confidentiality of names and responses by other participants within the focus group. Audio-recording began after obtaining signed consents.

Focus group discussions were conducted by the PI using a semi-structured guide with open-ended questions prepared in advance (See APPENDIX D). Each focus group was conducted in a place convenient to participants in relation to their mandatory campus classes with pizza and drinks provided to all who participated during each focus group.

**Methodological Considerations**

**Assumptions.** Participation was voluntary and students would be truthful about revealing what they do and do not know when completing the PCQN and FATCOD tools. Students would be open, honest, and respectful when discussing their experiences during focus groups. EOL care knowledge could be gained from sources other than the EOL elective course.

**Limitations.** Some limitations threatened internal validity. Randomization of students into groups was not possible due to the elective nature of the Palliative and EOL course and the requirement for all senior nursing students to complete the Senior Practicum course. Participants’ EOL education and experience prior to the study could not be manipulated since participants may have heard EOL content in other nursing courses or experienced dying patients in nursing clinical settings. Therefore, EOL education and experience were assessed on the demographic questionnaire and presented as descriptive data.
Data Analysis

Quantitative analysis. Raw scores for knowledge and attitudes toward care of the dying were computed for a mean score at pretest and posttest for each group. Although Analysis of Covariance (ANCOVA) statistics were originally planned, with only two groups involved and the major covariate being course participation, statistical $t$-tests for significant differences in group means were conducted. The two groups were not assumed equal due to non-randomization of students in the senior practicum course and self-selection by students in the EOL elective. Statistical analyses of $t$-tests were performed on pre-test and posttest group means for knowledge and attitudes to determine differences within each group and between the groups. Mann-Whitney $U$ tests of significance were conducted on non-parametric data, such as highest level of education, previous EOL education, experience with someone terminally ill, and present anticipation of losing someone close.

Descriptive statistics of demographic data are summarized and presented in table format in Chapter Four to describe and compare both groups. A Chronbach’s Alpha was computed for the FATCOD and PCQN to verify consistency of these instruments within this convenience sample of BSN nursing students.

Qualitative analysis. To further explore similarities and differences in perceptions about death and dying between groups, a hermeneutic analysis, also called an “interpretive” analysis, of the data from focus group transcripts was conducted based on Benner’s (1994) guidelines specific to nursing education. The process of thematic analysis included: 1) reading transcripts from each focus group for prominent concepts and ideas, 2) identifying significant themes from the compiled concepts and ideas, 3) identifying similar and contrasting ideas or descriptions and numeracy of descriptions within each focus group, and 4) identifying exemplars from the
narratives of each focus group. Analyzing students’ words regarding their experiences with death and dying between groups was key to evaluating similarities and differences in affective learning related to end-of-life experiences. The thematic analyses revealed greater insight into the traits attributed by students to concepts such as empathy, comfort, and respect. Such affective qualities are difficult to quantify by instrument scores, yet necessary for providing the kind of care that matters most to dying patients and their family members (Brereton et al., 2012; Heyland et al., 2006).

**Integrating results.** After analysis of quantitative data to determine if there were significant differences in knowledge or attitudes toward care of the dying between groups, results of qualitative data were compared and contrasted between groups. Qualitative results were integrated with quantitative findings to address the initial research questions concerning BSN nursing students’ knowledge, attitudes, and learning experiences with dying patients. Data from focus groups provided greater insight than quantitative measures of knowledge and attitudes toward EOLC.

Mixed data sources have the potential to affirm or disconfirm beliefs, values, and emotions that shape students’ attitudes toward EOL care during their progression in nursing education (Hayes, Bonner, & Douglas, 2013; Joshi, 2013). Quantitative measures of knowledge and attitude have been positively correlated with EOL education. However, qualitative results affirmed greater depth of affective learning, which is comprised of attitudes encompassing one’s beliefs, values, and emotions. Although difficult to measure, such qualities are explicit in the American Nurses Association (ANA, 2015) Code of Ethics for guiding professional care. In relation to quantitative measures of knowledge and attitudes, qualitative data supported a specific strategy for EOL education in providing at least ten hours for students to spend “being with”
dying patients to acquire knowledge and improving attitudes toward the care of the dying. Integrating data provided a more comprehensive understanding of effective EOL education among BSN students as a fundamental way for improving the quality of EOL care for patients and families.

**Summary**

To assess knowledge and attitudes toward care of the dying among BSN students, EOL and palliative knowledge was assessed quantitatively before and after two different courses using a 20-item, Palliative Care Quiz for Nurses (PCQN) (Ross et al., 1996). Attitudes were measured before and after participants’ respective courses using Frommelt’s (1991) Attitude Toward Care of the Dying Scale (FATCOD). Focus groups were conducted near the end of each course to obtain qualitative data regarding students’ EOL learning experience of “being with” dying patients or experiencing EOL nursing care.

The two quantitative instruments and a demographic questionnaire were used with a convenience sample of two groups of BSN nursing students. One group of students was enrolled in the palliative and end-of-life elective course, which provided weekly didactic ELNEC content and ten hours of experience, “being with” dying patients without requirements to provide physical care tasks. The comparison group consisted of students enrolled in the required senior practicum course comprised of 172 hours of patient care experience within various acute care settings. Practicum participants had varying experience with dying patients due to different clinical sites.

Qualitative data were obtained from students through focus group discussions with each group toward the end of the semester. Discussions were semi-structured using the same open-ended questions to address students’ EOL experiences and learning throughout their respective
courses. Prompts were used to draw out student beliefs, values, and emotions experienced in the past or during EOL education or nursing clinical experiences. Additional questions were used to clarify comments during focus groups.

Quantitative data on knowledge and attitudes were analyzed by conducting $T$-tests for significant differences within each group and between the groups at pretest and posttest. Demographic data were compiled to describe characteristics of each group. Qualitative data were analyzed for significant themes and attributes for a better understanding of affective learning among students and to determine the paradigm of EOLC for each group. Findings from the combined data sources were integrated to answer the research questions of the study.
Chapter IV

Findings

This chapter presents results gathered from a mixed methods study of knowledge and attitudes toward care of the dying with a convenience sample of BSN students in spring semester, 2016. Participants were categorized into the elective and the comparison group. Those enrolled in a palliative and EOL nursing care elective course were the ‘elective group.’ Students enrolled in the required senior practicum course served as the ‘comparison group.’

Demographic characteristics are presented for each group. Described is the extent of EOL education and amount of experience with dying patients for each group, assessed as a baseline at pretest and then again at posttest. Next, a discussion on instrument reliability is presented followed by data to address the research questions. Quantitative findings on the dependent variables of knowledge and attitude scores are presented, first for the elective group and then for the comparison group to address the first and second research questions respectively. The differences between groups are then presented to address research question three. Research questions four, five, and six concerned student attitudes, beliefs, values, and emotions toward care of the dying. These questions are addressed respectively by presenting findings from focus groups conducted with the elective group, the comparison group, and then differences between the two groups. Limitations of the study are described at the end of the chapter.

Sample Demographic Characteristics

Elective group. There were 15 students enrolled in the palliative and EOL nursing care elective and 10 agreed to participate in the study (See Table 4.1). Three were lost to attrition for a total of seven participants who completed instruments and attended a focus group at posttest.
The mean age of the participants was 32 (SD = 13.6) and their ages ranged from 21 to 54 years. All participants were female.

Table 4.1

Pretest and Posttest Demographic Characteristics by Group.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest (N = 29)</th>
<th>Posttest (N = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Comparison n = 19</td>
<td>Elective n = 10</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>29.2 (8.7)</td>
<td>30.7 (12.5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n (%)</td>
<td>n (%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age by Decade</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-30</td>
<td>13 (68.4)</td>
<td>6 (60)</td>
</tr>
<tr>
<td>31-40</td>
<td>1 (5.3)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>41-50</td>
<td>2 (10.5)</td>
<td>2 (20)</td>
</tr>
<tr>
<td>51-60</td>
<td>1 (5.3)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>No Response</td>
<td>2 (10.5)</td>
<td>0.0</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>17 (89.4)</td>
<td>10 (100)</td>
</tr>
<tr>
<td>Male</td>
<td>1 (5.3)</td>
<td>0.0</td>
</tr>
<tr>
<td>No Response</td>
<td>1 (5.3)</td>
<td></td>
</tr>
<tr>
<td>Level of Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Associate</td>
<td>0.0</td>
<td>2 (20)</td>
</tr>
<tr>
<td>Bachelor</td>
<td>17 (89.4)</td>
<td>0.0</td>
</tr>
<tr>
<td>Masters</td>
<td>1 (5.3)</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Independent Samples t Test; † Mann-Whitney U; ‡ Pearson’s Chi Square. *p < .05

In addition to completing the palliative and EOL nursing care course, a majority (85.7%, n = 6) of participants had heard EOL topics in other nursing courses. All students reported at least 10 or more hours of experience with a dying patient and all participants had experienced the
death of someone close. The most recent death of someone close had occurred within the past 12 months for two students, between 12 months and five years for another three participants, and greater than five years for two participants. One participant was anticipating the death of someone close within 12 months.

**Comparison group.** Thirty students were enrolled in the senior practicum course and 19 agreed to participate in the study. At posttest, eight were lost to attrition the week prior to exams, and 11 completed posttest instruments. Of the 11 remaining, six participated in a focus group at posttest. The mean age for the comparison group at posttest was 30.2 (SD = 9.5) and ages ranged from 21 to 53 years. With the exception of one male, all participants were female (90.9%). Since all students in the comparison group were in the Accelerated BSN track, all had previous college degrees. The highest level of education completed was a master’s degree by one participant (9.1%) with the rest having completed a bachelor’s degree in a subject other than nursing.

No participants from this group had taken an EOL course. However, 9 (81.8%) participants had heard EOL topics in other nursing courses during the semester. See Table 4.2 for exact numbers and corresponding percentages. Six participants reported having had EOL care experience. Three participants reported having had ’10 hours or less’ and three reported having had ‘greater than 10 hours’ of EOL care experience. Five participants responded ‘Not Applicable,’ indicating no EOL experience during their senior practicum course. Eight of the 11 students had experienced the death of someone close, with the most recent having occurred between one and five years ago. No one was anticipating the death of someone close within 12 months. As expected, there were significant differences between posttest groups on EOL care experience and the amount of direct care experience with dying patients and families.
### Table 4.2

**End-Of-Life (EOL) Education and Experience by Group.**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Pretest (N = 29)</th>
<th>Posttest (N = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Comparison n = 19</td>
<td>Elective n = 10</td>
</tr>
<tr>
<td>EOL course taken</td>
<td>n (%) p</td>
<td>n (%) p</td>
</tr>
<tr>
<td>Yes</td>
<td>1 (5.3) .460</td>
<td>0.0 .000*</td>
</tr>
<tr>
<td>No</td>
<td>18 (94.7)</td>
<td>10 (100)</td>
</tr>
<tr>
<td>EOL in other courses</td>
<td>.065</td>
<td>.829</td>
</tr>
<tr>
<td>Yes</td>
<td>16 (84.2)</td>
<td>6 (60)</td>
</tr>
<tr>
<td>No</td>
<td>1 (5.3)</td>
<td>3 (30)</td>
</tr>
<tr>
<td>No response</td>
<td>2 (10.5)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>EOL Care Experience</td>
<td>.089</td>
<td>.036*</td>
</tr>
<tr>
<td>Yes</td>
<td>7 (36.8)</td>
<td>7 (70)</td>
</tr>
<tr>
<td>No</td>
<td>12 (63.2)</td>
<td>3 (30)</td>
</tr>
<tr>
<td>Amount of Care Exp.</td>
<td>.253</td>
<td>.044*</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>12 (63.2)</td>
<td>3 (30)</td>
</tr>
<tr>
<td>&lt; 10 hrs.</td>
<td>0.0</td>
<td>2 (20)</td>
</tr>
<tr>
<td>≈ 10 hrs.</td>
<td>1 (5.3)</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt; 10 hrs.</td>
<td>5 (26.2)</td>
<td>4 (40)</td>
</tr>
<tr>
<td>No response</td>
<td>1 (5.3)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Death of someone close</td>
<td>.353</td>
<td>.197</td>
</tr>
<tr>
<td>Yes</td>
<td>13 (68.4)</td>
<td>9 (90)</td>
</tr>
<tr>
<td>No</td>
<td>6 (31.6)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>Recent mo./yr. of death</td>
<td>.554</td>
<td>.211</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>6 (31.6)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>≤ 1 yr.</td>
<td>3 (15.8)</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt; 1 yr. up to 5yr.</td>
<td>7 (36.8)</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt; 5 yr.</td>
<td>3 (15.8)</td>
<td>9 (90)</td>
</tr>
<tr>
<td>No response</td>
<td>0.0</td>
<td>2 (28.6)</td>
</tr>
<tr>
<td>Anticipating a death</td>
<td>.197</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>2 (10.5)</td>
<td>1 (10)</td>
</tr>
<tr>
<td>No</td>
<td>16 (84.2)</td>
<td>9 (90)</td>
</tr>
<tr>
<td>No Response</td>
<td>1 (5.3)</td>
<td>0.0</td>
</tr>
</tbody>
</table>

*Independent Samples t Test; * Mann-Whitney U; * Pearson’s Chi Square, * p < .05
**Instrument Reliability**

All quantitative measures were analyzed using the Social Science Statistics Package (SPSS), Version 22.0 on a Macintosh computer. The Microsoft Word Program 2011, Version 14.6.6 was used on a Macintosh computer for enumerating key words from qualitative transcripts.

**Palliative Care Quiz for Nurses (PCQN).** The PCQN consists of 20 items to assess basic knowledge of palliative care using three subscales 1) four items: 1, 9, 12, and 17 for philosophy and principles of palliative care, 2) thirteen items: 2-4, 6-8,10, 13-16, 18, and 20 for pain and symptom management, and 3) three items: 5, 11, and 19 for psychosocial and spiritual care. Each item was answered *True, False, or I Don’t Know* and then scored by summing the total number of correct answers. Each correct answer was assigned one point. No points were awarded for incorrect answers. No points were awarded for items answered with *I Don’t Know* to avoid points gained from guessing. The overall Cronbach’s alpha at posttest ($N = 18$) was .614, indicating poor internal consistency reliability (See Table 4.3).

**Frommelt Attitude Toward Care of the Dying Scale (FATCOD).** The FATCOD Scale consists of 30 items answered using a Likert scale from 1 = Strongly Disagree to 5 = Strongly Agree. Thirteen items are positively worded and 17 are negatively worded. The negatively worded items were reverse coded before calculating a Cronbach’s alpha. The overall Cronbach’s alpha for the pretest sample ($N = 29$) was .753 and at posttest ($N = 18$) was .745, indicating acceptable internal consistency reliability (See Table 4.3).
Table 4.3

**Reliability for PCQN and FATCOD**

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Pretest Cronbach’s Alpha ((N = 29))</th>
<th>Posttest Cronbach’s Alpha ((N = 18))</th>
</tr>
</thead>
<tbody>
<tr>
<td>PCQN Score</td>
<td>.385</td>
<td>.614</td>
</tr>
<tr>
<td>FATCOC Score</td>
<td>.753</td>
<td>.745</td>
</tr>
</tbody>
</table>

**Findings to Research Questions**

**Research question one.** To what extent does participation in structured EOL education based on the ELNEC curriculum and planned experiences “being with” dying patients affect students’ knowledge and attitudes toward EOL care?

Findings on a paired samples \(t\)-test revealed that elective group knowledge scores were not significantly different from pretest \((M = 65.7, SD = 9.8)\) to posttest \((M = 65.0, SD = 12.2)\), \(t(6) = .11, p = .92\). Such findings indicated that participation in a structured ELNEC curriculum and concurrent experience with dying patients through a semester long course demonstrated no statistical significance on basic palliative and EOL care knowledge for this sample of students. A paired samples \(t\)-test similarly revealed that elective group attitude scores were not significantly different from pretest \((M = 122.9, SD = 10.2)\) to posttest \((M = 126.9, SD = 7.2)\), \(t(6) = -1.2, p = .28\), which indicated that the elective course demonstrated no statistical significance on participant attitudes toward care of the dying for this sample of students.

**Research question two.** To what extent does 172 hours of clinical experience affect students’ knowledge and attitudes toward EOL care?

Findings on a paired samples \(t\)-test revealed that comparison group knowledge scores at pretest \((M = 48.6, SD = 10.5)\) were not significantly different at posttest \((M = 53.2, SD = 17.6)\), \(t(10) = -.74, p = .48\), which indicated that 172 hours of varied clinical nursing care experience
revealed no statistical significance on basic palliative and EOL care knowledge for this sample of students. A paired samples t-test also revealed no significant differences between comparison group attitude score at pretest \((M = 116.8, SD = 7.2)\) and posttest \((M = 117.7, SD = 6.15)\), \(t (10)\), \(= -0.342, p = .74\), which indicated that 172 hours of clinical experience revealed no statistical significance on attitudes toward care of the dying.

**Research question three.** Is there a difference in knowledge and attitudes toward EOL care between the elective group and comparison group?

In order to critically examine differences, knowledge and attitude scores between groups were compared from pretest findings to establish baseline differences. Pretest variances for the total sample were equally distributed for PCQN scores \(F (1,27) = -2.42, p = .33\), and FATCOD scores, \(F (1,27) = -2.44, p = .47\), indicating a normal distribution. However, there were significant differences in PCQN and FATCOD scores between the elective and comparison groups. Findings from an independent samples t-test at baseline revealed a significantly higher PCQN mean score for the elective group \((M = 61.50, SD = 12.03)\) than the comparison group \((M = 51.32, SD = 10.12)\), \(t(27) = -3.45, p = .023\). Similarly, the FATCOD mean score for the elective group \((M = 123.9, SD = 9.2)\) was significantly higher than the mean score for the comparison group \((M = 116.53, SD = 6.9)\), \(t(27) = -2.44, p = .022\). Both findings indicated greater baseline knowledge and attitudes toward care of the dying by participants enrolled in the EOL elective compared to those enrolled in the senior practicum course (See Table 4.4).
Table 4.4

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Pretest (N = 29)</th>
<th>Posttest (N = 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Comparison</td>
<td>Elective</td>
</tr>
<tr>
<td></td>
<td>n = 19</td>
<td>n = 10</td>
</tr>
<tr>
<td>PCQN</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>Total Score</td>
<td>51.32 (10.1)</td>
<td>61.50 (12.0)</td>
</tr>
<tr>
<td>FATCOD</td>
<td>116.53 (6.9)</td>
<td>123.90 (9.1)</td>
</tr>
</tbody>
</table>

Independent Samples t test. * p < .05

At posttest, variances on PCQN, $F(1,16) = -1.54$, $p = .49$) and FATCOD ($F(1,16) = -2.88$, $p = .86$) scores were equally distributed between groups indicating a normal distribution. An independent $t$-test revealed no significant differences in PCQN mean scores between groups, even though the elective group scored 12 points higher ($M = 65.0$, $SD = 12.3$) than the comparison group ($M = 53.2$, $SD = 17.7$), $t(16) = -1.54$, $p = .142$). However, the elective group scored significantly higher on attitudes FATCOD ($M = 126.9$, $SD = 7.2$) than the comparison group ($M = 117.7$, $SD = 6.2$), $t(27) = -2.88$, $p = .011$), indicating more positive attitudes toward care of the dying (See Table 4.4).

**Qualitative Findings**

Research questions four; five, and six are addressed by presenting qualitative data from focus groups. First, procedures for participant follow up and conducting each focus group are presented. Analysis of the data from each group is also explained. Findings from the data are presented first for the elective group, second for the comparison group, and then differences between the two groups are presented.
Focus Groups (FG)

**Participant reminders.** As a follow up reminder for participants scheduled for focus groups, electronic mail reminders of the EOL study were sent since study participants were anonymous to the primary investigator (PI). All students enrolled in the EOL elective and Senior Practicum course were sent reminders. Reminders were sent at one week prior to and again the day before each focus group. Reminders included: the date, day, time, and place for completing posttest instruments, and location of focus groups with pizza provided for participants. The last four digits of participant identification numbers (IDs) were also listed for each group. Directional signs were posted on classroom doors and hallways on the morning or afternoon of each focus group.

For participants in the elective group, additional reminders were given about where and when posttest instruments would be available after the elective course class, should they decide to complete participation. On those days, the PI left the elective course early to allow participants freedom to complete posttests before attending a focus group. A list of focus groups with participant IDs listed for each group was also provided as a reminder of the day and time they chose at the beginning of the semester. However, participants could attend either group since the total number within each group was smaller than anticipated.

**Timing.** Focus groups were conducted within eight class days before the final exam week. In this time frame, participants from each group had completed course work, and clinical or volunteer experiences. Participants scheduled for each focus group completed posttest instruments. At posttest, four of six focus groups were conducted. Two focus groups were conducted with elective participants and contained five and two students respectively. Two of three scheduled focus groups were conducted with comparison participants and contained three
and two students respectively. For the third scheduled focus group one student showed up to participate, making it an individual interview.

Comparison group focus groups were conducted between noon and three p.m. and except for one male, all participants were female. Pizza and drinks were provided before focus group discussion started. Focus group questions were aimed at evoking knowledge and attitudes about EOL, death, and care of the dying from two time periods; first the earliest memories prior to entering nursing school, and second, the time period after entering nursing school up to the present.

**Group discussion.** All focus group discussions were semi structured. Questions prepared in advance were used to keep discussions focused on attitudes toward EOL and EOL care. Questions were formatted to query students about the earliest events or experiences they could remember that most impacted their beliefs, values, and feelings about EOL. Students were asked about EOL experiences from the earliest age they could remember prior to entering nursing school. When participants had nothing else to add to discussion about past significant events, a clear transition was made to more current experiences, which included experiences since entering nursing school.

**Data Analysis**

Five transcripts of qualitative data from the focus groups were analyzed based on Benner’s (1994) guidelines for a hermeneutic, or interpretive phenomenology (IP) specific to nursing education and development. Benner’s guidelines (Benner, 1994; Brykczynski & Benner, 2010) emphasize three interrelated processes for analyzing the text from focus groups: 1) a thematic analysis, 2) identifying exemplars, and 3) identifying paradigm cases of the phenomena being investigated.
The three processes are interrelated in what Benner (1994) describes as a repetitive pattern between examining smaller parts within the text individually and then examining those parts again in context of the larger text as a whole group or the whole phenomenon being studied, which is EOLC. Smaller parts within the text may represent individual comments or concepts, which may provide greater depth and insight when examining the phenomenon being studied from the text as a whole (Brykczyński & Benner, 2010). By using this repetitive pattern of analysis, more insight may be revealed about the phenomenon as a whole. New insight may also be revealed about the phenomenon as expressed by individuals within the group. “To understand any given part, you look to the whole; to understand the whole, you look to the parts” (Smith, Flowers, & Larkin, 2009, p. 28).

This circular pattern of analysis between the parts and the whole, theoretically referred to as a hermeneutic circle, has no objective endpoint in studying human sciences because individuals within their circumstances are in constant motion and subject to changing interpretations at any given moment in time, including interpretations by the researcher (Benner, 1994; Miles, Francis, Chapman, & Taylor, 2013; Smith et al., 2009). Therefore, an infinite number of interpretations can result because of multiple views of the smaller parts and/or views from which to examine the larger phenomenon (Benner, 1994; Miles et al, 2013). The limiting factor is the extent to which a clear and reasonable description evolves toward answering the research question (Brykczyński & Benner, 2010; Smith et al., 2009).

Along with the text from transcripts, hermeneutic interpretation includes observations of participants and their behaviors to glean the most insight underlying the text (Benner, 1994). All focus groups were audio-recorded and transcribed verbatim by the PI, which was advantageous for the analysis in that physical behaviors by various participants based on field notes were
recorded next to their corresponding comments on transcripts. Transcripts also included field notes of non-verbal responses visibly noticed or audibly heard from others at certain moments during the discussion. Such notes provided additional affirmation of emotions identified and captured by the PI but not clearly recognized from transcribed words. Thus, transcripts including field notes revealed underlying emotions, observations, and impressions concerning student perceptions and approaches to EOL care.

The following processes were conducted for promoting coherence of the interpretation (Benner, 1994; Smith et al., 2009). Processes included: 1) an initial reading of individual transcripts for prominent words, phrases, concepts, and ideas, 2) re-reading transcripts while examining the prominent words and phrases for similar or repeated concepts with broader but more significant sets of related ideas emerging as themes, 3) identifying contrasting views of repeated concepts of an emerging theme related to the purpose of the research, 4) identifying exemplars from the major themes, and finally 5) identifying a paradigm of EOL care from among the exemplars provided. Each process added more layers of insight until major themes emerged from which to identify exemplars, which in turn provided a paradigm of EOL care from each group.

**Thematic analysis.** Further details of the first three processes conducted for the thematic analysis are described. In the first process, transcripts were read initially to identify and write a list of prominent words and phrases for each group as a whole. In the second process, words and phrases with similar meaning were collapsed into thematic categories encompassing various aspects of an emerging theme. The third process involved identifying slightly different or clearly contrasting views within each thematic category. Each slightly different and contrasting view was read in context of the whole transcript to determine if the view was related to any of the
emerging themes. If related, the contrasting view was added to the same thematic category as a varying characteristic or degree of an emerging theme. Views unrelated to death, dying, EOL, or nursing care were considered extraneous to the phenomenon of EOLC, and therefore excluded.

Transcripts were then read in light of all the thematic categories to identify significant themes related to beliefs, values, feelings, and behaviors specifically concerning EOL, dying, or EOL care. Any theme identified by at least two or more participants within each group was considered significant. The contrasting views were included if related as a variation of the same thematic category. Thematic categories recurring with the greatest frequencies were further collapsed into brief descriptions.

Further affirmation of major themes came from field notes and corresponding non-verbal sounds heard on audio-recordings. Field notes by the PI included words from a theme and corresponding sounds made in response to the theme. All field notes and non-verbal responses such as such as hmm, ah, or oohhh, on transcripts were reviewed in light of the themes. Although not transcribed into text with linguistic meaning, they indicated reactions that further identified or clarified important themes. Major themes that emerged were written out and re-coded by shortening a word that best represented the major theme. The final codes were used to represent the major themes expressed by both groups.

Identifying exemplars. With major themes clearly identified, transcripts were read again to identify exemplars, or clearly articulated examples epitomizing a major theme. All possible exemplars were examined individually from the transcript. Some excerpts were short but unequivocal in terms of the concept within a major theme. Other examples included lengthier accounts with more descriptions of emotions and related thoughts about a major theme. All possible exemplars, whether suggestive or explicit, were examined as individual cases of a major
theme. Contrasting views retained earlier when categorizing differences were included to provide a relative range of exemplars. According to Benner (1994), the goal in interpretive research “is to develop a range of exemplars that allows the reader to recognize the distinctions the interpretive researcher is making in practice” (p. 117). Exemplars were then read in context of the overall phenomenon of EOL care. Exemplars were singled out if they described a major theme that resonated with other participants. Other participants often affirmed the exemplar by describing a similar experience or by directly referencing the speaker of the exemplar case, further supporting the exemplar as a defining reference for a specific theme.

**Paradigms.** Finally, transcripts were searched for paradigms of EOL care congruent with verbal and nonverbal affirmation from participants within the group and in context of the overall discussion. According to Benner (1994), interpretive analysis employs exemplars as operational definitions to describe a paradigm of the phenomenon being studied. Therefore, paradigms convey more complete descriptions of the phenomenon of interest by incorporating the various exemplars from participants within the group (Benner, 1994). Participants with narratives identifying concepts from an exemplar case supported the exemplar. Examining field notes of participant observations while listening to audio-recordings was instrumental in determining how many participants responded to concepts within the exemplars of EOL care. A paradigm becomes apparent from analyzing qualitative descriptions epitomizing the collective thoughts, beliefs, reactions, concerns, and experiences of a major phenomenon (Benner, 1994, Brykczynski & Benner, 2010).

**Research question four.** From focus group discussions, what attitudes, beliefs, values, and emotions about EOL care did students from the elective group express (See table 4.5).
Table 4.5

Elective Group Major Themes and Modifying Subthemes

<table>
<thead>
<tr>
<th>Discomfort</th>
<th>Comfort</th>
<th>Meaningful Relationship</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional Intensity</td>
<td>Feeling State</td>
<td>Quality Time</td>
</tr>
<tr>
<td>Fear</td>
<td>Relieved</td>
<td>Acknowledge presence</td>
</tr>
<tr>
<td>Sadness or grief</td>
<td>Gratified</td>
<td>Express appreciation</td>
</tr>
<tr>
<td>Anger</td>
<td>Happy</td>
<td>Reminisce</td>
</tr>
<tr>
<td></td>
<td>Privileged</td>
<td>Do special activities</td>
</tr>
<tr>
<td></td>
<td>Honored</td>
<td>Be attentive</td>
</tr>
<tr>
<td>Lack of Knowledge</td>
<td>Action</td>
<td>Getting to Know</td>
</tr>
<tr>
<td>Apprehension with EOLC</td>
<td>To be present</td>
<td>Memorable bond</td>
</tr>
<tr>
<td>Communication</td>
<td>To listen</td>
<td>Close feeling</td>
</tr>
<tr>
<td>Misconceptions</td>
<td>To make smile</td>
<td></td>
</tr>
<tr>
<td>Guilt</td>
<td>To converse</td>
<td></td>
</tr>
</tbody>
</table>

Elective focus group profiles. Before expanding on the major themes, a brief profile of each elective focus group (EFG) is presented. A total of seven students from the elective group participated in two focus groups. The first elective focus group (EFG1) contained five students and the second elective focus group (EFG2) contained two students. Pseudonyms selected by the PI are used in place of participant names.

Elective focus group one (EFG1). The first focus group (EFG1) contained five participants referred to by pseudonyms. All participants spent 10 hours during the elective course visiting hospice patients rather than providing clinical care. Anna was a 24-year-old female. She remembered the loss of her grandmother. She was eight or nine years old at the time and recalled being angry about her grandmother’s memory loss before her death. Other
than the hospice visits, Anna had no EOL care experience. Beth was a 22-year-old female, who remembered the traumatic loss of her grandmother. Dana was a 21-year-old female who recalled the difficult emotions from the loss of her grandfather and memories of him at EOL. Ella was a 21-year-old female who had no experience with personal loss prior to the semester. She had experience as a hospice volunteer, which she started two weeks prior to enrolling in the palliative and EOL course. All of these participants recalled memorable EOL experiences with a hospice patient from their elective course volunteer experience. The fifth participant was Cara. She was 53 years of age and already a registered nurse working on her baccalaureate degree in nursing. She had past experience providing EOL care in a hospice setting. She had experienced the death of family members from the past and recalled a memorable experience with a hospice patient as a volunteer.

**Elective focus group two (EFG2).** The second focus group contained two participants, referred to by the pseudonyms Greta and Fran. They were 36 and 46 years of age respectively. Each recalled memorable EOL experiences of a close family member. Fran admittedly had a “fascination for death” and once considered mortuary school. However, a difficult experience with her father’s death six years previously and exposure to hospice nurses influenced her decision to embark on nursing as a career. Greta recalled vivid memories of her grandfather’s “good death” and her grandmother’s “awful death.”

All participants shared experiences about EOL or the death of someone meaningful in their life such as a family member or one of the hospice patients from the palliative and EOL elective course. Three major themes were evident: 1) discomfort, 2) comfort, and 3) meaningful relationship. Subthemes moderated different degrees of some major themes, which provided more depth and perspective about their knowledge and attitudes toward EOL or EOL care.
Elective Group Major Themes

Theme: Discomfort. The first theme associated with EOL and death was discomfort, which was marked by “feeling uncomfortable” and coded as discomfort. The underlying characteristic of discomfort was an unpleasant feeling. Two subthemes moderated the degree of discomfort, emotional intensity and lack of knowledge. Participants recalled how they felt from the death of someone to whom they were close. Most were not present at the death but they recalled strong responses to the loss, such as sadness or grief. Some who witnessed a loved one at EOL also felt fear, anger, and guilt. Varying intensities of emotion were described as shock, anxiety, or frustration. Intense emotions were impressed on them from seeing physical distress or loss of function at EOL for the first time, usually while visiting a close family member at EOL or a hospice patient.

Subtheme: Emotional intensity. As a subtheme, emotional intensity moderated the discomfort with EOL. All participants recalled significant reactions of sadness or grief over the loss of someone significant or seeing that person at EOL prior to death. Emotional intensity describes how strong participants reacted when they recalled memories of an EOL experience, which was usually marked by seeing physical and/or emotional distress at EOL for the first time. Certain details stood out about such uncomfortable incidents. For example, Dana (EFG1) recalled her grandfather screaming out in pain at EOL and was fearful. Greta (EFG2) remembered her grandmother’s “grotesque” physical appearance. Anna (EFG1) remembered being so “angry” that her grandmother never recognized her before she died.

Fear, sadness, and anger were the most common emotions of discomfort identified. Most social scientists and researchers of emotions document four basic emotions: fear, sadness, anger, and happiness as “primary emotions” because of their universal identification and expression
across cultures (Turner, 2009, p. 342). Different terms used to describe a primary emotion often
indicate the intensity of the emotion, such as depression indicating a greater intensity of sadness
(Kemper, 1987; Parrott, 2010, Turner, 2009). Secondary emotions such as shame, guilt, or pride,
are often combinations of the primary emotions and generally considered socially or culturally
conditioned (Bericat, 2016). Participants identified all the primary emotions in an EOL situation,
which occurred when much younger as an adolescent or younger for many. Varying descriptions
of an EOL incident indicated the intensity of their initial emotions, reflections about the EOL
situation in hindsight, and their thoughts about EOL and EOLC based on new information and
education since the incident.

*Fear.* Fear from the first EOL experience was discomforting for most participants
because of circumstances and emotions that involved people they cared about. Participants were
especially discomforted about loss of a family member. Dana remembered the unpleasant
experience with her grandfather at EOL. She was 14 years old at the time:

It was scary because I saw my grandfather go through it and *I don’t know.*

It [pain medications] just didn’t seem to work for him because he was like, screaming out
in pain sometimes. It just wasn’t pleasant. So it was kind of scary to me. But now it is
nice to know that people can die a good death. It’s not *all* like that [referring to
her grandfather’s screaming at EOL]. (Dana, EFG 1)

Dana implied that her grandfather had received something for pain but it did not work. Fear was
present from Dana’s recollection of hearing him scream, and lacking knowledge of why “it”
didn’t work. Her impression was based on that vivid memory of someone she loved crying out
in pain, yet receiving inadequate relief. Given this experience, Dana was relieved by the
knowledge that a “good death” was possible, which she implied her grandfather did not have.
Dana also remembered how she felt prior to her first hospice visit in the past semester, particularly of getting close to someone dying:

I was scared the first time [meeting a hospice patient]. Luckily I had somebody to go with me that had some experience. So that was really helpful. But it was really scary for me to go cause I was afraid of that relationship, of like getting close to someone. (Dana EFG1)

Dana remembered her fear of the emotional connection. Her only memory of EOL before that first hospice visit was the fear associated with the “very hard” EOL and loss of her grandfather. It was understandable why she feared getting close to someone dying again.

Before meeting her hospice patient through the EOL elective, Ella (EFG1) had never experienced the death of someone she knew personally. She recalled what she thought of building a relationship with someone dying:

I was definitely afraid of getting close to a dying person. Before this class I was already volunteering with hospice, but I hadn’t had an experience where I had gotten close to a person or a patient before they died and the idea of building up a relationship with someone who had less than six months to live, like knowing that, going into it was kind of off-putting for me I guess . . . I feel like I’d enjoy the experience less. (Ella, EFG1)

Because she had already been volunteering in another hospice, Ella thought building a relationship with a patient would take away from her experience. She seemed to enjoy her hospice volunteer experiences before getting to know a patient more personally through the EOL elective. She seemed to fear the sadness that comes from losing someone personally close.

Anna (EFG1) on the other hand, recalled a higher intensity of fear before visiting her first hospice patient, “I was trying to picture the inevitable that they were going to be gone and I just couldn’t really do it. It just scared me. I was actually petrified in all honesty.” Anna later
clarified her fear of not knowing what to expect, “It’s like you would go into the situation, with what we’ve been told [by volunteer coordinator]. You just walk in the room and you have no idea what to expect.” When asked about her first EOL experience, Anna (EFG1) described her grandmother, with whom she was very close as a child. Not knowing what to expect was a strong trigger for her initial reaction to her grandmother’s distant behavior at EOL:

Mine was with my grandmother and I was a lot younger than I am now. Before I even knew what Alzheimer’s dementia was, I didn’t really understand, why every time I would go up there and visit….she’d never recognize me or my brother or even my mom. I was like eight or nine. At that age you can’t really grasp why. I just remember spending so much time being angry and upset . . . . I wish someone just had explained it better to me . . . It was just a really hard feeling like, not knowing what was going on. . . . [Anna’s head faced straight down at the floor as she spoke more slowly and in a soft tone of voice] It got progressively worse and her memory never came back. (Anna, EFG1)

Anna emphasized what she remembered most at that age, the duration of her anger. Because she had no knowledge of Alzheimer’s or dementia at the time, Anna did not understand why her grandmother did not acknowledge her as a family member. Although Anna and her family continued to spend time with their grandmother, the dementia only worsened. Her grandmother’s memory never returned before she died. It may have felt personal to Anna since no one had explained anything about her grandmother’s dementia as the possible reason for her distant behavior. Not knowing what to expect before meeting her hospice patient also triggered Anna’s fear.

Greta’s (EFG2) reaction to seeing her grandmother in the hospital before she died was difficult to interpret because of her quizzical chuckle to describe the experience simply as
“weird.” When asked to clarify what was weird, Greta chuckled: “Oh I was just kiddin [sic]. I mean I was just a kid and the, you know, changes that happen before you die, and she didn’t look like the person I knew.” When asked how she felt at the time, Greta was reluctant to talk and turned to Fran (EFG) asking her to share instead. Fran (EFG) shared about her father’s difficult death with a sense of ease, which seemed to allow Greta (EFG) some space for deciding whether to share about her grandmother.

Greta (EFG), a 36 year-old female, wanted to talk about a positive experience with her grandfather’s death. She was about 13 years old at the time. Her grandfather died in the hospital several years before her grandmother died. She described his death as a “really neat experience” because his whole family was present in the room. He was conscious and communicative before slipping into a coma and taking his last breath. She recalled wanting to go to his funeral. Sensing her reluctance earlier to talk about her grandmother at EOL, she was asked about her grandmother’s funeral. She didn’t go to her grandmother’s funeral. In contrast to how she described her grandfather’s death, Greta was more serious and her tone was stern as she described more details about her grandmother:

I was there [Greta’s emphasis] when my grandfather died. I was like, in the room when he died. In other cases, I got to visit, like with my grandmother before she died, and that was weird. . . . . I was a kid. I was a kid. I was not ok with the idea of dying . . . . She had ovarian cancer and she had the opposite of a good death, one of the worst I can imagine. It was awful. When I went to visit her, she was attached to tubes to drain the ascites from her abdomen. She had [intravenous] IVs and eventually they put her on a ventilator. She had all this garbage! And she had lost weight, so her abdomen looked even more grotesquely distended. They [health care providers] just pushed round after round of
chemo and round after round of radiation and they said ‘This may help make the tumor smaller.’ It was all garbage. (Greta, EFG2)

Greta was not “ok” with dying the way she saw her grandmother, whom she did not recognize because of her physical appearance. She repeated being “a kid” as the reason for calling it “weird.” Reflecting on the weight loss and abdominal distension as “grotesque” and the IVs attached as “garbage,” Greta expressed a sense of disgust. From her knowledgeable and accurate medical description of the details, she concluded it was “the opposite of a good death.”

Greta’s description was an exemplar of a bad death in a hospital, which was her grandmother connected to tubes, physically disfigured beyond recognition, unable to communicate because of a ventilator, IVs connected for multiple treatments, and health providers saying that the treatment may help her tumor. Greta could not imagine a worse death because of the opposite experience with her grandfather. His EOL in the hospital was her reference point for a good death. What she saw as a kid seemed “weird.” Based on her recollection of that experience, what seemed worse to Greta was the rationale from health care providers that pushing all the treatments may help, which she criticized as “garbage.”

Although the words “bad death” were never said, the concept was clear from their words, “the opposite of a good death.” Likewise, Dana (EFG1) was relieved to know that people “can die a good death.” She alluded to her grandfather’s screaming in pain as a bad death by expressing relief to know that “it’s not all like that.”

Sadness. Participants expressed varying degrees of sadness over losses at EOL or anticipated loss. After their last hospice visits, Anna (EFG1) and Dana (EFG1) expressed their sadness. Anna (EFG1) said: “I was really sad yesterday. It was not a fun car-ride home yesterday.” Dana (EFG1) added, “I know. That’s how I was. I was playing happy music on the
way home trying to get in a better mood because I didn’t want to leave.” Participants were also saddened by the loss of physical independence and inevitable death:

- It’s very sad to know that they’re not going to be there anymore and you can’t go back and see them. (Dana, EFG1)

- Just watching her decline . . . She was so aware of that loss. It just made me sad . . . to not be able to do basic things for themselves is devastating. (Greta, EFG2)

- I was sad every time I left. Because I knew, for one, I was going to be done for this project and I don’t live close enough to go see her as often as I would want to, and [second], knowing that she just didn’t seem very happy where she was . . . She always seemed so sad . . . I felt stuck because there was nothing I could do, especially during this time when she’s deteriorating. (Dana, EFG1)

- If I wasn’t there, they might have not had some of the conversations or might not have gotten what they needed. So I feel like if I’m there, I’m improving their life in some way even if it is like a sad experience. (Beth, EFG1)

Dana was saddened to the point of feeling helpless to improve her patient’s circumstances, which was compounded by the patient’s physical deterioration.

Ella (EFG1) expressed a sense of sadness much stronger than what she had anticipated earlier as “off-putting.” Ella visited two hospice patients during the semester. One died after a single visit. She said, “If I had to stop seeing my other lady, I would probably fall to pieces . . . she had family present and all sorts of stuff going on and I felt like she needed more support compared to the lady I only saw once.” Having gotten to know her patient better, Ella felt “committed” to her patient and decided to continue visiting her until her death, even after the semester. Seeing her patient until her death was Ella’s way to avoid “falling to pieces,”
indicating the inability to contain her emotions or a sense of losing emotional composure. In contrast to her previous fear of getting close to someone as a less enjoyable experience for her personally, Ella’s sadness had focused on the patient’s need for support. She had developed a deeper concern for the patient’s wellbeing.

Dana (EFG1) expressed sadness to the point of shock after hearing her grandfather’s cancer diagnosis and poor prognosis:

He was diagnosed with stage four cancer and we literally thought he was just going to a regular doctor’s visit. They wanted to do exploratory surgery. We were waiting for them to come back after surgery and say ‘everything is fine.’ And the doctor came back and dropped a bomb on us ‘that he has weeks to live.’ So that was very hard and very unexpected. It was a very hard experience, and he just, like wasted away. (Dana, EFG1)

Dana was close to her grandfather and her analogy of a bomb conveyed the sudden and forceful impact of hearing that her grandfather only had “weeks to live.” The repetition and emphasis on “very hard” indicated her shock, which was compounded by the added image of her grandfather’s physical wasting.

Anger. Participants expressed anger over poor treatment or care at EOL. Beth (EFG1) remembered her grandmother who had chosen to live at her own home until she died from a sudden fall. Beth recalled how happy her grandmother was to be independent although alone. The pleasant memory of her grandmother in her home at EOL contrasted with the assisted facility where Beth’s hospice patient lived. Beth expressed anger to the point of frustration. She was appalled over the poor conditions. She considered lack of care to be poor EOLC based on how she described her hospice patient and other residents during visits:
I was frustrated. . . I don’t like seeing people sitting in their own urine, [the] same spot all day, every day, [and] that they only have one hallway to go down and to go back… they’re medicated, and in their wheelchairs all day, I just don’t like the system. (Beth, EFG1)

Beth’s comment drew responses from other participants. Some participants seemed to agree by nodding their heads in unison as Beth spoke. Others expressed disapproval of the disrespect toward dying patients. They described insensitivity toward care of the dying:

I don’t feel like my patient was being treated the way she was supposed to be treated because she was such a great person. When I was there, it didn’t seem like she was a big priority to anyone. . . The caregiver just didn’t seem like she wanted to help these people.

It was like they were more a burden for her. (Dana, EFG1)

Cara (EFG1), who had hospice nursing care experience, was naturally angered that a caregiver ignored her patient’s request for pain medication. Cara advocated for pain medicine for her patient by speaking to the nursing staff. Her patient had leg surgery over a week ago. Cara described the attitude of caregivers toward her patient: “I felt like they all [caregivers] felt that my patient wasn’t having pain but she was the pain. So it really angered me.”

Beth seemed the most affected by the anger felt around the room. She expressed her resolve in the form of an admonition:

I feel like I’ve been interested in end-of-life care, but now I kind of see it as, ‘If I want to see a change, it’s almost like a duty, I feel like it’s a responsibility for each person that has the knowledge and has been informed of this system, if they really feel that it’s that bad, that they should do something to change that.’ Now I feel like it’s more of a passion that I feel like I need to change or help change. (Beth, EFG1)
Beth’s anger made her more than interested in EOLC. She expressed her determination to change EOLC. Instead of a nursing responsibility, Beth expressed her duty to improve EOLC as more of a mission.

Fran (EFG2) implied her anger over her father’s EOL as the reason for going into the nursing profession. She described aggressive procedures her father had endured despite his frailty at the time. His EOL was characterized by multiple complications from procedures, which were never explained or anticipated beforehand. She felt that her father was pressured into having the procedures:

They told my mom and dad that ‘if you don’t do this surgery you’re going to die’… He was 79 and not in that great of health any way. He never bounced back. But it never occurred to me that he was dying. He bounced back and forth between skilled facilities and the hospital. It took him a year to die. It was just this horrible protracted process. I mean part of that is what fueled me to want to get into hospice practice and be an advocate. (Fran, EFG2)

Besides her father suffering at EOL, lack of knowledge or options for EOL from that experience fueled Fran to advocate for a better EOL than what her father had endured.

*Subtheme: Lack of knowledge.* Lack of knowledge was also a subtheme that modified discomfort by making participants apprehensive with EOLC, particularly communication. Lack of knowledge was also the underlying basis for misconceptions about the dying and guilt felt from seeing a loved one suffer at EOL. Some participants experienced EOL for the first time at an early age. The lack of knowledge when much younger evoked reactions of fear, shock, or anger over what they did not understand. Earlier, Anna (EFG1) recalled her anger as a child because no one had ever told her about her grandmother’s dementia. Her anger was in response
to not knowing “what was going on” with her grandmother. Dana (EFG1) described earlier her fear from not understanding why something wasn’t working to relieve her grandfather’s pain at EOL. Greta (EFG2) recalled the whole experience of her grandmother’s visit as “weird,” because she did not recognize her grandmother or all the medical devices or attachments. Dana (EFG1) and Fran (EFG2) expressed their guilt from wishing for death of a loved one instead of watching them suffer. Dying was the only solution that they knew of at the time to end suffering.

Apprehension with EOLC. In context of EOL nursing care, lack of knowledge was an underlying reason some participants were apprehensive about care of the dying. Although participants were not responsible for physical nursing care as hospice volunteers, Anna (EFG1) remembered feeling “almost blind” from not knowing what to expect before walking into her hospice patient’s room. Greta (EFG2) admitted, “I guess I’d be nervous if in a nursing kind of stand point . . . I’ve never like, cared for a patient. That’s different, very different.”

Communication. Participants recalled their dread of communicating with dying patients or even talking about death and dying before the EOL elective. Greta (EFG2) recalled how she and her family avoided the subjects of death and dying around the time of her grandfather’s death, “No one wanted to directly talk about it with him . . . We all pretended it wasn’t happening.” Since enrolled in nursing school, Greta (EFG2) commented, “Even nurses don’t talk about it. We don’t talk about dying.” Fran (EFG2) added, “Our culture is so death averse. Aging creeps up on you and suddenly you’re in this place where you like say ‘Crap, I’m dying’ and nobody ever talks about it.” Participants recalled their apprehensions about communicating with someone dying:
• It’s hard to carry on a conversation with someone that you know is dying. Like it’s a big
elephant in the room. (Dana, EFG1)

• I was anxious just because I was scared I was going to say the wrong thing, just cause
everyone is so different and I thought I would say something that might make them mad
or make them feel worse. (Anna, EFG1)

• In the past I had a 30 year-old patient who was in end-stage liver disease from cirrhosis
and I had no idea how I was going to talk to this kid. He was only 30 years old. I can’t
say ‘die’ to a 30 year old. (Greta EFG2)

Although participants had experienced personal loss and had talked to someone dying in
the past, they expressed apprehensions about what to say in the context of a nurse-patient
relationship. Lack of knowledge had made them nervous with the idea of caring for and
communicating with a dying patient.

_Misconceptions._ Participants had misconceptions about dying patients and EOLC due to
faulty assumptions or misperceptions. Anna (EFG1) for example, had assumed all dying patients
were in pain, “I always had the image that, despite the circumstance, they all had pain, the one
thing in common.” Greta’s (EFG2) misconception of palliative care was clear, “I assumed
palliative care was mostly pain medicine, like oxygen therapy you know, and like… people in a
room left to die.” Greta referred to some of her classmates in nursing school who thought the
same, “There’s this connotation that the nurses will just leave you alone in the hallway. Or park
you in the day room and call that social time.” From her hospice care experience in the past,
Cara (ECF1) agreed that “there are a lot of misconceptions” about EOLC, but did not elaborate
further.
Dana (EFG1) expressed her misperceptions of working with “dying people” in health care as impersonal and mechanical until she experienced getting to know someone at EOL as a hospice volunteer. She described a “new” respect for individuals at EOL from a health care perspective. Her description was an exemplar of respect for someone dying in a health care relationship:

It gives you a whole new respect for dying people, especially people you don’t know. I mean working in healthcare people die, and that’s just how it is. And you gain a little more respect for them as a person. I have through this class. They’re not just ‘some’ body who’s passing away, dying. They’re somebody’s mom or somebody’s grandparent or somebody’s sister. They’re a person, and you do more than just push morphine [laughing lightly]. You have to do more [in serious tone].

Dana implied her impersonal views of a dying person as “somebody who’s passing away” and a mechanical perception of EOLC to “just push morphine.” From getting to know her hospice patient, Dana gained a new respect for people at EOL. From a health care perspective, she viewed someone at EOL as significant because of his/her connection to another person, such as a family member. She viewed care of someone dying as more than just giving medication.

**Guilt.** Two participants described guilt as another source of discomfort related to the lack of knowledge about how to end suffering. Dana (EFG1) and Fran (EFG2) remembered wishing for death of a family member instead of seeing the member suffer at EOL. Other than death, both participants lacked knowledge of how to end the suffering. Dana was most likely referring to her father, whom she remembered crying out in pain at EOL:

I was like relieved at one point. I mean you don’t want to ‘want someone to die,’ but when you see them suffer so bad, it’s almost like a relief that they’re not suffering. It’s
definitely real sad. Yeah it feels wrong to say, but it’s true. (Dana, EFG1)

As the person responsible for her family in health and medical matters, Fran (EFG2) felt guilty because her father suffered so much. She felt that physicians pressured her father into having invasive surgical procedures, which she believed led to more complications and all the suffering he experienced at EOL. According to Fran’s mother, all they ever said was “you have to do this now. Go home. Pack your bags. You’re checking into the hospital.” Not enough information about possible risks were explained, especially for someone as frail as her father was at the time. No other options were offered. Fran (EFG2) remembered her guilt wishing her father would die instead. Feeling responsible for her father’s suffering, her description was an exemplar of guilt that her father suffered so much EOL:

I was the navigator for my family for the medical stuff cause I understood it better than anybody else in my family. So I was intimately involved with what was going on and had conversations and was always the one that had to have the conversation with other family members. I have always been the family mediator . . . . I was acutely aware of the indignity of my father’s situation and how embarrassed and humiliated he was to be in that position . . . that I know he would have never chosen if we as a family had understood better, the implications of the surgery that he had, that he would have never had the surgery and he would have had a completely different death. In retrospect, we shouldn’t have moved so quickly. As the months went on and things got more horrible, my dad was declining. It was just so awful. [Long silence]. There was guilt over my wishing him to go ahead and pass. I know he wanted to die. Oh I just wished he’d just pass and then I’d feel guilt for thinking that. That was an overarching theme for the last six months of his life. (Fran, EFG2)
Greta (EFG2) seemed to understand Fran’s feeling as a normal response by reassuring Fran, “I think that most people who watch someone struggle with a terminal illness for a length of time feel that though.” From Fran’s viewpoint as the family “navigator” at the time, she felt responsible for her father’s suffering. She lacked knowledge of other options at the time as the family navigator. From a more knowledgeable perspective, Fran agreed with the normal instinct to end suffering saying, “I don’t feel bad about it now, but I did back then . . . There would be something wrong with me if I didn’t want him to be out of this suffering.” Although Fran acknowledged the normal instinct to end suffering, she felt guilty wishing for death as the only solution at the time.

Earlier Fran (EFG 2) implied anger as part of the reason for pursuing nursing to be an advocate for better EOLC and a good death. Guilt may have been the other part of her reason to be an advocate for better EOL options. She wished her family had been given more information and time before proceeding as they did. With her mother being from Germany, English was her second language. All her mother ever remembered hearing was, “You have to do this now!” As a result, her father suffered from various irreversible complications of several procedures before he died. The lack of information, options, or time to decide what to do at EOL impacted Fran (EFG2) based on her emphatic expressions [italicized] and repetition:

He failed a non-stress test and he had a quadruple bypass with an [endarterectomy]. He should have never ever, ever, ever, ever, have had that aggressive of a surgery. And it happened so quickly. He literally failed the stress test one day and had the surgery the next day. Nobody ever told my family ‘you don’t have to do this.’ (Fran, EFG2)

Discomfort, rather than comfort, was a natural and somewhat expected response to death and loss as participants described personal EOL experiences that occurred before entering
nursing school. Even if difficult to talk about at first, participants revealed more details of their loss after talking about a death and hearing others identify with similar emotions. Greta (EFG2) was reluctant at first to share about her grandmother’s “awful” EOL and deferred to Fran (EF2) to share instead. After hearing Fran’s (EFG2) candid account about her father’s “horrible EOL,” Greta disclosed more details about her grandmother. Dana (EFG1) also included more details about her grandfather’s death after hearing others describe how they felt about loss. When everyone shared emotions that someone else could identify with, participants seemed more relaxed to disclose how they felt, which was helpful for determining consensus on certain topics.

**Theme: Comfort.** Comfort emerged as another major theme after a transition to more recent past EOL experiences. Participants described their experience as hospice volunteers for the EOL elective they had just completed. Given their status as nursing students, participants shared what they had observed as important to patients and families at EOL from a nursing standpoint.

In light of earlier discomforts associated with EOL, two subthemes described how participants generally perceived comfort. The first was a positive feeling state as the result of something previously feared about EOL or something new learned. In light of death and dying, many participants felt relieved, gratified, happy, privileged, or honored. The second subtheme was action. Although their role as hospice volunteers did not require physical nursing care tasks, participants perceived comfort as part of their responsibility as nursing students to learn about with dying patients. Many participants focused on behaviors to provide comfort to a patient or family member. They were gratified to see patients and families comforted by simple acts on their part to be present, to listen, to make someone smile, and to converse. Although volunteers, two participants felt compelled to step out of that role and advocate as a nurse for the comfort of
their patients by speaking to nursing staff or the volunteer coordinator. The participants felt satisfied to know that their concerns were addressed for the patient’s sake.

*Subtheme: Feeling state.* Participants expressed feeling somewhat relieved and gratified. They described what they learned from memorable events or incidents with a patient or family member, from which they received some degree of relief or gratification. For example, several participants expressed relief to discover that talking with or developing a close relationship with someone who was dying was not as fearful as they had anticipated. Others described varying degrees of comfort from seeing patients smile or patients and family members expressing final sentiments before a death. The following participant comments expressed feeling states indicating their comfort and the cause:

- I’m not as scared to form a close relationship with someone that’s close to dying. (Anna, EFG1)
- It wasn’t as bad as I thought it was going to be. (Dana, EFG1)
- For me I was happy for the family because after the dad said what he did . . . I was happy for them that they had that moment [to exchange final sentiments before death]. (Cara, EFG1)
- I was kind of dreading this project . . . and then once I started doing it, I loved going to meet with my patient and I loved getting to know her. (Dana, EFG1)
- Seeing any kind of relief on their face, watching them be happy. (Beth, EFG1, describing what she saw with her hospice patients)
- I’m more knowledgeable about what dying looks like. Being open and acknowledging that death is a part of life, that’s *ok.* (Greta, EFG2)
• It’s a privilege to be allowed to take care of people at that time in their lives. I’d be honored to do it. (Fran, EFG2)

• I felt privileged just to share that time with them. (Cara, EFG1)

• I really enjoyed that book that we read in class . . . my perspective of what is beneficial to the patient that I wasn’t aware of, like being interactive with pets. (Beth, EFG1)

• I think faith too, that it helps when you believe that there is something bigger out there, that they’re in a better place. (Dana, EFG1)

• When asked if her grandfather believed in a “better place after death,” Dana (EFG1) added, “Yes. I can’t imagine not believing in that and having someone pass away like that.”

Cara (EFG1) expressed praying with patients as a comfort measure from a religious standpoint.

Fran (EFG2) expressed a great sense of relief knowing her father would finally be comforted with hospice care instead of suffering any longer. In the context of the last six months of his life, during which her father suffered from complications, Fran felt an overarching sense of guilt feeling responsible for his suffering. When her father was finally admitted to hospice care, Fran was so relieved because she didn’t know how to help her father at that point. The insurance was confusing to her family and she did not know what else could be done. Her description was an exemplar of relief to know that her father would finally be comforted:

Oh the hospice nurses that were working with my dad were increeeeeeedible! [Fran’s emphasis]. They helped navigate. None of us understood any of his health care insurance and so they had to transition him to Medicaid. The nurses were fanstasssstic. They were incredible! They were the most [pause to preface her next statement], I say this with the utmost fondness. They were the slowest group of nurses ever. They come in and they sit
first, and they talk. For about ten minutes they talk before they even look at you. There was *no other nurse* or no other caregiver that *ever* did anything like that. It definitely made a big impression on me for sure. . . . . By the time he was actively on hospice, he was in a skilled nursing facility and he waited until the day after my mom’s birthday then he passed. (Fran, EFG2)

Fran was relieved to learn that her father would not be “bouncing back and forth between skilled facilities and the hospital,” and that he would be cared for by hospice nurses in one skilled facility. She also felt relieved from the guilt of wishing he would “just pass” instead of suffer longer. She implied relief from the stress of not understanding his health insurance. Besides exaggerated expressions, Fran conveyed an extreme degree of happiness with her descriptive use of superlatives such as “*none of us . . . the most . . . the slowest* [in a positive sense] group of nurses *ever . . . There was no other nurse or no other caregiver that ever did anything, like that.*”

Greta (EFG2) was positively impressed by the experience of witnessing her grandfather’s death. With eager facial expressions and an animated voice, she described his EOL, which sounded more like a family reunion than a death. Her narrative included details of who was there, who was coming, the last time they were all together, where someone flew in from, and what time he got there. From her lengthy narrative, the abbreviated excerpt below included what she emphasized [italicized] and repeated that made his death a “really good” experience. Greta’s description was an exemplar of a good death and gratifying experience:

*We were all there, the family. . . . *Everyone was there, his kids and grandkids. It was important to all of us and it was kind of a neat thing. *We were all together* and it was really a neat thing. . . . So just sitting around with my cousins and telling stories. It was
really kind of a neat thing, talking with him [grandfather], involving him while he was awake… before he went into a coma. Then it was just amongst ourselves. It was a really good experience, honestly . . . But he died the way he wanted too. He didn’t die on a vent. He would not go on a ventilator. He had pain medicine. He had oxygen thru a nasal cannula. That was all he would allow. He didn’t want a mask. So you know, his family was there and it was… He was laying [Sic] there and then he just stopped breathing and that was it. (Greta, EFG2)

**Subtheme: Actions.** The act of providing comfort was the second subtheme of comfort. Participants realized the comforting effects of simple acts to be present, to listen, to make a patient smile, and to converse with patients and/or families. They also described other actions that seemed to comfort patients and/or family members at EOL. Participants were most surprised that their presence was comforting to patients and family members, whether or not engaged in conversation or an activity. It was often after several visits that the patient or the patient’s family member expressed gratitude and appreciation for the participant’s presence and company. Participants described what they learned to be comforting or beneficial for their dying patients or family members:

- The fact that it seemed so satisfying to both my patient and her family just to have me there for the past couple of months was a really good thing. . . that I was just there.  
  (Anna, EFG1)

- I would just sit next to her while the TV was on. (Ella, EFG1)

- I would push her in her wheelchair and she’d like sing along to it. (Beth, EFG1)

- We would play scrabble. (Ella, EFG1)

- Make them smile, like get out of themselves for a second. (Beth, EFG1)
• Spending time with her. (Beth, EFG1)

At first Greta (EFG2) chose not to share when asked about the EOL experience with her grandmother, which she described as “weird.” She deferred to Fran (EFG2) to share instead since Fran admitted a “fascination and interest” about death. Fran talked openly about her father’s EOL, which was not a pleasant experience until he was admitted to hospice care. Greta (EFG2) seemed comforted by Fran’s (EFG2) sense of ease talking about death and dying. Only after Fran shared her experience did Greta (EFG2) seem comfortable enough to talk about how she felt about her grandmother’s death.

Fran’s comfort with talking about death and dying also seemed to have an impact on the communication between her hospice patient and the patient’s daughter. Fran’s patient could openly talk with her about death, but not in front of her own daughter who was afraid to say the word ‘death.’ Fran’s (EFG2) ability to discuss death so easily seemed to make her patient and daughter feel more comfortable. Fran was moved by the communication between her patient and daughter at the last few visits:

The lady I was assigned to and her daughter, well the daughter could never say the ‘D’ word. Her mom was very matter of fact [with me]. She said to her daughter, ‘you’re much better talking about death now.’ We all got teary eyed when she said that. That was a very poignant moment and it was good. That was a positive interaction for them . . . . Yeah. It was a real privilege that my patient could talk so openly about it while her daughter was there. (Fran, EFG2)

Greta (EFG2) attributed the mother’s and daughter’s comfort to Fran, who was comfortable talking about death:
Your being there probably facilitated that happening because you were so comfortable with the idea of that and talking about death and dying. It makes it *ok* for other people to talk about death and dying. (Greta, EFG2)

That sense of ease felt from hearing Fran talk openly about death seemed to be Greta’s experience too before sharing about her grandmother’s EOL.

**Theme: Meaningful relationship.** Meaningful relationship was a major theme participants remembered about significant EOL experiences. Participants referred to “a close relationship, building a relationship, forming a relationship,” or “that relationship” to indicate a special relationship instead of an acquaintance. Meaningful relationship encompassed the subthemes of 1) quality time and 2) getting to know someone, or already knowing someone such as a family member. Family members were described first in recalling meaningful relationships. Although, kinship did not necessarily characterize a meaningful relationship. Instead, participants described spending quality time together and knowing someone in a personal or special way. Participants characterized *quality time* by recalling special moments or events with someone significant, which made the death of that person more memorable or important.

The subtheme of *getting to know* was described as a process of knowing someone in a close or more personal way than knowing an acquaintance. Sentiments of appreciation were often expressed as a result of *getting to know* or having known someone a long time. Characteristics in meaningful relationships included: acknowledging the presence of each other, being attentive, and expressing sentiments of appreciation or love for getting to know a specific person or having known someone. The subthemes were often intertwined because spending quality time together fostered getting to know someone personally or in a privileged way, which was usually acknowledged and/or appreciated in meaningful relationships at EOL.
Subtheme: Quality time. With quality time, participants remembered special times together with someone, which were memorable because of the significant person involved. The most common attributes described during quality times were to 1) acknowledge presence and 2) express appreciation. Participants described quality rather than quantity of time together, as some developed meaningful relationships with hospice patients in as little as ten hours. Participants described different ways to acknowledge another person or express appreciation, depending on the type of relationship. The most common ways were to reminisce, do special activities, and be attentive.

Reminisce. With family members, reminiscing was a way for participants to acknowledge a dying person’s presence. Recalling shared stories indicated the importance of those moments over the course of the relationship. For example, what stood out for Dana (EFG1) and her grandfather was “spending time with him and reminiscing all my funny stories. That was probably the most important.” Earlier Dana (EFG1) described how difficult her grandfather’s death was because of their close relationship. The funny stories he recalled of Dana indicated special moments he remembered. Greta (EFG2) also remembered reminiscing with her grandfather before he went into a coma and died, “sitting around with my cousins and telling stories. It was really kind of a neat thing, talking with him, involving him in those stories while he was awake.” Involving her grandfather was a way to acknowledge his presence while conscious. Recalling pleasant memories involving the dying person was also a way to express appreciation to the person for those memories.

Do special activities. At EOL, Anna (EFG1) and her grandmother would do special activities together, which was a way for Anna (EFG1) to acknowledge her grandmother as someone special in her life. Due to progressive Alzheimer’s dementia at EOL, her grandmother
did not recognize Anna or the rest of her own family. Anna could not reminisce about past times together:

I’d probably have to say, even though she didn’t know it was me, it was doing the things we could always do when I was younger. We would do puzzles. We would watch certain movies. I knew she didn’t know it was me, but just being able to do those things, despite that aspect [of her memory loss] for myself was what I liked. (Anna, EFG1)

Even though her grandmother did not recognize her, those activities reminded Anna of special times when much younger. That time together was a way for Anna to acknowledge their meaningful relationship before her grandmother died.

For Beth’s grandmother (EFG1), expressing love and appreciation for Beth was important before she died. Since childhood, Beth was very close to her grandmother. Beth was an adopted child, yet never knew until high school. When her grandmother died, she recalled how traumatic it was because of their meaningful relationship and her grandmother’s last sentiments for Beth. Her narrative was an exemplar of expressing appreciation for a meaningful relationship at EOL:

I was really close with my grandmother growing up. And I actually didn’t know she wasn’t even my biological grandmother until I was in high school. She never mentioned it. So she called me one day and was like, ‘I just want to let you know that you are my favorite.’ It was kind of weird and she was like: ‘I love you even more than my own actual grandchildren.’ And I was thinking ‘Where is this coming from? This is very strange.’ Then she died the next day and it was a very traumatic thing . . . . It was very tragic, but it was very strange how she called me like she knew that [she was going to die]. (Beth, EFG 1)
Rather than physical presence, Beth’s grandmother called to express her last sentiment that Beth was favored and loved more than her biological grandchildren. Because of the special relationship with her grandmother, the death was traumatic. Her grandmother’s comment seemed strange at the time, but hearing her grandmother’s last sentiment the day before her death was especially meaningful to Beth as the only adopted child in the family.

*Be attentive.* Participants learned how to be attentive in order to acknowledge presence, especially if a communication barrier was present among hospice patients. Beth (EFG1) recalled her hospice patient who had difficulty communicating, which made it harder to get to know the patient. At one point, Beth described using her cell phone to play hymns that her patient enjoyed. Beth could hardly determine if her patient was comfortable or distressed while trying to communicate during visits:

She had a hard time formulating words . . . It would take a long time. Half the time I would get her and half the time I wouldn’t get it. So like I’d ask her if she had kids and it would take her five minutes to answer ‘no,’ and she wasn’t married. So there wasn’t anything I could connect with her about . . . When I gave her a gift [at the last visit] she said, ‘I don’t really care what we’re doing, as long as we’re together.’ It was just the sweetest thing . . . . Even though I don’t know her that well, she obviously just appreciates someone just sitting there with her. She felt really special. (Beth, EFG1)

Beth expressed attentiveness with actions. Instead of verbal communication, Beth listened patiently, played music, and tried to converse with the patient. It touched Beth to realize that her patient understood her actions all along and appreciated her company.

In meaningful relationships, spending *quality* time together was not taken for granted. Participants described quality times at EOL as opportunities to communicate special sentiments
of appreciation or love before it was too late. For this reason, they described a sense of urgency to spend quality time together before the person died or became cognitively impaired, unconscious, or too sedated to communicate. Ella (EFG1) developed a special relationship with her hospice patient. Concerned about her patient’s worsening condition, Ella wanted to be sure and communicate how special she was to Ella before she died. By the time of Ella’s last visit her patient was uncommunicative:

The closer we got, the more she declined . . . I’m afraid she doesn’t have a whole lot of time. . . . Just seeing how our relationship has changed. . . . I saw her to give her [final] gift and talk to her but she couldn’t hear me and so for the first time I actually tried to use paper and pencil to write it out [because] she’s so important to me. (Ella, EFG1)

At Ella’s final visit, the patient’s daughter was present. She revealed to Ella how much her mother thought of Ella and how she appreciated their visits together. Ella felt reassured to learn that the patient reciprocated her sentiment about their relationship.

With her patient’s declining physical condition, Cara (EFG1) recognized how important it was for her hospice patient’s family to visit when they did. Her description was an exemplar of quality time to express final sentiments, especially at EOL:

What stood out to me was that his family was there [present]. He was cognitively with it so he was able to communicate, [because] he knew he was going [to die], and he said ‘what better way to go than on this day, the Super bowl,’ . . . That the patient was cognitive enough to communicate with his family and say what he had to say, and just watch them share this intimate moment cause they were all in tears . . . . I mean they were crying, but they were happy to hear him say ‘It’s ok. I’m ok,’ cause he knew he was going. (Cara, EFG1)
Cara saw how sad that moment was for her patient’s family, but also how happy they were to hear the patient say he was ‘ok’ with dying. The patient died two days later and Cara remembered his words, ‘what better way to go than on this day.’

Greta (EFG2) expressed an urgency to visit her grandfather at EOL as a way of acknowledging for the last time:

With my grandfather, he was very important to me and I wanted to go. My mom called me . . . told me he was hospitalized…[it] was going to be his last time. He had been in and out [of the hospital], like people tend to do. I got the kids up for school and left right after that and went, and [I] was lucky enough to get there while he was still awake.

(Greta, EFG2)

Greta got there in time to reminisce with her grandfather and cousins before he died that day. Part of what made his death a “really neat” experience for Greta was that he had the opportunity to reminisce with them while conscious. (Greta, EFG2)

**Subtheme: Getting to know.** Another subtheme was *getting to know* someone in a privileged way that left a special memory. Major aspects described were a memorable bond and a close feeling. A memorable bond was common among family members and reinforced by reminiscing, which indicated a special bond developed over many years in meaningful relationships. Participants also described a close feeling, or connection with someone through sharing intimate or private thoughts with hospice patients. Whether a relationship developed over years or months, participants remembered knowing and/or getting to know someone in a way that left a special memory with personal meaning.

In context of a meaningful relationship outside of biological ties, participants described a close feeling, or a sense of connection with hospice patients or their family members. As Fran
(EFG2) shared earlier, her patient could talk to her more openly about death than she could with her own daughter. She and Fran connected by sharing thoughts about her death. Fran cried when the patient and her daughter could finally talk openly with each other about death, “Yeah. It was a real privilege that my patient could talk so openly about it while her daughter was there.”

Contrary to earlier fears of getting close to someone dying, some participants described their experience of getting to know hospice patients as “cherished” and “meaningful.” Anna (EFG1) for example, seemed surprised, “I never really thought that I’d be able to form a relationship with someone that obviously is dying, that I’ve never met before, so quickly and actually cherish it.” Ella (EFG1) also enjoyed getting to know her hospice patient saying, “After this semester and having more of a chance to really build a relationship with one of my patients, it’s definitely really sad, but it’s one of the most meaningful relationships to have.”

Despite her hospice patient’s decline, Ella (EFG1) expressed an increasing connection getting to know her patient better:

I realized that wasn’t working out so well because she would fall asleep. I had to learn just how to gauge my time with her, whether or not she was up for it . . . . She’s not very vocal, even though she couldn’t communicate too much . . . . We really didn’t need to talk all about that much to get closer . . . . I told the daughter that I’m going to come more frequently like twice a week but for shorter visits because she gets so tired. (Ella, EFG1)

Being attentive to the patient’s responses enabled Ella to “gauge” what she could handle during visits. Ella decided to shorten her visits based on her knowing more about her patient’s physical responses.
For Dana (EFG1), she valued a special object that her grandfather gave her before he died. It was a significant reminder of their special bond:

Right after he found out he had cancer he built me a bed out of an oak tree that was in their front yard. That is something I still have that me and my husband sleep in now and I’m thinking it is so important to me. (Dana, EFG1)

After his terminal diagnosis, her grandfather knew his strength would not last. Perhaps as a lasting token of his appreciation for Dana, he made the bed with wood from his own yard, which he knew would outlast his life. This explains Dana’s earlier emphasis and repetition of how “very hard” it was to see him waste away.

Anna’s (EFG1) anger toward her grandmother at EOL seemed to be a contrary characteristic of a meaningful relationship. Anna’s memory of her anger indicated how much she valued their close relationship, which her grandmother never acknowledged before she died. Anna resented that no one had explained dementia as the reason for her grandmother’s behavior. In context of Anna’s age and without any explanations, her grandmother’s lack of recognition may have felt like rejection to Anna. Despite the anger she had felt for so long at the time, Anna spent time with her grandmother doing the things that reminded her of their special relationship, even if her grandmother didn’t remember it. That was a close feeling for Anna.

**Elective Group Paradigm of End-of-Life Care**

Participants remembered the emotions and people involved from memorable EOL experiences to shape their paradigm of EOLC, which revolved around a “good death” preceded by good EOLC. Most social scientists agree on the fundamental idea that emotions manifest “the importance that an event in the natural or social world has for a subject” (Bericat, 2016, p. 493). The emotions felt at special moments indicated the significance of those moments as meaningful
in the context of a caring relationship. Despite fears of the sad emotions due to the loss of someone close, participants recalled gratifying relationships with hospice patients. Participants were relieved to see a dying person in comfort at EOL and to know they contributed to a dying person’s comfort. They were relieved to know that people can die a “good death” if preceded by good EOLC. Their paradigm of EOLC included relief from pain or suffering, attentive and respectful care of dying patients by all caregivers, the presence of family members, and open communication about death and dying. For Fran (EFG2) and Greta (EFG2), open communication included information about alternative options at EOL, especially for patients with grave conditions or extreme frailty. Given their negative experiences with a family member at EOL, having adequate information about possible options was necessary to make informed decisions to facilitate a good death they would not regret.

**Good death.** Characteristics of a good death from exemplars included: physical comfort without signs of suffering or struggle, the presence of family before the dying person becomes unconscious, and time to exchange last sentiments of love, appreciation, or final wishes for EOL. Insights about a good death were also drawn from contrasting examples of a bad EOL. From Fran’s and Greta’s (EFG2) experiences, they valued adequate information and full disclosure of risks and benefits from medical health care providers to patients and families, with the patient’s right to make any final decisions. Facilitating a good death for surviving members included providing necessary explanations or options at EOL and assuring personalized care by attentive caregivers.

**Physical comfort.** Physical comfort at EOL meant relief of physical suffering, which also affected family members. Given the experience with her grandfather’s suffering, Dana (EFG1) was relieved to know that one could die peacefully without pain. A good death specifically in
the hospital included physical comfort with minimally invasive treatments, which according to Greta’s exemplar of a bad death excluded IVs, drainage tubes, or a ventilator. Greta’s (EFG2) exemplar of a good death in a hospital included dying peacefully and according to a patient’s wishes, as she experienced with her grandfather. Based on her description earlier of her grandfather, a good death meant: dying exactly how one wants to, not on a ventilator, oxygen only by nasal cannula and not a mask, with adequate pain medication, family members present, and alert enough to engage with family before becoming unconscious. Greta implied a peaceful death in saying, “He breathed in and then he didn’t, and that was all,” to which Fran (EFG2) agreed, “That’s about as good as it gets.”

**Presence of family.** For most participants, family presence was important for a good death. From Greta’s (EFG2) exemplar of a good death described earlier, she emphasized family presence as the most important thing by repeating “we were all there, everyone was there, his kids and grand kids . . . It was important to all of us . . . We were all together.” From Cara’s (EFG1) exemplar of quality time together, what stood out to her was that her patient’s family was there while her patient was cognitive enough to express final sentiments before he died. Fran’s (EFG2) father chose to die alone because he was a very private man, but he received hospice care and died when he wanted to, after her mother’s birthday. Most participants felt that death could be good and even dignified if pain free, well supported by family members, and well cared for physically by care providers at every level.

**Time for final sentiments.** A good death included time to exchange final sentiments of love, appreciation, or final wishes before death. Greta’s (EFG2) grandfather was firm in what he wanted and did not want at EOL. He made his wishes clear before his death, which made it a “good death” to Greta and her family. From Cara’s (EFG1) exemplar of quality time for
exchanging final sentiments, her patient was cognitively “with it” to communicate to his family that he was “ok with dying.” The patient and family were sad but happy they had that moment before he died. As an exemplar of meaningful relationships, it was important for Beth’s (EFG1) grandmother to call Beth and express her last sentiment of love and appreciation for Beth before she died the next day. Greta (EFG2) had the same experience with her grandfather, who died after he had engaged with everyone in his family. Participants who said their last “good bye” to hospice patients were saddened to know it would be a permanent and final sentiment. Many had developed meaningful relationships with their patients. Instead of negative thoughts about the inevitable loss, most remembered feeling happy or gratified for having contributed to a dying patient’s or family member’s comfort at EOL, especially Anna (EFG1):

She [her patient’s daughter] said she’d go back every year and be happy that I was just there. I mean, during that time it made me just really happy and I wouldn’t mind doing it again just because it was so gratifying to be there in that part of someone’s life and be able to be there for them. (Anna, EFG1)

**Good EOL care.** Participants described aspects of EOLC necessary for facilitating a good death. From Dana’s (EFG1) exemplar of respect, EOLC was personalized by treating each patient as unique with significant ties to another human being. Nursing care included more than administering medications. Insight from Fran and Greta’s (EFG2) contrasting experiences of disregard indicated the goal of EOLC to honor a patient’s feelings and thoughts about every aspect of treatment to facilitate a good death. From Fran’s (EFG2) exemplar of guilt due to lack of knowledge, adequate information about alternative options for EOLC was necessary for patients and families to make decisions they would not regret. Fran’s exemplar of relief from the complex insurance plans indicated the necessity of hospice nurses for informing and directing
EOLC according to the patient’s wishes. After meeting the hospice nurse who admitted her father, Fran’s description was an exemplar of relief from watching her family member suffer and knowing he would finally be comforted. The hospice nurses made her feel comfortable about her father’s care, despite her horrible description of his EOL. She implied that his death was peaceful and in his own timing. From her exemplar, EOLC included comfort from hospice care nurses who took the time to sort out details about EOL needs physically and financially. Although Fran was not present at his death, her experience with his long suffering at EOL had a lasting impact on her.

Anna (EFG1) expressed regret that no one had ever tried to explain Alzheimer’s dementia to her before her grandmother died. In retrospect, Anna wished someone had tried to inform her even if she didn’t grasp an understanding of the disease. Anna felt that “not knowing what was going on” felt worse because of the anger she recalled. For Cara (EFG1) and Beth (EFG1), sensitive or attentive care for the dying was a duty and responsibility of nurses to provide, whether directly or by delegated caregivers regardless of residence.

Bad death. For most participants, a bad death included one or more of the following attributes prior to the actual death: unrelieved or prolonged suffering, hospitalization with poor quality of life sustained by medical devices, and physical or emotional neglect by caregivers in an unfamiliar environment.

Unrelieved suffering. Dana (EFG1) recalled her father crying in pain and expressed relief to know that a good death was possible. Until her knowledge about a good death, Fran (EFG2) associated prolonged suffering as a characteristic of death. In Fran’s (EFG2) exemplar of guilt over wishing that her father would die rather than suffer, she attributed his prolonged suffering to medical health providers. Her father had inadequate information about the surgical
procedures, lack of options to consider, and lack of time to think about the decision. As a result, he suffered from irreversible complications that contributed to his prolonged suffering. Fran (EFG2) also felt that medical health providers disregarded her father’s feelings about overall outcomes, “Nobody ever told my family ‘you don’t have to do this.’” The lasting impression of guilt from seeing her father suffer at EOL impacted her career choice, which could be considered a positive response to a negative circumstance.

Unresponsive. A bad death in a hospital included being unresponsive, connected to several machines, and dependent on a mechanical device to sustain life. From Greta’s (EFG2) exemplar, she described specific aspects of a bad death in the hospital from a family member’s point of view. Her image included: someone unrecognizable and uncommunicative, grotesque physical disfigurement, drainage tubes, a ventilator, and multiple IVs inserted to treat the malignancy. The worst part for Greta was the sense of disregard for her grandmother’s physical well-being or comfort, which she interpreted from medical health providers who “pushed” chemo and radiation hoping to “make the tumor smaller.”

Neglect. Participants expressed a strong degree of anger toward neglect of dying patients, especially if in unfamiliar surroundings within a facility or hospital. Fran (EFG2) and Beth (EFG1) expressed anger to the point of pursuing a professional career with the intention of advocating for a good death and providing good EOLC. Fran (EFG2) seemed the most impacted from seeing her father’s EOL as a “horrible protracted process.” She saw him “withering in embarrassment and humiliation,” which fueled her to enter hospice nursing as an advocate of facilitating a good death. Beth (EFG1) was interested in EOLC before her hospice visit experiences. After seeing her hospice patients neglected by caregivers from assisted facilities, she expressed more of a resolve to improve EOLC, “I feel like it’s more of a passion that I feel
like I need to change or help change.” Greta (EFG2) expressed the paradigm for EOLC many others touched on:

I think it is real important that people be treated with more care. You’re like, ignored at the end of your life when you really should be embraced and cared for and acknowledged for the unique and special person that you are. (Greta, EFG2)

**Research question five.** From focus groups, what attitudes, beliefs, values, and emotions about EOL care did participants from the comparison group express? Major themes and subthemes are summarized (See Table 4.6).

Table 4.6

<table>
<thead>
<tr>
<th><strong>Comparison Group Major Themes and Modifying Subthemes</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Discomfort</strong></td>
</tr>
<tr>
<td><strong>Lack of Knowledge</strong></td>
</tr>
<tr>
<td>Unexpected</td>
</tr>
<tr>
<td>Shocked</td>
</tr>
<tr>
<td>Distressed</td>
</tr>
<tr>
<td>Unprepared</td>
</tr>
<tr>
<td><strong>Close Relationship</strong></td>
</tr>
<tr>
<td>Personal</td>
</tr>
<tr>
<td>Detachment</td>
</tr>
<tr>
<td>Emotional attachment</td>
</tr>
</tbody>
</table>

**Comparison focus group profiles.** Two focus groups with comparison participants were conducted. The first comparison focus group (CFG1) contained three students. The second
comparison focus group (CFG2) contained two students. The third focus group scheduled after
the last mandatory class day was on a Monday with exams later that week. Likely due to class
project grades returned on the last day of class and final exams later in the week, only one
student was available for that focus group. The participant consented to an interview with the PI
using the same format used with focus groups. She was reminded that the interview would be
audio-recorded for transcription purposes and her confidentiality maintained. The thematic
analysis for the comparison group included data from six participants. Participant names were
replaced with pseudonyms selected by the PI. A profile of participants within each group is
presented to provide personal background of EOL experiences.

*Comparison focus group one (CFG1).* The first comparison group contained two
females and one male referred to by pseudonyms Helen, Ida, and Jeff respectively. Helen was a
23 year-old female who had never experienced the loss of a close family member. However, she
recalled the painful loss of her dog just prior to entering nursing school. She described the dog
as her “baby.” After one week of unsuccessful treatment in a veterinary hospital for apparent
kidney failure, Helen could not bear to see her dog suffer anymore and had it euthanized. Her
first experience with human EOL and death was during her senior practicum in an intensive care
unit (ICU). She cared for a dying patient for six hours until the patient died and she assisted with
post mortem care while a family member was present.

The second participant was Ida. She was a 27 year-old female who referred to the deaths
of family members. She did not consider them a “loss” because she never knew them well,
including her biological mother who died when Ida was two years old. She referred to her
grandparents as close losses because of her relationship to them. In her prior job she assisted
with X-rays in a pediatric trauma department. She assisted with the most severe trauma patients,
most of who were young children less than five years of age. She saw many children who were already dead on arrival. “To me that was completely detached. I didn’t think about that they are dead. To me, this is a job.” However, Ida felt emotional over the loss of her pet, a ferret that had pancreatic cancer. She had no clinical experiences with EOL care while in nursing school.

The third participant Jeff, was a 28 year-old male. At age 19 he experienced the death of his older brother, which he described as a slow “deterioration” ending in a drug overdose nine years ago. He was very close to his brother. Because of the severe mental illness his brother suffered for many years, Jeff believed his brother’s death was a suicide rather than an overdose. Jeff also made references to the deaths of several friends from childhood. Jeff had no EOL care experience personally or from nursing school. He recalled seeing a dead body unexpectedly in the emergency room (ER) during his practicum experience.

**Comparison focus group two (CFG2).** The second comparison focus group contained two females Kate and Libby. Kate was a 24 year-old female. She experienced the death of two family members who had hospice care, which she stated was a positive experience because it was “very necessary and really helpful for the family.” She was 18 or 19 years old at the time. Kate referred to the emotional loss of her dog. Her first experience providing EOL care was in the intensive care unit (ICU) during her senior practicum. Kate described how pleasing it was to care for the patients physically while supporting family members who were present. During her senior practicum of 172 hours, she provided EOLC for at least one patient every time she was at clinical.

The second participant was Libby, a 26-year old female. She had never experienced the death of someone close or provided EOL care in nursing school. However, she referred to seeing one young patient periodically during her senior practicum. The patient had mitochondrial
disease, which is incurable. She did not consider those encounters EOL experience because the patient was fully functional.

**Comparison focus group three (CFG3).** The last participant was Martha, a 44 year-old female. She had experienced the loss of her father a little over a year ago. Her father did not want to be hospitalized or be administered life saving treatment. He wanted to be at home and receive hospice care with his family present. His terminal diagnosis was very unexpected with a life expectancy of four to six weeks. He died in less than 30 days. As a result, Martha experienced denial for a long time after his death. She recalled disturbing memories of his EOL, which were difficult for her to comprehend. Her senior practicum experience was on an oncology unit where she recalled the distress seeing “people in the hospital in such excruciating pain that is never going to go away.” However, she had a positive experience helping a clinical care technician with post mortem care. She helped prepare the body for the family to view, which was very memorable for her in helping her accept the finality of death. Martha was grateful to share her account of her father’s death.

**Summary of EOL experiences.** There were a variety of EOL or death experiences among comparison group participants before entering nursing school. Four participants described the loss of a family member or someone personally close. They described what they remembered most from their personal experiences that left the strongest impressions. Jeff (CFG1) and Martha (CFG3) each described specific details about suffering and death that were distressing, which influenced their views about EOL and EOLC. Kate (FG2) described her positive experience with three close family members that had died at home while receiving hospice care. She was most impressed by the care they received as “very necessary and really
helpful for the family.” Two participants, Helen (CFG1) and Libby (CFG2) had never experienced EOL or the death of someone close before entering nursing school.

Clinical EOLC experience during nursing school also varied among participants. Three participants had EOL clinical experience and remembered specific incidents, which left strong impressions about EOL and EOLC. Three participants had no EOL clinical experiences. Ida (CFG1) and Jeff (CFG1), who had no EOL clinical experiences, remembered brief EOL-related incidents from the clinical setting to which they reacted emotionally. Some participants remembered learning about EOLC in specific nursing courses from hearing hospice nurses in class or seeing a documentary video of hospice nurses caring for patients. Comparison participants described a wide variety of experiences for learning about EOLC. Despite the range of EOL experiences, two major themes emerged: *discomfort* and *a comfort to comfort*, which participants considered a priority or goal of EOLC, but also a personal feeling from providing comfort.

*Discomfort* as a predominant theme was a natural response to loss from a personal perspective. Based on the subthemes of *discomfort*, responsibilities expected of them as nurses heightened their discomfort with EOL and EOLC. *Comfort* was the second major theme. Participants discussed *comfort* as a priority for patients and families at EOL, as an outcome or goal of care. Some participants also referred to *feeling comfort* from comforting patients and/or families. Participants also described *comfort* as a theme within the nurse’s role, under specific considerations at EOL.

**Comparison Group Major Themes**

**Theme: Discomfort.** Discomfort was considered an inherent quality of EOL or loss and expressed by feelings of shock, sadness, or distress. Two subthemes affected the intensity of
discomfort at EOL. The first was lack of knowledge about EOL and the second was a close relationship to the dead or dying. Lack of knowledge heightened their discomfort regarding EOL care, which participants characterized by fears of the unknown or unexpected, distress from seeing physical or emotional suffering, and feeling unprepared to comfort in an EOL situation. A close relationship intensified the effects from a death. Most participants described personal loss of a family member and/or a pet because of a close relationship to the person or animal that died. Close or personal losses were described from a family member perspective. All participants considered sadness or grief a normal response to EOL or death based on experiences with a family member or close pet.

Most participants also expressed some degree of sadness or grief about EOL or loss about patients in general, regardless of experience. However, participants described their first clinical EOL experiences and the discomfort that arose from lacking specific knowledge about symptoms of active dying, effective treatments for severe pain, and how to console family members immediately after bad news or a death. Participants without EOL experience during a nursing clinical described more of a generalized anxiety of fear of the unknown and being unprepared to comfort someone dying.

**Theme: A comfort to comfort.** This theme describes how participants experienced comfort at EOL. Participants described patients and family members they saw in comfort at EOL or nursing interventions provided to promote comfort for a patient and/or family member in a clinical setting. Participants also described the priority of comfort as a patient goal at EOL, but felt lacking in knowledge or experience to recognize EOL symptoms and provide comfort. These participants gave examples of specific EOL knowledge needed before attempting to
comfort. Whether participants had EOLC experience or not, comfort was described predominantly from a nursing perspective as an expectation of nurses.

**Subtheme: Lack of knowledge.** Lack of EOL knowledge was a predominant concern influenced by EOL education and/or clinical experience with a dying patient. Participants expressed fears of the unknown or unexpected at EOL, specifically with physical and/or emotional distress. They feared being unprepared for the responsibilities as a nurse to comfort patients. Some felt uneasy about what to say about EOL to patients and family members. Participants with clinical EOLC experience described situations that were discomforting, primarily when confronting EOL unexpectedly for the first time. The most common feelings expressed were shock and distress. Participants described patients and family members distraught at EOL.

*Unexpected.* Three participants experienced shock and distress from what was unexpected about EOL for the first time during practicum. They were not expecting to see or deal with an EOL situation.

*Shock.* Facing the unexpected was especially shocking to Helen (CFG1). Her first experience was in the intensive care unit (ICU). She described one of her patients with sepsis. Helen and her preceptor suspected the patient “was dying” based on declining physical parameters from the day before. Within two hours the patient died. Helen did not expect death to happen so fast. She did not know how to address the daughter who was present, but focused on monitoring physical parameters. Her knowledge of palliative care was very limited:

The patient I had was like so quick of a deterioration. There wasn’t a lot we could do. Her white blood cell count was like, twenty something on a Monday. When I came in on Tuesday, it shot up to 55. Her blood pressure dropped. Her temperature was elevated. All
happened within like two hours . . . . For us the palliative care was just giving her antibiotics . . . . It was just like ‘we’re going to keep giving you the antibiotics’ and just monitor while the family was in there . . . . and it came on real quick . . . . Very unexpected . . . . When I had that patient die, I was like ‘whoa.’ It was really quick . . . . I was in shock because it happened *soooooo* fast. I didn’t know you could deteriorate that quickly. (Helen, CFG1)

Despite recognizing the patient’s declining physical parameters, she had not expected such a sudden death. Helen talked about this experience throughout the focus group, which indicated the impact of the sudden death for her. She recalled family members who were present at the time, but reflected on her own response in the situation. When asked about attitudes about death before nursing school, Helen (CFG1) said “avoidance.” Jeff (CFG1) and Ida (CFG1) nodded in agreement.

Two participants who had no EOLC experience in a clinical setting also expressed shock and fear. Ida (CFG1) remembered family members who had died suddenly and thought palliative care was for patients with longer lasting terminal illness. After hearing Helen’s account of the unexpected death, she exclaimed:

> Oh wow! I didn’t have any idea of what it [EOL] entailed. I wouldn’t even know what to believe about palliative care . . . . My family members that have passed were more sudden than like a terminal illness. . . . Oh it’s a scary thing. I mean it’s like the unknown. Nobody’s able to tell me what happens. So to me it’s terrifying.” (Ida, CFG1)

In a different focus group, Libby (CFG2) also expressed fear of the unknown about EOLC because of her lack of experience:
I thought it would be scary or uncomfortable, but again I haven’t been with someone as they were dying. But just being able to talk about it is more comfortable. I used to think it was an *unspoken thing*. Like ‘ooooo, don’t talk about it.’ (Libby, CFG2)

Libby’s preconceived idea of dying as an *unspoken thing* may have contributed to Libby’s lack of knowledge about dying.

Jeff (CFG1) also expressed shock when he unexpectedly saw a dead body during his practicum in the emergency room (ER). On one occasion during practicum, he was assigned to take over compressions on a female patient in route to the ER. Jeff heard emergency medical technicians (EMT) say that the patient had been unconscious for some time before the ambulance arrived at her home. She was receiving mechanical cardiopulmonary resuscitation (CPR) in the ambulance while in route to the ER. Since Jeff was expected to take over her CPR on arrival, he was expecting to see the patient. When she arrived and the mechanical CPR was removed, it was too late. A physician saw her first and pronounced her dead. On another occasion, Jeff was caught off guard. He was looking for his preceptor and found her in a trauma bay with a patient:

I walked into the trauma bay where my preceptor was by herself and I didn’t realize the patient was still in there, but *not* there. They are dead, but the body was still on the table, just covered up. When I realized it, I thought ‘oh gosh, they didn’t make it.’ It was kind of a shock. (Jeff, CFG1).

Jeff was not expecting to see a dead body in the trauma bay still on a stretcher. He was a little shocked after realizing that the patient was dead. When asked if that was his first experience seeing a dead body, Jeff continued:

Yes. I didn’t want to see my brother’s dead body. He was cremated. So the lady in the ER was a first experience with a dead person. With my brother, I wasn’t with him when he
passed. I got the phone call [that he was dead]. I did not want that to be the last image that I saw of him. (Jeff, CFG1)

For Jeff, the dead body evoked memories of his brother who died nine years ago. He remembered getting that call from the ER. As he explained, he did not want the last image of his brother to be like the covered body he saw on a stretcher.

*Distress.* Fear of the unknown or uncertainty about death was more distressing for Jeff. He remembered the stress prior to his brother’s death. Jeff’s older brother battled mental illness and addiction that ended in an overdose nine years ago. Jeff struggled with the uncertainty of when his death would occur. He also described the discomfort of feeling out of control. Jeff recalled the constant stress he and his family went through during that time, calling it a “nightmare:” “You have control over how you feel about the death, but before, you had no control over whether or not he was going to get better. At least there was a conclusion.” Another participant, Martha (CFG3) described the distress from uncertainty about her father’s breathing at EOL: “The length of time my father took to stop breathing and the distress of wondering if he was going to take another breath or not was distressful.” Jeff (CFG1) and Martha (CFG3) described the discomfort of uncertainty or feeling out of control.

Martha (CFG3) described shock and distress from the unexpected loss of her father, which was her first EOL experience. She was 43 years of age when her father died over a year ago. Her father had seen a doctor for mild but lingering abdominal pain. A week later, he returned to the doctor for the test results. Based on the results, he had a terminal illness associated with a life expectancy of four to six weeks. His prognosis was poor. Because her father was a doctor, he did not want extreme measures and had made it clear that “Absolutely under NO circumstances am I to be hospitalized.” He wanted to “die” at home with pain
medications from hospice care and with his family present. On hearing this news, Martha drove from two states away to be with him. By the time she arrived at his home to see him, he was very agitated. He died in less than 30 days from the date of the diagnosis. Given her lack of knowledge or experience with EOL, her description was an exemplar of distress on many levels of the unexpected and unknowns about EOL:

I thought there would be more time . . . . I felt it was something like post-traumatic stress. . . . . It was hard to recover even given notice [and] having the opportunity to say some last words. Even with that, it’s so so traumatic . . . . The Cheyne Stokes breathing is very distressing to family members because it sounds like the person is in pain and struggling. But to me, during it [Cheyne Stokes] I thought ‘Oh this is horrible.’ . . . . He was agitated. That is a very difficult thing to see as a family member. The agitation like you can’t describe until you see it. I don’t know. I just don’t know what that is [Looking down at the floor while barely whispering]: I don’t know. It’s hard. It’s hard. Martha (CFG3)

The unexpected diagnosis and EOL symptoms stood out for Martha. She was shocked over his brief EOL between diagnosis and death. She did not know what to expect at EOL, especially about symptoms, which were distressing to see for the first time.

Unprepared. Martha (CFG3) was distressed, feeling unprepared about what to do as her father’s symptoms worsened, even while receiving hospice care. Given his short life expectancy, she struggled whether to medicate him for the pain or keep him alert so she could interact with him. Her description was an exemplar of the discomfort at EOL from not knowing what to do as a family member. Her voice lowered to a whisper while explaining her struggle at the time:

At one point you want them conscious so you can have those last interactions, but
on the other hand, they’re in so much pain that you have to give that up, your personal
need to have an in interaction, versus their need to be out of pain, which is difficult. . . . If
I give them this medicine, they’re going to fall asleep, but they’re in excruciating pain.
You know, it’s, it’s difficult. . . . It was stressful. The hospice nurse had left the
medications, but you’re still not sure how to administer them. Most of them were oral and
that was ok, but towards the end the oral medications don’t work cause the person can’t
swallow. (Martha, CFG3)

Distress from lack of knowledge also characterized Martha’s (CFG3) first EOL clinical
experience during practicum on an oncology floor. From a nursing perspective, she described
how she felt about not knowing what more to do for EOL symptoms. Although thankful for her
experienced preceptor, she felt stressed and helpless. She sounded distressed as she spoke very
fast with a high-pitched voice. Her description from a nursing perspective was an exemplar of
discomfort, from lack of knowledge about how to comfort patients at EOL.

It’s distressing when a patient is dying and the family member is there. They’re crying.
They don’t know what to do. Like one of the patients in hospice was soo oo agitated. She
was pulling out her IVs, her oxygen. She was never going to get out of that bed and we
knew that. She was on strict comfort care measures. But she wasn’t comforted. And
that’s hard to see. And the family member was there. She [family member] was kind of
calm about things. But the agitation is hard to reconcile. There’s panic sometimes. . . .
I’d seen the family members [of another patient] earlier and they were in total panic
mode saying ‘where’s the doctor. I NEED a doctor! We need somebody. He needs more
medicine!’ It was those last few hours and he wasn’t medicated enough because he was
severely agitated and severely crying out in pain. The family members at that point were
panicking. They were in the hall yelling for the doctor. They wanted more pain meds for him because he was crying out. But he had been given everything that was prescribed to the max dose and we were waiting for the doctor to call back for more orders . . . .

[Another patient] calmed down after we gave the Dilaudid but it wasn’t lasting that long. We had to repeat it. I couldn’t believe how strong she was. After I gave it, she’d calm down but was still awake and we’d given her all that was ordered and still had to call the doctor for more…. Oh I felt so helpless, like I can’t do anything about this. I did all that I could do, but it wasn’t enough. (Martha, CPI)

Seeing patients suffering and families panic also heightened her stress. Despite administering pain medications, she could not rectify the pain or agitation and felt unsettled to the point of helplessness.

From Helen’s (CFG1) earlier description of her patient’s death, she revealed a lack of knowledge regarding palliative care or family needs at EOL by what she did not say. Helen never mentioned comfort in any descriptions of this patient or family member in the following excerpt or any other description afterwards:

I mean it was unexpected but we knew she was dying, so I only took care of her for half a shift . . . . We found out all this stuff and she was elderly. So we’re just looking at her like, ‘that’s it . . . .Your antibiotics aren’t working.’ She had Clostridium-Difficile (CDIF) the day before, on top of her pneumonia, and her urinary tract infection (UTI) . . . . So there wasn’t really that much that we did. We kind of let the family be in there and just let it happen. . . . One of the daughters would not leave the bedside even when we were doing post mortem care, which was kind of freaky. Cause I would not want to see my mother, like get put in a body bag [chuckling], but she was there. So that was interesting .
Like I did not know the body was going to be so….like it was hard to touch. The body was so rigid. It was just really a sad experience. (Helen, CFG1)

Helen had never dealt with a personal death or had prior clinical experience with EOL until this rapid death in practicum. She was unaware of how death affected the family. The daughter who “would not leave” surprised her. She found it “interesting” that the daughter wanted to be present for post mortem care. From Helen’s lack of knowledge and experience with EOL, she was unaware of the daughter’s need for support as a means of comfort. Later in the discussion, she reiterated her learning from that experience:

It was a good experience seeing that happen, recognizing that my feelings were . . . . I mean I was in shock because it happened sooooo fast. I didn’t know you could deteriorate that quickly. So next time I’ll keep that in mind when you see septic shock.

(Helen, CFG1)

In contrast, Kate (CFG2) expressed empathy and discomfort from lacking knowledge about comforting family members. Kate had positive past experiences with close family members who had received hospice care. She was comfortable providing physical care at EOL. However, she expressed how hard it was to deal with family emotions, particularly what to say. She was saddened and empathetic:

When you hear their guilt and everything kind of coming out like: ‘I wish I could have been here, if I was only listening to this one call…’ That’s when it’s very hard because that’s when I feel sadness or anger for them, and their frustrations, their emotions. I feel comfortable taking care of the patient, but we hear a lot of family members’ unjustified guilt, like they say ‘I wasn’t here. I should have taken her to this appointment. I was just with her an hour ago and now things are different.’ It’s hard because I feel empathetic
towards them. I know if it was my loved one I would feel the same way. But I can’t alleviate their guilt because sometimes that’s out of reach and you can’t do that and you don’t know always what to say. You can say something like ‘You couldn’t have done anything differently.’ But, you really just don’t know what exactly to say just to help them. (Kate, CFG2)

From her own past, Kate understood the emotional discomfort of loss in admitting her empathy. The discomfort was associated with a lack of knowing what to say. She knew she couldn’t alleviate the guilt but wanted to know how to comfort the family.

**Subtheme: Close relationship.** The second subtheme was a close or personal relationship to the dead or dying, which modified the emotional effects from a death. Participants expressed more discomfort if they personally knew the person that died. They also described emotional effects from losing a pet because of a close relationship to the animal. Participants considered the loss of a pet different from human loss. However, they felt the pain from losing a close relationship with a pet because of an emotional attachment. Of all participants, Martha (CFG3) experienced the most recent death of a close family member. Her father died a little over a year ago.

**Detachment.** Detachment, the opposite of attachment, was true for the deaths of friends and family members with whom participants did not have a close relationship or emotional attachment. Such deaths had no lasting emotional effects. For example, Ida (CFG1) and Jeff (CFG1) recalled losses of family members and friends that had little emotional effect. Ida recalled:

> I’ve had friends of friends die but they weren’t that close to me, but I still felt my friends’ sadness. I think it kind of depends on their relationship to you. Because my biological
mom, I never really knew her because she passed when I was two. So I don’t have that emotional attachment. But at the same time, I feel the loss because I never got to know her. But my grandmother and grandfather, I knew them and they were always doting on me . . . . So it depends on the person and your relationship to them. The connection, who they were to you, [effects] how deep of a loss you feel. (Ida, CFG1)

Jeff (CFG1) also recounted various deaths and how he felt based on the relationship:

Both of my grandparents on my father’s side died before I was born. Then on my mother’s side, my grandmother died eight or nine years ago and I wasn’t really that close with her . . . so it really didn’t affect me that bad. The harder ones are the ones like my brother, and there have been several other friends . . . . We just grew up together. I think it depends on how close you were to the people, on how much it affects you. (Jeff, CFG1)

Ida (CFG1) described emotional detachment from the deaths of pediatric patients in her previous job. She assisted with X-rays of young children, even infants. Some were already dead when she assisted:

I had to deal with some of those instances where they would already come to our unit already passed away and we’d have to take X-rays of that. To me that was completely detached. I didn’t think about that they are dead. To me, this is a job. You have to go in and it was just babies. It was just awful. But there was an instance where I had a patient who went from being admitted [alive] to them dying in a span of like two hours. To see the beginning and the end was really hard for me. I had never dealt with death in that scenario. Yeah it was a tough experience for me to see that because she was a young kid. To see that and like all the care put in and it didn’t [shaking her head]. So that was a hard
experience for me because I had never had to deal with being in that whole end of the spectrum, of having to care for a patient that didn’t make it, especially a child. I think that’s the hardest . . . I guess I didn’t think of that until now. It didn’t enter my mind until now. I didn’t have an emotional attachment to them, but still, as a nurse and a person you still have some sort of, I hope you have some sort of reaction. If you don’t [chuckling] there might be something wrong with you. (Ida, CFG1)

Ida attributed caring for a patient from a nursing perspective, to emotional attachment. Ida’s job did not include caring for a patient in this job. What stood out to her was sadness as a normal response to death as uncomfortable, especially children or infants.

*Emotional attachment.* Participants identified strong emotional effects from loss and suffering of pets because of an emotional attachment from the relationship. Not all participants could identify with emotions from personal human loss but described loss of pets. Participants nodded their heads in unison with each story of suffering or loss of a pet. Jeff described a strong attachment to his dog:

The closest thing I’ve experienced to actually being in the death process was last year when my dog died . . . Her joints gave out. She couldn’t walk . . . It was really tough because I had to make the decision to [euthanize her] or try everything I could to keep her alive for another year and have her go through all that suffering. (Jeff, CFG1)

Helen (CFG1) had never experienced the death of a close family member. She distinguished pet loss differently from human loss but could identify with the discomfort from watching her dog suffer. She described a *human-like* relationship to her dog:

My dog died. I know it’s not the same thing. But it really hurt . . . He was not even three but he was my baby. One day he just couldn’t walk . . . We went through a whole week
of checking him for what was wrong. His creatinine shot up . . . . He was so edematous that he couldn’t even breathe anymore. We were fighting for his life with fluids, yet his kidneys couldn’t remove the fluid. His eyelids were so swollen he couldn’t even shut his eyes.  (Helen, CFG1)

Ida (CFG1) expressed the sadness from watching her pet ferret suffer, “We [considered] surgery but it wouldn’t keep her comfortable . . . she lost all bodily function, was the worst thing ever. I couldn’t let her go on like that anymore. It was really sad.”  From CFG2, Kate described the loss of her pet and the importance of physical presence:

I did have a dog that we put down six years ago and I was really sad about that . . . . I had her since she was a puppy. But she had bone cancer. She had dysplasia . . . My parents, sister, and I, we were in the room when we had to put her to sleep. We had her for 10 yrs. . . . I wanted to be in there with her. Just being present, we knew that it was best for her. (Kate, CFG2)

Kate (CFG2) also recalled how important family presence was to her grandfather before he died. Kate had learned from a hospice nurse that took care of her grandfather that hearing was the last sense to diminish at EOL. She believed that he could sense his son’s presence just from the sound of his voice over the phone. Kate’s grandfather was unresponsive at EOL. All members of his family were present except for one son, Kate’s uncle. Kate (CFG2) described the sense of connection her grandfather had to his son:

I heard one of the nurses saying that hearing was one of the last senses to go, so you should keep talking to them. He was completely unresponsive and they were basically just keeping him kind of alive with drugs and whatnot. Most of my family was there, but he was missing one son and I said, ‘we should call uncle and have him talk to our papa.
Cause we were all there and I felt like my papa needed that, to hear that so he could just go. We just called him on the phone and had him on speakerphone just to say his ‘good byes.’ And then he died. So I always remember that. (Kate, CFG2)

Kate felt that her grandfather’s sense of hearing was intact because he died after his son said ‘good bye’ by speaker-phone. Because of their close connection, Kate believed that her grandfather might have felt his son’s presence from hearing his familiar voice.

From CFG1, Jeff described the personal relationship with his brother, which made his death harder. They were physically and emotionally close. He recalled:

I was the closest to him. We were best friends, like inseparable. I stuck with him during all that. I didn’t push him away because of his drug use. Whereas, the rest of my family kind of did and distanced themselves away from him. So when he died, my whole family looked to me for support because they felt so guilty about not being around and not spending quality time with him while he was still alive. (Jeff, CFG1)

Jeff’s physical presence and emotional support to his brother during his drug use made the death more difficult emotionally. Although Jeff was relieved of the stress from wondering if his brother would get better or not, he expressed sadness over the loss of their relationship.

**Theme: A comfort to comfort.** The code *a comfort to comfort* encompasses the intertwined descriptions of comfort as a priority outcome or goal and a nursing role, which were necessary in EOLC. Comfort was characterized by 1) priorities at EOL, and a 2) nurse’s role or the expectation to comfort. The subthemes emerged separately based on participant perspectives during an EOL experience. To distinguish the context when describing comfort, the subthemes were noted as 1) priorities, and 2) nurse’s role.
The subtheme of *priorities* indicated fundamental factors for comforting the dying person and involved family members. All participants experienced EOL and/or death at some point in their lives with a close family member, a patient, a family member of a patient, or a special pet. From various perspectives, they described comfort as *the* priority. The paraphrased priorities of comfort from their narratives were: absence of suffering, patient’s preferences, physical care, family presence, and support to family members. Participants described priorities in terms of ideal situations and outcomes for patients and involved family members at EOL.

An equally important subtheme was the *nurse’s role* to comfort, which stemmed from their expectation to provide comfort especially at EOL. Participants described concerns about EOLC earlier under the major theme of discomfort due to lack of knowledge or experience. However, participants also expressed comfort with EOLC gained from personal or clinical experience and other sources of knowledge about EOL or EOLC. They revealed their level of experience and comfort with EOL or EOLC as they described aspects that were comforting, encouraging, or supportive for providing EOLC. Some participants gave examples of giving comfort at EOL. Others provided sources of knowledge about EOL and EOLC that were comforting in that they felt relieved to learn what was expected. Both types of examples were comforting to participants and considered equally important for the nurse’s role to comfort at EOL. They described what was comforting in context of their experience or concerns with lack of experience.

**Subtheme: Priorities.** Participants described comfort or alleviating pain and suffering as priorities at EOL from a family member or nursing care provider perspective. From a nursing perspective, participants with EOL care experience described priorities of comfort for patients and/or family members at EOL in the acute care setting. For example, Kate (CFG2) described
the priority of comforting patients physically and family members emotionally at EOL during her practicum in the ICU. From family member perspectives, some participants described factors they felt comforted by at EOL or were comforting to a family member at EOL. Participants who had no experience with a family loss described their pets that suffered at EOL. Although they distinguished comforting animals as different from comforting humans at EOL, they identified with comfort as the priority when seeing suffering at EOL.

*Absence of suffering.* Participants valued the absence of suffering at EOL, whether physical, mental, or emotional:

- I felt like my papa needed that, to hear [sound of his son] that so he could just go. Cause hearing your voice might be very soothing. (Kate, CFG2)
- We found comfort in knowing that she would be better off…. The cancer was spreading and she was having trouble walking, eating, just her quality of life. (Kate, CFG2, describing her dog)
- Receiving pain relief even if it’s to the point of unconsciousness. Pain with no hope of recovery is so totally different from pain with hope of recovery. (Martha, CFG3)
- I think it’s important to let whoever is dying have most of the control over their care and support for them to be comfortable and to be free to choose whether or not they want to live anymore. (CFG1)

Others described scenarios in which they were glad when symptoms of suffering were relieved at EOL. For example, Jeff (CFG1) was comforted *after* his brother’s death in that he was no longer suffering. He and his family were relieved from the distress of uncertainty regarding his brother’s condition while he was alive:
• Just watching him get worse and worse until finally he overdosed and passed away. He was suffering from his mental illnesses and not being able to be happy. So in some ways, when he did pass, it was somewhat of a relief . . . . Although it’s never going to be a happy thing, it was nice to know he wasn’t suffering any more. (Jeff, CFG1)

• We’re putting them out of their misery. This is a good thing . . . that they’re not hurting. (Helen CFG1, after euthanizing her dog)

Kate (CFG2) prioritized comfort for patients and family members especially in the ICU setting. She had witnessed or assisted in withdrawing life sustaining aggressive care from at least one patient at EOL every shift. She described diminishing the appearance of suffering or “alarming” symptoms at EOL for the patient’s comfort and for the sake of the family members who were present. Her description was an exemplar of the absence of suffering as a priority of comfort:

Our priority was making them comfortable but also making it seem like they were comfortable. They develop a lot of secretions . . . [and] the breathing is very alarming to family. So . . . administering medications that would dry up the secretions so it wouldn’t seem like they were having as much labored breathing. Watching all their vitals for possible pain and treating. . . making sure that every time you’re in there, they’ve got Vaseline on their lips [and] they look good. . . so you’re really caring for the body even though you know you’re withdrawing care. We still would reposition them every hour. We would be sure that they just looked comfortable. (Kate, CFG2)

*Patient’s preference.* The patient’s preference for comfort at EOL was the main source for guiding comfort, especially regarding pain relief for two participants because of their experiences. Jeff (CFG1) was clear about preferences for supporting patient choices. Because
his brother suffered mentally and physically, Jeff said, “I think it’s important to let whoever is dying have most of the control over their care, and support for them to be comfortable, and to be free to choose whether or not they want to live anymore.” Martha’s (CFG3) only source of comfort about her father’s death was from honoring his wishes at EOL. She described an exemplar of honoring a patient’s wishes:

For him to have gotten what he wanted at that moment, that he got to die at home, with the pain medications offered by hospice, that he had a choice. Cause he did not want extreme measures . . . So I mean that was the most important thing, that I felt we were following his wishes . . . Knowing what a family member, or anyone wants, that you’re following them, I think gives the only comfort available. (Martha, CFG3)

Knowing patient preferences for care was also described in context of the nurse’s role in EOLC, to honor a patient’s wishes for health care by initiating advanced directives. Martha and Jeff expressed views of the nurse’s role to honor a patient’s wishes for total pain relief. More comments about choices are described under the nurse’s role.

**Physical care.** Physical care of the body was comforting for patients and families, but also for some participants who had clinical EOLC experience. As Kate (CFG2) described earlier, treating physical symptoms and maintaining a comfortable appearance of the body were important for families. She also received personal comfort from providing physical care, “I feel a sense of calm when I’m taking care of a dying person. I find it very methodical and soothing just taking care of the body…. I find it comforting to comfort somebody else.”

Martha (CFG3) was relieved from her experience with physical care post mortem during practicum. Although hesitant at first from not knowing if the body would be “messy, bloody, or traumatic,” she helped the patient care technician (PCT) wash and prepare a dead body for the
family to view. She remembered seeing the patient earlier in the day in pain and his family members panicking in the hall. Martha described how that experience demonstrated respect for the body and for the family. Her description was an exemplar of respect for the life of the person and death of the body:

And he [patient care tech] was very respectful of the body, making sure he was clean, positioned in a nice manner, getting the patient ready for the family to come back and see him. [We] didn’t put a sheet over his head. Oh no. We made him look like he was just sleeping. We had his arms crossed nicely.’ You don’t want the family to come in here and have to pull the sheet down. That was just out of respect. It had an effect on me. I can totally picture it in my head and probably will for a long time. It was closure for the nurse who had him when he was crying out in pain, agitated and all. She said he looked soooo peaceful now, and he’s at rest. (Martha, CFG3)

Support to family. Support to family was important especially for the patient’s sake. Most participants described the importance of family presence. Earlier, Kate (CFG2) and Martha (CFG3) described treating physical symptoms and/or meticulous care of the body for the sake of families who viewed the body, whether alive or post mortem. Helen (CFG1) described the daughter who wanted to be present at her mother’s post mortem care. Although to Helen it seemed “interesting,” it was important for the daughter. As Helen described it: “We gave them time [with the body] afterwards. Especially one of the daughters would not leave the bedside, even when we were doing post mortem care, which was kind of freaky.” Kate (CFG2) earlier described her grandfather’s death, that all his family members were present. Hearing the voice of his son on a speaker-phone was another way Kate felt that her grandfather could sense the
presence of his son. Other participants touched on family presence as comforting for the dying and for close family members present:

- My parents, sister, and I were in the room when we had to put her to sleep. I wanted to be in there with her. Just being present. (Kate, CFG2, describing her dog)

- To me it was like comforting when we put her to sleep. I was holding her hand and I was the last thing she saw. I think it was comforting to her too. (Ida, CFG1, describing her pet ferret)

- They appreciate it so much because they don’t want to leave the room. They want to be there when their family member dies. (Martha, CFG3)

- It’s almost like you’re very involved because the families that are all in there, basically holding vigil at the bedside. (Kate, CFG2)

- He got to die at home, surrounded by family, having the option to have family there I think was important. (Martha, CFG3)

Supporting family members was part of the priority in comforting patients and family members. From personal experience, Martha (CFG3) and Kate (CFG2) found it crucial to include family members throughout the dying process and afterwards. Martha learned from a hospital palliative care specialist that family members were included in hospice care of the dying patient. She remembered how her mother was supported after her father died:

Hospice isn’t just about the patient, it’s about the surviving family members and the care that hospice offers them after the death . . . . The palliative specialist said, ‘even if there are only 10 minutes [left to live], get the paperwork signed so they can get into hospice because then the family member falls under the umbrella of hospice after care for after
the death of the patient.’ I’ve seen it make a difference . . . I mean she [my mother] just got a letter once a month to follow up on how she was doing. (Martha, CFG3)

As a family member, Kate (CFG2) remembered her own family members who had received hospice care, “My only experience with EOL care was seeing family members on hospice. . . . The care that I saw was very necessary and really helpful for the family. So I really had a positive impression of it.” Kate (CFG2) and Martha (CFG3) were the only participants who had clinical experiences supporting family members at EOL. They each described how they supported family members:

- They don’t understand what’s going on. So your role is to kind of be there and interpret for them what’s going on. (Kate, CFG2)

- I think she kind of understood, but I think that she lost that kind of hope inside of her. And that’s when you kind of have to redirect, like saying ‘he might be able to hear you so you should still talk to him . . . You kind of, like have to keep motivating them [the family member] to keep doing what’s also helpful for them. You know they’re kind of in the grieving process . . . I do think that’s also a way the family can feel like they are there contributing something to the comfort as well. (Kate, CFG2, speaking of a family member)

- The least we could do for the family is make sure she had something to eat like crackers or a drink or something. That was all we really could do while waiting . . . It was such a little thing but it was something we could do for the family. Then we ordered the chaplain to come…. [to speak with] the one who is staying by the bedside, that’s the least we could do. (Martha, CFG3)
Ida (EFG1) never had direct EOL care experience, but described an incident in which she supported a distraught family member who received bad news. Ida was present when the doctor gave the bad news to a family:

The day I was there, they were talking about options because she had a liver mass and her family was there . . . the doctor came and talked to them . . . To me that was really hard because all the family just started breaking down and crying. . . Someone grabbed me [a family member] at one point and started crying on my shoulder. For me that was an experience because I was actually able to sort of provide some comfort even though I didn’t really say anything. (Ida, CFG1)

The idea of heaven or the “after life” was peaceful and comforting to Ida and Helen from CFG1. In light of suffering in terminal illness, Ida felt comforted by her belief in a better place after death for terminally patients:

I always believe there is a heaven or hell, but for the terminally ill, I believe they go to a better place. . . . I also get a sense of peace because I do believe there is something out there, like heaven. It’s a bit of both I think, fear of the unknown but also peace at the same time. (Ida, CFG1)

Ida admitted earlier knowing nothing about palliative care and feeling terrified about the unknown. But her faith in heaven, or belief in something unseen provided a sense of peace despite fears of the unknown. Helen (CFG1) also expressed how nice it felt to sense the family’s belief in a better after-life. In retrospect of her first EOL experience in the ICU:

When I had that patient die, it made me think a little bit more about you know, the after life and stuff, because I’m not particularly religious. But I like to think people go to a
better place and I could tell that the family felt the same way too. They were pretty religious. It was nice. (Helen, CFG1)

Whether perceived as religious or not, expressions of belief in a better place after death offered peace and comfort to participants.

**Subtheme: Nurse’s role.** The nurse’s role to comfort was described as an expectation to provide comfort for patients and families. Participants were comforted to learn how to fulfill that part of the nursing role specific to EOLC. Knowledge specific to EOL was also instrumental for meeting the expectation to comfort someone dying, especially for participants who felt lacking in EOLC knowledge or clinical experience. For example, Ida (CFG1) had earlier expressed discomfort about EOLC because nobody was able to tell her anything about it. Participants who had clinical experience with EOLC described what they learned or practiced as fulfilling expectations of their nursing role. Others described their expectations of the nurse’s role to comfort based on several sources of learning.

**Expectation to comfort.** Some participants were able to provide EOL care in the clinical setting as expected of the nursing role. Earlier, Kate (CFG2) and Martha (CFG3) gave examples of supporting family members at EOL in the clinical setting, which were comforting in view of their expectations of the nursing role. Although brief, Ida (CFG1) expressed how encouraging it was to “sort of provide some comfort” to a crying family member who had just received bad news. Ida said of that experience:

I felt better about the situation. As a nurse, my entire goal is to try and help and heal people. In that instance, I couldn’t heal the patient but I could help heal the family a little bit. . . . Yes, that was a good learning experience for me to deal with dying patients. (Ida, CFG1)
Ida felt comfortable doing what was expected as a nurse to help the family, even if unexpectedly. Martha (CFG3) expressed her relief from a clinical situation because she wasn’t expected to provide post mortem care. She decided to help and learned from the experience saying, “I was allowed to have space, a safe space. There weren’t any expectations.” Earlier, Kate (CFG2) described her comfort with taking care of the body. She said of the physical aspect of nursing, “For me, I like that and I wouldn’t shy away from doing that.” Martha also reflected on the nurse’s role after seeing patients panicking:

I think that the ability of a nurse, no matter what floor they’re on, to know the resources available to the family is critical. Like getting a chaplain, a social worker, a palliative care specialist, because it’s distressing when a patient is dying and the family member is there. (Martha (CFG3))

Participants expressed the desire to learn more about EOL to lessen their fears of providing the expected level of EOLC as a nurse. Earlier, Libby (CFG2) expressed relief from talking about death, “just being able to talk about it is more comfortable.” Because of her lack of personal or clinical experience, Libby did not know what to expect at EOL and expressed relief hearing about death and EOLC. From practicum, she recalled a pediatric patient with chronic and incurable Mitochondrial disease, which she knew resulted in death at an early age. She said, “I don’t know how exactly I’m going to respond when that happens, but it’s good to hear feedback from classmates and what she does [looking directly at Kate, CFG2].”

Participants who had EOLC experience during practicum also expressed the desire to know more about EOL in order to provide better EOLC. Kate (CFG2) expressed her expectation to know more about EOL symptoms despite her EOLC experience in the ICU, “Just so you also
know as a practitioner what is expected and what isn’t and you kind of know like, ‘Should I be treating something?’

Martha (CFG3) expressed the nurse’s role to know about options for comforting patients. Earlier she described the distress of seeing patients in pain. She recalled feeling helpless when the highest dose of narcotic she administered failed to keep her patient comfortable. She recalled her preceptor’s demonstration of how to advocate for her patient:

Luckily I had a preceptor with huge experience. He said ‘this is what we’re going to do. We’re going to call the doctor and we’re going to do it now. We’re not going to sugar coat the situation. We’re going to describe the situation. We’re going to say extremely distressed so the physician knows you need to get to this right now,’ cause this was on a Sunday. He said ‘never down play a situation. Be as honest and descriptive and use adjectives to get the attention you need.’ So knowing what your options are to make someone feel more comfortable, the family and the patient, I think is critical. (Martha (CFG3))

Honoring patient preferences for EOL care, especially pain relief, was a high priority of comfort at EOL for Jeff (CFG1) and Martha (CFG3). After witnessing his brother deteriorate and suffer before he died, Jeff (CFG1) expressed his expectation regarding a nurse’s role to support a person’s choice of comfort at EOL; “I don’t think it’s right to force someone to live and suffer when they would rather just move on. I think that should be a choice for anyone.” In view of the nurse’s role, Martha (CFG3) described education about advanced directives as a means for honoring a patient’s wishes in a hospital setting. Seeing patients in excruciating pain within a hospital setting influenced her view of the nurse’s role:
If you’re in a medical setting, they [nurses] have the capacity to make it a peaceful transition through medications… people need to know about the process and to have directives because not knowing what someone wants is very difficult. It’s about educating and you want to know what your choices are.

*Essential EOL knowledge.* Given the nurse’s expected role to comfort, essential knowledge specific to EOL was important for some participants. Some recalled EOL knowledge from nursing courses. From a nursing care perspective, Kate (CFG2) remembered what she heard in context of what all nurses would need:

> Hearing [from hospice nurses], how they care for dying patients and how they help the families would be helpful, to have their first hand experience, a little bit more than what we got just in community cause I do think we’ll all encounter it even if we’re not expecting it. And I think there is a fear there when you haven’t dealt with it, you know ‘what am I going to do or say?’ (Kate, CFG2)

Participants expressed what they felt was essential to know as a nurse in order to educate patients and families:

- How the body goes through very distinct things when you’re dying, like physical changes and . . . what exactly happens. (Kate, CFG2)
- What’s going to be next, sort of to anticipate what should be done. (Libby, CFG2)
- And so you know and you’re also not freaking out if you see it happening. (Kate, CFG2)
- Knowing responses like the simple example with the reflexes [palmar grasp], you’re not like ‘Oh my gosh, that’s a great sign!’ (Libby, CFG2)
- You *need* to be able to educate them and tell them what’s normal and what’s not. (Libby, CFG2)
• Knowing what your options are to make someone feel more comfortable, the family and
  the patient, I think is critical.  (Martha (CFG3))

Sources of knowledge. When asked if they thought they had changed regarding EOLC,
participants who had no clinical EOLC experience felt that their perceptions had not changed
much. However, Jeff (CFG1) described how and when his thinking about EOLC changed from
seeing a documentary in class:

When my thinking was changed was when I saw a documentary about hospice in
correctional facilities. That’s when I got the most realistic perspective of what EOL care
is. I liked it cause you got to see actual people who were terminal in the documentary. It’s
like the hospice workers would shave their face and help them brush their teeth. Just
trying to keep their lives as normal as possible and keep their dignity while they knew
they were dying. They could still feel like they were human. That is where my
experience with seeing palliative care comes from.  (Jeff, CFG1)

His thinking changed after seeing a realistic example of EOLC with nurses assisting
terminally ill patients. What stood out to Jeff was the example of assisting the terminally ill with
normal activities as a way to maintain their human dignity. Although Jeff described the change
in his thinking, he was most impressed by the affective aspect of palliative care for maintaining
human dignity. Similarly, Ida (CFG1) felt that her perception of EOLC had not changed much,
“I don’t think mine has really changed very much because we learned about it in class. Mine was
really more educative about it, like what palliative care entails.”

Participants learned about EOL from listening and talking with classmates about patients
dying in clinical. Earlier, Libby (CFG2) commented, “just being able to talk about it is more
comfortable.”  Libby learned from listening to Kate (CFG2) describe what she learned about
EOL in clinical during the focus group. Martha (CFG3) recalled what she heard from classmates:

One of my classmates saw a child that had just died for the first time and was kind of traumatized by it. She wasn’t ready . . . But if it was something you could think about first before that happens . . . Oh she talked to everybody about it. I think that’s part of it, is that we need more people talking about it to take away the gasp of it. . . . Just today someone was saying that the patient they had the other day had died. . . . We definitely learn about it from other students talking about it. (Martha, CFG3)

Health care providers in the clinical setting were another source of knowledge and EOLC experience for some participants. They learned by talking to, observing, and modeling other nurses or patient care technicians (PCT). At almost every clinical during her practicum, Kate (CFG2) described withdrawing life sustaining treatments and providing comfort to a patient and/or family member at EOL. She recalled what she learned from other nurses about educating family members about the physical changes at EOL and what not to say:

One of the other night nurses was talking to me because she also does hospice as her other gig. She’s like ‘I describe what I’m seeing and don’t make any comments like ‘I think they’re going to die in 10 minutes.’ Just state observations. So that’s what I kind of tried to model as well, like ‘I see that he’s turning more blue. He’s becoming a little hypoxic. He’s not able to perfuse his body as well. . . . or ‘hearing is one of the last senses to go so you should keep talking to them . . . . when they grab with their hand [palmar grasp], sometimes these are reflexes that the body still has [with brain death]. (Kate, CFG2)
Earlier, Martha (CFG3) described her experience learning about physical care of a body post mortem from a PCT. She learned respect of the body after a death. However, Martha expressed regret that her father was taken away so quickly by the funeral home after he died. In light of her father’s unexpected death and quick removal of his body after death, she reflected on that experience of washing and preparing the dead body:

We didn’t have that washing, and rituals, how important they are. Our’s [dad’s death] was just like…’get out. He died. He’s gone.’ There’s nothing else we can do but wait for the professionals to come here. So I didn’t have that experience with him. I’m not sure if I want it or not, but I am happy for the experience that the patient care technician had for me . . . . I think seeing, touching, and preparing the body that had died impacted how I feel about the death in that it kind of took away, not the fear, but just that ‘this is it. He’s not here anymore.’ It’s different than seeing a body in a funeral home. Something about having just talked and interacted with someone and now they’re gone, dead. [It] was interesting to see the physical symptoms and the finality of life, the realness. (Martha (CFG3))

Martha seemed to have benefitted from seeing the patient alive at first, and then seeing, touching, and preparing his dead body. That experience seemed to have helped Martha process the finality of her father’s death.

**Comparison Group Paradigm of End-of-Life Care**

Participants described the paradigm of EOLC in context of patients’ preferences to die at home or in an acute care setting. In either location, exemplars and comments indicated comfort as the main priority of EOLC with the patient’s choices guiding directives for care, especially pain relief. Although Jeff (CFG1) had no clinical EOLC experience, what stood out to him about
palliative care at EOL was maintaining human dignity for terminally ill patients. From seeing a documentary in class, he pointed out the nurses providing EOLC in the patient’s place of residence instead of an acute care setting. He noted nurses assisting with “activities of daily living” as a way to maintain human dignity at EOL, which changed his thinking about EOLC.

However, most participants described the goal of comfort at EOL as absence of physical, mental, and emotional suffering for the dying patient, which included support to family members. Two participants, Kate (CFG2) and Martha (CFG3) experienced mixed responses to hospice care from personal deaths of a family member. Kate had a positive impression of hospice care, which influenced her view of EOLC as necessary and helpful for family members in a clinical setting. Martha had a negative impression of hospice care because of her father’s distressing symptoms. Her negative impression from the symptoms influenced her views about suffering at EOL, regardless of setting. Participants described a paradigm of EOLC in light of their practicum experience and their concerns with the nurse’s role. They described a paradigm of EOLC within an acute care setting with nurses expected to be the primary caregivers or to facilitate comfort. Expectations of the nurse’s role in EOLC were contingent on basic knowledge of EOL and EOLC, which most participants felt necessary, regardless of their experiences with EOL.

**Comfort.** As a priority for a dying patient, comfort meant the absence of pain and suffering based on the patient’s perceived level of relief. Comfort included physical care of the body, the absence of struggle, adequate pain relief, a comforting physical appearance, and support to family members involved. Due to the nurse’s role to provide or facilitate comfort, participants expressed requisite EOL knowledge in order to provide comfort according to the
patient’s and family’s wishes for EOLC. Knowledge needed to provide adequate comfort is described in detail as ‘essential knowledge’ under the nurse’s role.

**Treatments for pain and suffering.** Not all participants expressed a singular view regarding treatment for pain and suffering. Kate (CFG2) favored trying alternative measures such as a massage for patients at EOL. From her exemplar of comfort as a priority to the patient, it was important to maintain the appearance of physical comfort through meticulous hygiene, body positioning, and medical treatment for pain as indicated by the patient’s symptoms. Her exemplar also included medical and nursing treatments for any symptoms indicating struggle for the patient as perceived by family members present. Martha (CFG3) and Jeff (CFG1) expressed the patient’s right to control the choice of medication for comfort, and the amount necessary to achieve complete relief. For Martha, “excruciating” physical pain should be relieved completely, even to the point of palliative or complete sedation if necessary. Only she expressed an interest in researching assisted suicide as an option for total relief of pain in terminally ill patients without hope of recovery. Jeff (CFG1) supported a patient’s right to choose death as a means of ending suffering. He did not include nurses for assisting a patient’s choice for death. However, he felt strongly against nurses *forcing* patients to live and suffer.

**Comfort to family members.** Nursing comfort to families included allowing them to be present with the patient, facilitating their constant presence by providing snacks or drinks, and describing and/or interpreting what they did not understand about physical changes or responses. As described from Kate’s (CFG2) exemplar of comfort, it included treating patient symptoms perceived by family members as a struggle for the patient, such as eliminating excess secretions that make breathing sounds difficult. Making the patient appear comfortable was comforting to
families. Applying Vaseline for dry lips and repositioning the body were interventions for maintaining an appearance of comfort.

**Nurse’s role.** Although not all participants had clinical experience with EOLC, most indicated essential knowledge needed to comfort as expected of the nurse’s role at EOL. As the primary caregivers in an acute care setting, nurses were expected to carry out major functions specific to EOL, especially regarding physical care and comfort. Nurses were also expected to facilitate comfort by knowing about resources for EOLC, such as palliative care specialists, social workers, chaplain services, or the hospice transition process.

**Essential knowledge.** Knowledge was critical in light of the expected role of nurses to comfort, facilitate comfort, educate, and support family members at EOL. Participants with EOLC experience during practicum felt that their nursing role to comfort at EOL could be improved by essential knowledge specific to EOL. Participants with no EOLC experience also provided examples of essential knowledge to fulfill the nurse’s role in EOLC, which included:

- What to expect as normal and abnormal signs or symptoms
- Physical changes distinctive of active dying
- Symptoms requiring treatment
- How to treat symptoms
- How to communicate specifically with dying patients or family members about EOL in order to console, support, provide options, educate, or explain in order to prevent false hopes of recovery
- Initiating advanced directives and/or other options of EOLC to honor patient and family wishes at EOL
Available EOLC resources such as a palliative care specialist, social worker, Chaplin, or hospice nurse

**Research question six.** Do students who participate in a structured EOL course express different attitudes, beliefs, values, and emotions about EOL care from students who do not participate in a structured EOL course but who participate in 172 hours of clinical experience?

**Attitude.** Attitude encompasses a way of thinking and feeling about someone or something, which is typically reflected in a person's behavior (Dictionary, Version 2.2.1 (194) [Apple Inc. Software]. In reference to nursing care, attitude is a broad term encompassing beliefs, values, and emotions expressed through behaviors of care (Charalambous & Kaite, 2013; King-Okoye & Arbor, 2014). Therefore, attitude describes one’s general approach toward nursing care that is revealed from the beliefs, values, and emotions adopted and expressed when providing care.

Regardless of elective or comparison group, a participant’s demeanor and words used to describe a memorable EOL experience revealed an underlying emotional response, indicating the significance of the experience. What participants did not say also provided insight about attitudes about EOLC. For example, elective group participants never said “bad death,” but referred to it as the “opposite of a good death.” Comparison group participants discussed aspects of a peaceful EOL and a “distressing” EOL from personal experiences, but they never said “bad death” or “good death” indicating their uncertainty with what to expect at EOL and about EOLC. Focus group discussion and responses to one another revealed the concerns, thoughts, and emotions about EOLC, which emerged as major themes for each group. The paradigm of EOLC for each group included the beliefs and values indicated by memorable experiences and knowledge gained from nursing education. A summary of each group’s attitude toward care of
the dying is provided below. Each summary includes a consensus of negative and positive aspects of EOLC indicated by their emotions regarding the most important beliefs and values to each group as a whole.

**Elective group summary.** Elective participants expressed negative emotions first. They felt sadness in response to loss of a meaningful relationship, seeing physical deterioration of a patient or family member, or feeling helpless to improve a patient’s situation at EOL. Frustration and anger were common responses toward unrelieved suffering and disregard for the care of patients and family members at EOL. Stronger emotions of anger and/or guilt were associated with medical care providers who disregarded patients’ and family members’ concerns about EOL. Although sadness and grief were unpleasant, they were considered natural responses to death or loss.

Elective participants also recalled very positive emotions related to EOL. Participants expressed gratification and relief about the possibility of a good death, one without pain or struggle. Participants were satisfied and appreciative from getting to see and personally know someone dying within a meaningful nursing experience. Comforting someone at EOL was considered a privilege. Participants expressed willingness to provide emotional EOLC in the future because of the comfort patients or family members expressed from participants being present to listen or talk.

Participants valued respectful care toward patients at EOL because of their vulnerable condition and valuable contributions as an individual during their previous roles as a parent, grandmother, or sister. A meaningful relationship with someone dying was valued because of the mutual satisfaction and appreciation received by the patient and the participant. Adequate information, pain relief, attentive physical care, and emotional support including family members
were all necessary for promoting a good death. Being present with someone dying was seen as a valuable act of comfort, whether or not engaged in conversation or activity.

Overall, the elective group expressed an optimistic attitude toward EOLC that reflected their relief, certainty, and appreciation for facilitating a good death and preventing a bad death. The ideas repeated from narratives included relief, satisfaction, comfort, and appreciation. They described encounters with dying patients and family members with a sense of relief of anticipated fears and gratification from the comforting aspects of EOLC provided by simple acts. Strong negative emotions such as sadness, grief, and frustration were associated not only with the natural losses at EOL, but also with instances of disregard for the care or well-being of dying individuals and their family members. Attitudes from a nursing perspective ranged from a sense of relief about the expectations of comforting dying people to a sense of commitment to improve EOLC for dying people.

Comparison Group Summary. Comparison participants described a range of discomfort from feeling apprehensive providing EOLC to feeling terrified about not knowing what to expect at EOL. Shock was a common response when faced by an unexpected event at EOL for the first time, whether the event occurred during a personal or clinical experience. Participants were shocked from seeing a dead body covered by a sheet unexpectedly, experiencing the sudden death of a patient, seeing families panicking about a loved one in pain, and seeing physical symptoms at EOL. Not knowing what to do about the physical symptoms was more distressing. Most participants felt apprehensive about talking to or consoling patients and families at EOL or found it difficult to comfort families grieving or expressing guilt at EOL. Participants who had no EOLC experience expressed a general anxiety about not knowing how
they would respond in an EOLC situation. All participants expressed some degree of fear from not knowing exactly which signs and symptoms were normal or abnormal in active dying.

Participants also expressed positive emotions recalled about EOLC such as comfort from providing physical care or emotional support. Regardless of the source, participants were appreciative and relieved to learn more about EOLC. Participants were relieved: to learn more about a dead body in clinical, to model comforting behaviors and words from nurses, and to talk about death and dying with classmates or nurses during class. Most participants were comforted to learn more about the nursing role specific to EOLC from seeing real instances of EOLC.

Overall however, comparison participants expressed an apprehensive attitude toward EOLC because of the unknowns about death or dying and their performance expectations as a nurse to comfort, console, educate, and anticipate needed EOLC within an acute care setting. They described shock, distress, and sadness over physical symptoms at EOL and apprehension about comforting patients or families in distress at EOL. Their perspective of EOLC within an acute care setting evoked doubts about their nursing role. Many expressed the lack of exposure to dying patients or knowledge of EOL as factors contributing to their doubts about EOLC. They prioritized comfort as a goal of EOLC and the expectation of nurses to provide EOLC. However, there was no consensus on best methods for providing total comfort from pain and suffering. Participants described limited knowledge about comforting patients and families at EOL from a nursing perspective because of limited exposure. Many described silence as the default mode regarding communication with patients or family members at EOL due to lack of knowledge and experience about EOL.

Limitations
Attrition. A lower than expected return rate of posttest instruments limited generalizability. The return rate for quantitative data was 57.8% (11) and 69.8% (7) for comparison and elective groups respectively. Consequently, attrition rates of 42% and 30% for the respective groups may have influenced accuracy of quantitative posttest findings. Although statistically significant findings were obtained from posttest data, the small sample size may suggest attrition bias (Malone, Nicholl, & Tracey, 2014; Walker, 2012). Lower than expected focus group participation of six and seven participants for each group respectively may have diminished transferability of qualitative results to the target population as well. Although such sample sizes are appropriate for phenomenological studies (Malterud, Siersma, & Guassora, 2016; Mason, 2010; Morse, 2015; O’Reilly & Parker, 2013), depth and variability of the content may have been limited. However, each focus group discussion was lively. The transcript contents along with field notes were adequate for recognizing major themes and detecting redundancies indicating saturation (Malone, Nicholl, & Tracey, 2014; Walker, 2012).

Sample size. Small sample sizes limited how representative quantitative findings were of the target population of nursing students enrolled in both groups at pretest, and therefore how conclusions were interpreted from objective findings. The small posttest sample sizes may have limited validity estimates of student outcomes for knowledge and attitudes as measured by the instruments and consequently, reliability estimates for each instrument (Field, 2009). However, given the small numbers in each group, appropriate statistical tests for significance were carefully considered before calculating posttest results. Tests of normality, or normal distribution of the data, were also conducted before proceeding with the appropriate tests of significance for each data set (Field, 2009). The small number of participants within each focus group may have diminished the depth and variability of data, thus influencing how much content
could be obtained (Morse, 2015a). However, regardless of small numbers, the data yielded rich findings based on criteria for qualitative reporting representing those within the focus groups (Jayasekara, 2012).

**Enrollment.** Study findings may have been affected by a smaller than average total enrollment of 35 nursing students in the senior practicum course and 15 students in the Palliative and EOL elective course. Previous enrollments for these courses have been larger and have varied based on semester and course offering.

The high ratio of accelerated students (n=34) to traditional students (n=1) in the comparison group may have influenced attrition for posttest study participation. Students in the accelerated BSN track finish course work in four tightly packed consecutive semesters instead of five. Accelerated students may likely have been under greater pressure in their last semester than traditional students who have another semester to complete requirements. Thus, accelerated participants from this group may have been more likely to have less time for involvement in anything but required course . Given that study participation was voluntary, any extra time was most likely used to prepare for the final week of exams.

**Data collection.** Another limitation was the change of timing for pretest data collection by a study facilitator. Pretest data collection from the EOL elective group was planned for the beginning of the first day of class, which consists mainly of enrollment verification, course orientation, and viewing of a docudrama on EOL decision making by family and health care providers. Due to an unforeseen circumstance, data collection occurred at the beginning of the second class, thereby collecting pretest data that may have included information participants gained from the video. Timing of pretest data collection was intended to occur before students were exposed to EOL content from the elective course. In addition to course orientation on the
first day, participants in this group had watched a video about a paralyzed man’s wishes to
discontinue his life-sustaining ventilator. The video featured poignant interviews with his wife,
his primary physician, and the nurses who took care of him around the clock while in the
intensive care unit. The emotional resistance by health care providers gradually subsided and his
wishes were fulfilled. This video may have influenced the attitudes toward care of the dying of
those elective course students who participated in the study.

Summary of Findings

Knowledge. One of the aims of this study was to assess changes in student knowledge
toward care of the dying after participation in an elective course with didactic content,
experiential learning in class, and 10 hours of hospice volunteer experience “being with” dying
patients. Based on quantitative findings, there were no significant effects of elective course
participation on EOL knowledge scores.

Another aim of this study was to assess changes in student knowledge toward care of the
dying after 172 hours of clinical care experience without palliative or EOL didactic content.
Quantitative results indicated no statistical differences from pretest to posttest in knowledge
toward care of the dying after the clinical practicum course. Although EOL knowledge scores
improved after completion of the course, results were not statistically significant. In comparing
posttest knowledge scores toward care of the dying between groups, there were no significant
differences. Although the elective group scored 12 points higher than the comparison group at
posttest, the total mean score was not statistically different between groups.

Attitudes. Another aim of this study was to quantitatively assess changes in student
attitudes toward care of the dying after participation in an elective course with didactic content,
experiential learning in class, and 10 hours of hospice volunteer experience “being with” dying
patients. From quantitative results, there were no significant differences between pretest and posttest scores in attitude toward care of the dying in the elective group. In assessing attitudes toward care of the dying in the comparison group, quantitative results also indicated no statistical differences from pretest to posttest in attitudes toward care of the dying after the clinical practicum course.

In comparing attitudes toward care of the dying between groups quantitatively at posttest, the elective group had significantly higher attitude scores than the comparison group indicating more positive attitudes toward care of the dying. The findings suggest an effect of elective group participation on attitudes toward care of the dying.

Attitudes encompass affective qualities, often difficult to define and measure (Neumann & Forsyth, 2008; Miller, 2010). Therefore, focus groups were conducted to obtain qualitative data representing participant experiences with EOL and associated beliefs, feelings, and values about care. Analyses of the data provided further assessment of differences between the two groups in attitudes toward EOL care based on personal experience with dying families and/or patients.

Qualitative data from the elective group revealed positive affective responses, thoughts, and motivations for improving EOLC. Relative to previous misconceptions and apprehensions toward EOL care, participants were reassured about communicating with someone dying. They were relieved of unfounded fears of feeling awkward in conversation, saying something that might make a patient feel worse, or not knowing what to say to comfort a patient. The elective group expressed more positive affective qualities about EOLC than the comparison group.

Overall, the elective group expressed an optimistic attitude toward EOLC that reflected their relief, certainty, and appreciation for facilitating a good death and preventing a bad death.
The ideas repeated from narratives included relief, satisfaction, comfort, and appreciation. They described encounters with dying patients and family members with a sense of relief of anticipated fears and gratification from the comforting aspects of EOLC provided by simple acts. Strong negative emotions such as sadness, grief, and frustration were associated not only with the natural losses at EOL, but also with instances of disregard for the care or well-being of dying individuals and their family members. Attitudes from a nursing perspective ranged from a sense of relief about the expectations of comforting dying people to a sense of commitment to improve EOLC for dying people.

Elective participants were happy and gratified to know that people can die a good death without pain and suffering. Greta (EFG2) personally experienced a good death with her grandfather. However, most participants described aspects of a “good death” based on their experiences with hospice patients. From participant descriptions of patients, most were not crying in pain or expressing symptoms of suffering. Many were alert during visits. All patients were oriented enough to converse with or at least recognize the students who served as hospice volunteers. Contrary to previous fears anticipated about forming a close relationship with someone dying, the majority of participants enjoyed getting to know a dying patient better. They described their relationships as “cherished, a privilege, an honor, or meaningful.” Participants were happy to learn that dying patients were comforted by and appreciative of their company, which was the most gratifying part of the experience for participants.

Participants developed a greater appreciation for the dying because of meaningful relationships. Some felt privileged and honored to be present with patients or a family member to witness a patient’s death. Some felt that death was a sad but meaningful event. One participant expressed a sense of peace from the belief in a better place after death because of her
initial experience seeing a bad death. Many felt more comfortable having a better knowledge about EOL and talking about EOL. Several gained more respect for the dying person as unique in his or her past roles. All participants viewed family members as parts of the dying person and equally important in EOLC.

The elective group’s overall perception of EOLC reflected several assurances about their abilities that were gained from facing dying patients. They expressed more comfort by demonstrating the ability to communicating with dying people. They felt relieved of unfounded fears and hopeful about the possibility of a good death. Many expressed greater appreciation and respect for dying patients, the importance of family members at EOL, and a commitment to facilitating a good death at EOL. Participants manifested these beliefs by strong emotions of anger, frustration, and disapproval toward health care providers who disregarded a patient’s or family member’s concerns about EOLC or insensitive care toward dying patients.

In contrast, qualitative data from the comparison group reflected more discomfort with EOL and care of the dying because of the perceived lack of knowledge and experience with death and dying people or patients. Most participants felt apprehensive or inadequate to recognize symptoms of EOL or educate families about EOL. All participants felt uneasy about what to say to comfort grieving family members. Some participants felt that their attitude toward EOLC could be described as “avoidant” because they did not “really think about it much” or have any experience with EOLC.

Comparison group participants without personal or clinical EOLC experience expressed more anxiety in general. They did not know how they would react emotionally in an EOL situation involving patient care. With a few exceptions, participants talked very little about comforting a patient and/or family member at EOL. However, all participants expressed the
 KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING

expectation of nurses to comfort at EOL and a consensus about comfort as a priority for patients at EOL. Participants described comforting aspects about EOL. However, because of their uncertainty with what to expect at EOL and what to anticipate in EOLC, the idea of a “good death” was not mentioned. They were unsure about their skills and knowledge as nurses to provide physical and emotional comfort at EOL. Not all participants were aware of palliative care as a broader approach to EOLC, which included care of the family.

The qualitative data revealed an underlying thread of apprehension about providing EOLC due to lack of experience with dying patients. Uneasiness with EOLC was a repeated theme by all participants, even by those who had clinical EOLC experience in practicum daily. Participants who had no EOL experience personally or clinically considered an “educative knowledge” of EOLC from classroom content as having little impact on their perception of providing EOLC as a nurse. For these participants, just talking about death and dying seemed to be comforting because they rarely heard about the topics.

Other repeated ideas included: a patient’s freedom to choose how to end unbearable pain and suffering at EOL, shock or distress of seeing EOL symptoms, uneasiness about talking to family members after a death, uncertainty about normal or abnormal symptoms, how to educate families about physical deterioration, lack of EOL experience, fears of unknown emotional reactions to EOL or death, injustice of allowing someone to experience pain at EOL in an acute care setting, and finally, distress from lack of control over the timing of death. These ideas and emotions conveyed a different impression of EOLC than the elective group.

There were some positive emotions described from comparison participants. Many were from those who had positive experiences from seeing EOL care of close family members that had died or from EOLC experience in clinical. The positive emotions included: comfort from
providing physical or emotional comfort to a patient or family member at EOL, relief from the fear of a dead body, comfort from learning about EOLC from various sources, comfort from learning more facts about physical signs and symptoms of EOL, and comfort from talking more about death and dying.

The comparison group’s overall impression of EOLC was uncertainty and apprehension. Lack of experience or discussion about death and dying seemed to compound fears of the unknowns at EOL. Their experience with EOL and EOLC limited their expectations of EOLC. However, awareness of their lack of knowledge and experience with EOL seemed to make them more open to learning about EOL and EOLC.
Chapter V

Conclusions and Recommendations

Study Overview

The purpose of this mixed methods comparison study was to assess Bachelor of Science in Nursing (BSN) students’ knowledge and attitudes toward care of the dying, two factors associated with avoiding end-of-life-care (EOLC). A convenience sample of students were assessed from one nursing program that offered a Palliative and End-of-life (EOL) course as an elective. Participants from the palliative and EOL course volunteered as the “elective group.” Participants from the Senior Practicum course volunteered as the “comparison group.” Before and after each respective course, quantitative measures of knowledge and attitudes toward care of the dying were obtained and analyzed for changes within each group and then compared between groups. Toward the end of each respective course, focus groups with each group were conducted for qualitative data to further explore student beliefs, values, emotions, and behaviors reflecting attitudes specifically related to EOL and/or care of the dying.

Bandura’s (1989, 1999) social cognitive theory of learning guided this study. Tenets of the theory specifically address human learning under difficult circumstances by increased exposure to difficult circumstances similar to the originally feared circumstance. Attitudes are often expressed through behaviors and encompass beliefs, values, and emotions, which correspond to social, cognitive, affective, and behavioral dimensions of human learning addressed by the theory. Under naturally occurring or imposed difficult circumstances, learning requires a strong or resilient sense of self-efficacy and self-appraisal to persevere, which can be developed in learners. Care of the dying is difficult for nursing students, due to knowledge and attitudes, which EOLC requires. Therefore, quantitative and qualitative data were obtained to
identify learning in various domains to examine relationships proposed by the theory among students exposed to dying patients.

The theory was a good fit for studying participants in the “elective” group who were exposed to dying patients in a hospice setting. The elective included didactic and experiential instruction in class with content from one module of the End-of-Life Nursing Education Consortium (ELNEC) curricula each week. Students also spent 10 hours as hospice volunteers “being with” dying patients in two-hour intervals without providing physical patient care.

Although an elective course was required of all students, the Palliative and EOL course was one of several electives students could choose from, and therefore optional. Participants designated as the “comparison” group were enrolled in the required senior practicum course of a program with integrated EOL content. As seniors who completed all courses of the program, participants from the comparison group represented learning from an integrated format of EOL education.

The practicum course required 172 hours of direct patient care in one of various clinical sites, and therefore subject to varying opportunities for experience with dying patients. As characteristic of clinical courses during nursing school, experience with dying patients is unpredictable and not guaranteed. Therefore, students may or may not have experienced a dying patient in clinical prior to or during participation in the study.

Along with demographic data, quantitative measures were obtained for knowledge, attitudes, and total amount of EOL care in hours from personal and educational experience. Knowledge and attitudes were measured using the Palliative Care Quiz for Nurses (PCQN) instrument and the Frommelt Attitude Toward Care of the Dying (FATCOD) scale respectively. The 20-item PCQN provided a raw score representing basic EOL and palliative care knowledge that would be expected of new graduate nurses. The FATCOD provided a total score
encompassing feelings, thoughts, attitudes, and comfort levels with nursing care of the dying. Higher scores indicated more positive attitudes toward care of the dying. Questions included on a demographic sheet assessed previous EOL education, if a participant recalled EOL education in other courses during nursing school, and whether or not a participant had previously taken the palliative and EOL elective.

Qualitative data were obtained through audio-recorded focus groups. Benner’s (1994) methods of interpretive phenomenology (IP) were used for analyzing data specific to nursing care to understand how nursing students acquired nursing knowledge related to EOLC. Data analysis and findings were presented in Chapter Four to answer each research question underlying the study.

This chapter presents conclusions based on findings presented in Chapter Four. Conclusions were interpreted considering the different dimensions of learning addressed by social cognitive theory with consideration of the methodology, and findings from the literature about students’ knowledge and attitudes toward EOLC. The theoretic framework is described first to understand conclusions drawn on individual manifestations of self-efficacy within the social, cognitive, affective, and behavioral domains. The methodology is then explained to preface conclusions specific to each research question with corresponding implications. Final conclusions of the entire study regarding nursing student knowledge and attitudes are then listed with specific recommendations for education, practice, and future research before ending with a chapter summary.

Theoretic Framework

The social cognitive theory of learning was a good fit for understanding factors influencing students’ knowledge and attitudes regarding EOL as a difficult situation in nursing
school. The theory incorporates social, cognitive, affective, and behavioral dimensions of human learning in a holistic way that includes the influence of specific environments on individual feelings, thoughts, beliefs, and values to affect behaviors through the tenets of self-efficacy and self-appraisal. Social cognitive theory promotes developing a “resilient” or strong sense of self-efficacy and self-appraisal to persevere through difficulties in life. Strong self-efficacy beliefs from self-appraisal of performance consistently influence the likelihood of continuing the performance despite obstacles to achieve goals under unpredictable circumstances inherent in life (Bandura, 1986, 1989, 1999).

Bandura (1986, 1999) considered the social, cognitive, affective, and behavioral dimensions of human learning as inseparable influences on self-efficacy and self-appraisal, especially for learning intentional behaviors to achieve a valuable goal. Care of the dying is a difficult circumstance because of the universal effect of impending death on physical, social, cognitive, emotional, spiritual, and behavioral dimensions of human life. The holistic approach of nursing care and the nurse-patient relationship make nursing students susceptible to being affected in all dimensions of learning to care for patients (Ballesteros et al., 2014; King-Okoye & Arber, 2014).

Bandura (1999) considered the learner’s engagement within a specific environment as part of the social aspect of learning. Learning environments that provide students with accurate feedback in all learning domains enhance their resilience to persevere in various difficult circumstances. For this study, different amounts of EOL education and experience with dying patients between participants in the elective and comparison group made SCT a viable framework for examining influences of imposed environments on student knowledge and attitudes under different circumstances.
Review of the literature revealed that bereaved families rank psychosocial and emotional support very highly, yet provided the least by health care providers at EOL (Brazil et al., 2013; Burge et al, 2014; Shiozaki et al., 2005). Despite the holistic focus of nursing education, literature on students revealed an inability to cope with very stressful emotions at EOL as a major reason for feeling unprepared to face dying patients (Ek et al., 2014; King-Okoye & Arber, 2014). Inconsistent EOL education and experience during nursing education were implicated from the literature as gaps related to student skills with providing EOLC, particularly psychosocial comfort (Gillan et al., 2013, Gillan, Jeong, & van der Riet, 2014b; Lockard, 1989; Mallory, 2003). These gaps in the literature between EOL education and nursing student abilities to cope with emotions specifically at EOL were explored through the framework of SCT among students with different levels of exposure to EOL education and experience with EOL.

The mechanism of self-efficacy and self-appraisal. The mechanism that builds self-efficacy depends on the learner’s efforts within the difficult circumstance and subsequent feedback for re-adjusting his or her efforts relative to the desired outcome. Feedback affirming which of the learner’s efforts are related to the desired outcome results in a positive self-appraisal. Study findings about student knowledge and attitudes toward EOLC were interpreted in view of these tenets of self-efficacy and self-appraisal to influence learning and future behaviors regarding EOLC. Under the assumption of nursing students as adult learners, or active agents capable of choosing courses of action toward valued goals, study findings indicated attitudes to affirm what Bandura (1999) noted regarding active agents in learning:

People anticipate the likely consequences of prospective actions. They set goals for themselves and they plan courses of action that are likely to produce desired outcomes and avoid detrimental ones . . . . They do things that give them satisfaction and a sense of
self-worth, and refrain from actions that evoke self-censure. *The relative strength of external and self-sanctions shape what courses of action are pursued.* (p. 27). [Italics added]

Feedback on the learner’s effort is important for the mechanisms of self-efficacy and self-appraisal to project the degree learners persevere in performing specific skills under difficult circumstances. The terms “weak efficacy” and “inefficacy” within SCT refer to the learner’s beliefs about capabilities based on their efforts relative to the desired outcome. Bandura (2012) emphasized “situational constraints” within difficult circumstances of the environment that could lead to poor or faulty self-appraisal of capabilities. In environments that require numerous activities within several learning domains, students may have difficulty knowing which efforts correspond to capabilities specific for outcomes within a certain domain. Such constraints within the environment “distort the relation between self-belief of capability and action” (Bandura, 2012) rather than lack of knowledge or capability. Often a mismatch between effort and the proper learning domain leads to a poor self-appraisal of capabilities. For less tangible outcomes of learning such as emotional responses specific to the affective domain, feedback about capabilities is crucial to self-appraisal and self-efficacy.

Findings from this study affirmed the influence of the environment on self-efficacy beliefs specific to EOLC. Poor-self appraisals were influenced by environments in which some students experienced care of the dying. Given the focus of clinical practicum for learning numerous roles of the professional nurse as care provider, communicator, teacher, leader, and manager of care for individual clients and groups of clients, participants in the comparison group received less feedback from either patients, families, or preceptors on behaviors specific to comforting patients and families at EOL. One comparison participant without previous EOL
experience personally or during nursing school had only one opportunity to provide EOL care in an ICU during clinical practicum. As the first and only EOL experience during her nursing education, she saw her patient die and immediately provided post-mortem care as expected for the intensive care practice setting. Because of that one EOL experience, she preferred to “avoid” thinking about EOLC. This example reflected a situational constraint specific to the acute care environment that influenced the student’s self-appraisal of providing EOLC. As predicted by SCT, efficacy-beliefs about capabilities were distorted by the learning environment.

Some participants in the elective group had no previous EOL experience. As projected by SCT however, increased exposure to dying patients provided elective participants with opportunities to identify and work on their weaknesses within the affective domain. Increased exposure to an environment specific for learning about the affective domain required participants to either 1) manage their emotional weaknesses and/or, 2) become less threatened as perceived weaknesses diminished, thus building their self-efficacy to face a similar situation in the future. Findings revealed that elective participant fears about the dying diminished. As a result, they were relieved, gratified, and happy to learn how to comfort the dying based on feedback from comforted patients and family members at EOL, which lead to positive self-appraisals of their abilities to provide psychosocial care in the future.

Some participants in the comparison group had no previous EOL experience nor EOLC opportunities within the clinical practicum. None of the participants had taken the EOL elective due to scheduling conflicts or by choice. Regardless of the reason, all participants expressed a desire to gain more EOL education and experience with care of the dying to provide EOLC. According to Bandura (2012), accurate self-efficacy relies on beliefs in one’s capabilities to produce a desired outcome. Statements of positive intentions or desires to provide EOLC do not
affect self-efficacy with actual performance providing EOLC.

**Methodology.** Given postulates that cognitive, social, affective, and behavioral dimensions influence learning, including the learner's interaction within the environment, mixed methods were necessary for obtaining data reflecting cognitive, social, affective, and behavioral domains of learning specific to EOLC within different learning environments. The literature reports lack of knowledge about EOL as a major factor attributed to apprehension and fears about EOLC, therefore the PCQN instrument containing basic knowledge of palliative care served as an objective measure for the cognitive domain of learning on the same content among nursing students from two separate courses. The FATCOD instrument assessed various qualities of attitude using EOL scenarios to evoke emotional responses, which students numerically rated for an overall score reflecting the degree of their attitudes toward care of the dying. Objective instruments were practical for assessing the cognitive domain of learning, as a common method for assessing acquisition of specific content (Foss & Ellefsen, 2002).

Qualitative data were needed to examine the different dimensions involved in attitudes. Focus groups provided qualitative data revealing more insight into individual and group manifestations of social, cognitive, affective, and behavioral learning specific to EOLC reflecting all the dimensions of attitude. Focus groups provided subjective data of student experiences in different environments evoking affective responses at EOL. Interpretation of findings in view of SCT revealed more about how students defined “EOL knowledge” and the emotions, beliefs, values, and behaviors reflecting their attitudes about EOL and EOLC based on real patient experiences within the context of nursing education.

The research questions were designed for practical purposes of examining knowledge and attitudes among nursing students within different health care environments. Quantitative and
qualitative data were obtained separately as practical and feasible methods supported in the literature for examining knowledge and attitudes within students’ natural learning environment in preparation as nurses (Ballesteros et al., 2014; Bassah et al., 2014; Fluharty et al., 2012). The research questions were designed to separate quantifiable data from more subjective data on individual feelings, beliefs, values, and behaviors specific to EOLC and to minimize participant burden during data collection. The questions were specific for assessing the cognitive and affective learning domains specific to EOLC among students given different educational formats and degrees of exposure to dying patients. Therefore, conclusions and corresponding implications are presented specifically addressing each research question since findings were specific for knowledge and attitudes respective of the different courses and EOL experiences of students within each group. In view of all conclusions and implications addressing student knowledge and attitudes within the two different courses, final conclusions of the entire study are listed with recommendations for education, practice, and research provided before the chapter summary.

**Conclusions to Research Questions**

**Question one.** To what extent does participation in structured EOL education based on the ELNEC curriculum and planned experiences “being with” dying patients affect students’ knowledge and attitudes toward EOL care?

**Knowledge.** High knowledge scores by the elective group at pretest and at posttest did not change significantly, which reflected limited ability of the PCQN instrument to detect additional knowledge learned beyond the very basic content on the 20-item instrument. For example, the PCQN contained only three items to assess the psychosocial dimension of EOLC, yet qualitative data revealed learning about various psychosocial aspects of EOLC such as
responding to patients and families. Therefore, the PCQN was limited in reflecting increased knowledge in various other areas of the psychosocial dimension. Elective participants also learned about changes in physical, social, and cognitive responses in dying patients, which were not reflected on any items of the PCQN. Therefore, a generalized score on the PCQN was unreliable for determining changes in student knowledge within this group of BSN students. For participants in the elective group who had never seen a dying patient in the context as a care provider, qualitative data revealed cognitive learning of more foundational content. Scores on the PCQN instrument were unreliable as true indicators of student EOL knowledge sought in this study.

Students who chose to take the EOL elective may have reflected a high sense of self-efficacy to provide EOLC affirming the theoretic framework, which predicts that individuals with a strong self-efficacy for a certain area will choose courses of action related to that area. High scores on the instruments to measure EOL knowledge may have reflected the fact that within the elective group was an Associate Degree nurse (ADN) with prior EOLC experience and several other participants with personal EOL experience with dying patients and families. Therefore, selection bias may have confounded a true effect of EOL education and 10 hours of experience as a separate course for improving EOL knowledge.

Failure to demonstrate changes in knowledge scores at posttest may have indicated the limited learning about treatments and medications for symptoms at EOL since students were not allowed to provide physical care. Lack of providing physical care may have prevented students from learning about symptom management, thereby affecting knowledge of symptom management addressed by the instrument. Although knowledge scores were relatively high, findings from this study support the literature revealing that providing psychosocial care remains...
a greater challenge for students than providing technical or physical care at EOL (Ballesteros et al., 2014; King-Okoye & Arber, 2014). Qualitative findings from this study revealed that lack of basic knowledge about physical symptoms and the emotional responses at EOL seemed to make them feel more apprehensive about EOLC rather than lack of knowledge about more specific palliative care treatments at EOL. The literature reveals that dying patients and family members value physical comfort and information about a terminal condition, but noted that nurses “being with” the patient and/or family members stood out as the most helpful service provided before death (Clukey, 2007).

**Attitudes.** Participation in the elective course did not reflect a significant change in attitude as quantitatively assessed in several dimensions by the FATCOD at posttest. This finding was contrary to several reports from the literature. As an indicator of personal beliefs, values, and behaviors expressed toward care of the dying, authors have consistently reported an improved FATCOD scores after participation in EOL education (Dobbins, 2011; Frommelt, 2003; Kwekkeboom et al., 2005; Mallory, 2003). However, attitude was relatively high at pretest due to characteristics of the individuals in the group and their background experiences. A statistically higher attitude score by the elective group than the comparison group at pretest may have indicated the preexisting selection bias or interest by participants due to past personal experience. Although an elective course was mandatory for all students, different choices of electives were offered in the program to meet the requirement. Therefore, students with a proclivity toward EOLC from personal experience or education may have chosen the EOL elective, which may explain their higher attitude scores at pretest.

A high attitude score at pretest and posttest may also indicate a ceiling effect of the instrument reflecting less sensitivity for detecting smaller changes, a finding that converges with
Weismann (2011) who reported no changes in FATCOD scores after EOL education among Associate Degree nursing students. Weissman (2011) attributed high pretest attitude scores in both groups to prior nursing experience. The ADN participant in the elective group with prior hospice care experience most likely reached the instrument ceiling affecting results for the group.

**Implications.** Relying strictly on objective measures to judge student learning about EOLC diminishes the influence of other types of learning and knowledge, which is more difficult to quantify, but important at EOL such as compassion and empathy. Qualities of emotional responses and understandings indicate the affective domain of learning better revealed from qualitative findings. The National Quality Forum [NQF] (2014) sets priorities for health care performance measures based on feedback from patient and family members who value psychosocial qualities demonstrated by care providers at EOL. Affective skills such as empathizing or feeling compassion are more difficult to measure or quantify given the subjective nature of such constructs.

Quantitative findings implicate little progress toward improving EOLC skills by health care providers at large, or outside the confines of hospice for providing palliative care. Lack of measurable evidence by instrument scores may falsely justify EOL education as an optional elective in nursing education. The optional elective status may convey an optional value placed on EOL care, particularly affective skills needed for demonstrating “humane physical and emotional care,” or “the caring that helps people to live well while dying.” These were reasons recognized respectively by the American Association of Colleges of Nursing [AACN] in 1998 (2015) and the Institution of Medicine [IOM] in 1997 (2015) as justification for increasing EOL education within professional health curricula. Although highly valued, compassion and emotional care are more difficult to measure. Quantitative instruments did not reflect
improvements in student learning for such affective skills explicitly indicated by ‘emotional care’ and care to help dying people live well.

Research assessing the effectiveness of optional EOL education does not reflect true measures of improved knowledge due to confounding influences of self-selection or factors that prevent students from participating in EOL education. Findings from this study revealed that most participants from the elective group had previous EOL experience and one had prior hospice care experience. Findings also revealed that participants from the comparison group were unable to take the EOL elective course due to lack of time in their class schedule. For participants who had time in their class schedule, the EOL elective course was unavailable due to the limited number of students who could enroll in the course each semester. Such factors confound true results of learning about EOLC by nursing students who lack EOL knowledge, experience, and skills that predict further avoidance to provide EOLC. Given natural human responses of fear and sadness toward death and dying, traditional nursing students who are much younger in age and life experience will likely forego a course about care of the dying if given the choice. This notion is supported in the literature (Todaro-Franceschi, 2011).

**Question two.** To what extent does 172 hours of clinical experience without a didactic EOL component or ELNEC content affect students’ knowledge and attitudes toward EOL care?

**Knowledge.** Findings from the comparison group revealed no significant changes in knowledge, which supports previous findings of nursing student knowledge between an intervention and a control group enrolled in nursing programs without EOL content in the curriculum (Kwekkeboom et al., 2005, 2006; Dobbins, 2011; Frommelt, 2003; Hwang et al., 2005; Mallory, 2003). This study however, included findings from a comparison group of participants enrolled in a program with integrated EOL content. Participants recalled learning
about EOLC from their required nursing courses. With EOL care learned in context of other
nursing courses, students perhaps were not aware of concepts as exclusive to palliative care.
Comparison participants were knowledgeable about nursing care and different aspects about
EOL. However, the integrated format did not provide enough education about EOL nursing care
specific enough to recognize on the PCQN instrument.

Given the expectation of students to gain EOL knowledge and experience from clinical
practice, 172 hours of patient care experience in an acute care setting was not enough practice
specific to EOLC for most participants to recognize common symptoms at EOL or diminish their
apprehension toward providing EOLC. Regardless of the amount of experience with dying
patients reported by comparison participants, lack of improvement on knowledge scores
indicated the generalized lack of exposure to palliative care principles or practice as described by
the instrument. Nor did the instrument reflect student learning in other areas about EOL such as
the physical body after death, which affected students differently.

*Attitudes.* Completing 172 hours of direct patient care with integrated EOL content in
the nursing program did not affect attitudes toward EOLC as measured by the FATCOD scale.
Attitudes include behaviors that reflect thoughts, emotions, and beliefs. Quantitative measures
were unable to detect positive or negative changes in attitude as a result of specific EOL
experiences not included on the FATCOD instrument. For example, handling of a dead body
was a positive experience for a participant on an oncology unit with a supportive patient care
technician who guided her through the process. In contrast, another participant provided post-
mortem care after the death of her patient in the ICU during practicum. The participant had no
previous experiences with EOL or EOLC and expressed “shock” from her first and only EOL
experience during practicum. It affected her attitude toward care of the dying, which she described as “avoidant.”

Experience with dying patients was inconsistent for participants in the comparison group, which weakened the validity of measures for attitude towards care of the dying. For the majority of participants who had no EOLC experience during practicum, their attitudes as measured by the FATCOD were based on conjecture rather than actual experience in context as a nursing student. Their attitudes were likely based on experience from a personal loss in the past and influenced by lack of experiential knowledge of providing EOLC as a student. Authors have noted the weaknesses of self-report measures for attitudes toward care of the dying, but few have suggested the type or amount of actual EOL experience as a factor needing further research (Ballesteros et al., 2014; Bush et al, 2013). The FATCOD did not reflect differences in attitude between groups despite specific experiences that may have profoundly influenced student attitudes overall.

**Implication.** Attitudes of participants within the comparison group represented the integrated format of EOL education, which is the most common way students receive EOL education in the U.S. (Dickinson et al., 2008; Todaro-Franceschi & Lobelo, 2014). Findings from this study indicated that varied amounts of clinical experience with dying patients during nursing education, including 172 hours of clinical practicum in an acute care setting, were insufficient for affirming students’ knowledge of nursing skills specific to EOLC. Although two participants from the comparison group provided EOLC during practicum, they lacked enough feedback about their performance to judge their capabilities. Education about EOLC without exposure to dying patients in practice was not sufficient for participants to feel confident providing effective EOLC. Participants considered clinical application of EOLC content as a
condition of feeling “knowledgeable” about care of the dying. Feedback on performance with EOLC in practicum was also considered necessary “knowledge” about providing EOLC. In the acute care setting, students engaged in multiple domains of learning with immediate feedback on performance of numerous tasks. However, there were fewer opportunities to focus on affective skills or the necessary feedback for a positive self-appraisal of abilities to provide psychosocial care at EOL.

Designating 172 hours of clinical care experience within an acute care setting as the primary source for learning about patient care practice before graduation does not support a holistic nursing education that benefits one of the most vulnerable populations in all areas of nursing care, the dying. Findings from this study revealed varied experiences with dying patients in an acute care setting and no guarantees of having supportive staff to provide feedback for students during EOL situations. Nursing students need more experience providing comfort to dying patients through an interdisciplinary approach to EOLC for balancing the acute care focus of an inpatient setting, which is where the majority of nursing graduates will be employed after graduation (U.S. Department of Health and Human Services, [USDHHS], 2010). To develop skills and attitudes reflecting holistic values of the nursing discipline that benefit dying patients, students need to experience the care of dying patients. With little or no exposure to the interdisciplinary approach as a paradigm of EOLC, nursing graduates may not reflect care of the dying as prescribed by the American Nurses Association’s (ANA, 2015) Code of Ethics for Nurses, to “have invaluable experience, knowledge, and insight into effective and compassionate care at the end of life” [Italics added] (Provision 1, p.3).
Question three. Is there a difference in knowledge and attitudes toward EOL care between the elective group and the comparison group?

Knowledge between groups. Despite significantly greater EOL education and experience by the elective group than the comparison group at posttest, there were no differences in knowledge scores between groups as assessed by the PCQN instrument. Quantitative scores indicated limitations of the PCQN to assess knowledge beyond basic content on the instrument, as the ceiling or end-point on the amount of knowledge learned. Given the narrow scope of 20-items for assessing various dimension of EOL knowledge, the instrument failed to detect a difference between the two groups. Overall scores on the PCQN were unreliable for examining true differences between the groups in knowledge learned about EOLC.

An increase in knowledge scores on the PCQN within the comparison group at posttest reflected some degree of learning specific to palliative care. Although not a statistical improvement in knowledge overall, the increase was enough to eliminate a significant difference from the elective group revealed by pretest scores. However, PCQN scores did not indicate which types of knowledge improved since results were not analyzed by individual instrument item or by participant. Although not the purpose of this study, previous reports of improvements in knowledge were based on individual items answered correctly on the PCQN instrument. Arber (2001) reported improved knowledge based on the percentage of students who gave the correct answer for each item at posttest as compared to their answer at pretest.

The purpose of this study was for examining knowledge influencing students’ apprehension about EOLC. Mean scores for knowledge were analyzed within each group and between the two groups of students having different experiences with EOL education and dying patients. In this study, there were no significant changes within groups or between groups on
knowledge as measured by the PCQN. The instrument was limited to 20 items for measuring basic knowledge of a broad topic with learning in multiple domains. The PCQN was not helpful for indicating the type of knowledge contributing to student apprehensions about EOLC that were revealed in subsequent qualitative data.

**Attitude between groups.** A significantly higher or more positive attitude as measured by the FATCOD in the elective group than the comparison group at pretest and at posttest may have reflected self-selection bias. Although elective group participants had significantly greater amounts of EOL education and experience with dying patients than the comparison group, FATCOD scores within the elective group remained unchanged. This finding may reflect a possible ceiling effect of the instrument for detecting participants with attitudes greater than what the instrument could measure. Elective participants, who were all junior nursing students, had more positive attitudes toward care of the dying than senior nursing students in the comparison group. This finding supports a similar report by Mutto et al., (2010), of first and second year nursing students with more positive attitudes compared to fifth year (senior) nursing students in a program without EOL specific content in the nursing curriculum. Despite more clinical experience with terminally ill patients by fifth year nursing students, they were less comfortable with dying patients and considered EOLC less gratifying than first and second year students. Study authors concluded that without any EOL specific content provided in the program, more contact with dying patients and increased nursing care responsibilities by the last year of nursing school resulted in greater apprehension about care of the dying.

Findings from this study indicated relatively more exposure to dying patients by the senior year for some participants in the comparison group. However, all participants heard EOL content integrated throughout the nursing curriculum. Despite knowledge of EOLC and more
exposure to dying patients by the senior year for some participants, students’ overall attitude remained unchanged and were significantly lower or more negative than attitudes of participants from the elective group, all of whom were junior nursing students. Findings from this study failed to show the influence, if any, of integrated EOL content on the attitudes of participants in the comparison group despite more exposure to dying patients by the senior year.

Previous authors have reported equal attitudes at pretest between participants at the same grade level of nursing school (Mallory et al., 2008). As reported earlier, only Weisman (2011) reported unchanged attitudes at posttest among ADN participants due to previous nursing care experience.

**Implications.** Providing EOL education as an elective during nursing school does not assure that all nursing students will be able to provide quality EOL care as nurses. End-of-life education that is optional allows students to avoid the subject of EOL and specific content related to providing EOLC. Findings from this study indicated that students from both groups who had no EOLC experience were afraid to provide care to the dying, particularly psychosocial care. Based on the self-efficacy tenet, avoidance impedes developing the self-efficacy needed to provide psychosocial care, the most difficult aspect of EOLC for students and nurses (Arantzamendi et al., 2014; Ballesteros et al., 2014).

Allowing students to avoid their personal fears of the unknown related to EOL may further impede student learning and professional development. Findings from both groups indicated that nursing students needed to identify and deal with their own emotions and attitudes about death or dying before they could be sensitive to the needs of patients. The literature reports personal and professional growth by nurses and nursing students who dealt with their fears of death and dying by engaging mentally and emotionally with dying patients (Bailey 2011;
Ballesteros et al., 2013; Muñoz-Pinot, 2014). Findings from the elective group indicated that through self-reflection of their experiences with the dying, participants realized that dealing with personal fears allowed them to focus more on patients and family members. In contrast, participants from the comparison group who reported greater than ten hours caring for dying patients during practicum felt that they did not receive enough feedback or experience with EOLC. The acute care focus of the environment indicated a lack of time needed for students to reflect on their own performance and emotions specific to EOL.

Although most comparison participants knew about EOLC from various nursing courses, they felt apprehensive or avoidant toward care of the dying. They were especially uncomfortable about providing psychosocial comfort, indicating the need for affective skills. Affective skills are applicable for many difficult circumstances nurses must manage, and extremely important for students to develop. The amount of knowledge or experience with dying patients by participants in the comparison group was ineffective in changing their knowledge or attitudes toward care of the dying, particularly in dealing with their own emotions and those expressed by families at EOL.

With palliative care extending to patients with incurable and chronic conditions, earlier recognition of signs and symptoms indicating a downhill trajectory are important when conditions become life-threatening. Knowledge of physical, cognitive, and psychosocial parameters at EOL are necessary for understanding palliative concepts of care and recognizing when such care is warranted (Meier, 2011). Quantitative assessments used in this study however, did not indicate the fundamental knowledge students lacked about physical, cognitive, and psychosocial processes at EOL. Although the PCQN instrument represents basic knowledge of palliative care concepts, it may not be the answer for assessing knowledge students need in
order to understand palliative care or feel more comfortable about EOLC. Participants lacked basic knowledge of physical signs and symptoms indicating decline at EOL.

**Question four.** From focus group discussions, what attitudes, beliefs, values, and emotions about EOL care did students from the elective group express?

**Elective group attitudes.** As a result of participation in the EOL elective, major themes and subthemes from the elective group reflected positive beliefs, values, behaviors, and positive impressions about comfort at EOL. After spending more time with dying patients and family members getting to know them personally, elective participants were less apprehensive about EOLC than they anticipated. Their attitudes conveyed positive emotions, which resulted in changes in beliefs and thoughts about a “good death.” Comfort as a major theme described positive feelings of relief from fears concerning EOL, which in turn made participants more comfortable being with dying patients. Fears of the emotional responses by dying patients and families diminished over 10 hours of being with and interacting with them. Due to past personal losses, participants learned to identify with patients and family members to develop empathy, a manifestation of affective learning. Emotions also reflected cognitive learning of what to expect at EOL such as the physical, cognitive, and social changes at EOL. As a result of knowing what to expect to see in someone dying, participants felt “relieved” about the prospect of facing dying patients again and more capable of providing psychosocial comfort.

Comforting emotions revealed significant experiences that influenced cognitive learning leading to behavioral changes in communication. The level of difficulty of a behavior was less significant with feedback provided by patients and family members about feeling comforted as a result of efforts participants made to comfort them. Patient and family responses were significant for influencing students’ judgments of their abilities to provide psychosocial comfort.
Until patients and family members provided feedback, participants were unaware of the effect of their acts of *listening, smiling, causing a patient to smile, engaging in conversation, and being present* as comforting to patients and families at EOL. The positive feedback affirmed student abilities to comfort and communicate at EOL, which resulted in positive feelings of relief, gratification, happiness, and privilege. Participants became comfortable engaging other physical senses through touching, playing familiar music, or strolling with a patient outside. The feedback was a key influence on improving participants’ emotions and subsequent beliefs about providing effective psychosocial care, thus affirming SCT for predicting personal efforts within adequate environments and necessary feedback for learning about their capabilities to comfort at EOL, thereby affirming self-efficacy.

*Discomfort* as a major theme reflected participant beliefs and values regarding poor EOLC. For example, anger reflected beliefs about the injustice of disrespectful and insensitive care or dismissive attitudes toward patients in physical pain at EOL. Anger reflected their values of respect and appreciation in providing EOLC. Although discomforting, *guilt* about wishing for the death of a loved one suffering at EOL contributed to the belief in communication to facilitate a “good” death. Participants recalled decisions made, which resulted in long suffering of a family member at EOL due to insufficient information or options about comfort provided by health care providers. Discomfort from seeing poor EOLC was also an indicator of what students learned about what did *not* comfort patients at EOL.

The hospice experience fostered development of affective EOL skills. The major theme of *meaningful relationship* reflected important beliefs about knowing someone in a personal way as pertinent to caring for someone at EOL, whether a family member or a patient. Participants realized how meaningful qualities experienced with a loved one at EOL were somewhat similar
in experiences with hospice patients, which improved students’ sensitivity to emotions important for empathizing at EOL. Getting to know a dying patient seemed to help participants view sad emotions and comforting acts as more meaningful in the context of a personal relationship. Positive self-efficacy for managing the sad emotions at EOL was reflected by a participant’s self-appraisal: “I loved getting to know my patient.”

Overall, comfort was a major theme that characterized participants’ learning from time spent with patients and family members. Feedback from patients and family members at EOL was the most valued source of input influencing positive beliefs about death and EOLC. In learning new skills about EOLC, such feedback provided confirmation about their abilities to provide emotional comfort. This finding affirmed the theoretic relationship between self-efficacy and self-appraisal of abilities to produce a desired outcome. As predicted, exerting personal efforts in specific actions to comfort resulted in positive self-efficacy to produce the desired outcome of comforting patients at EOL. Positive self-appraisals were influenced by the learning environment specific for abilities at EOL and patient feedback from which to judge personal capabilities. Thus, positive feeling states and actions were related subthemes of comfort describing their experience with dying patients and families.

Implications. Knowledge of EOLC was not enough to influence participant attitudes about providing EOLC, it was the addition of time spent with patients and families. Ten hours of time spent with dying patients in short intervals addressed several dimensions of student learning specific to EOLC without the expectation to provide physical nursing care. Experience with dying patients diminished previous fears associated with death and dying and learned behaviors such as avoidance. Changes in emotions and thoughts did not occur in one visit however.
Several visits within a hospice environment allowed for learning to occur in several domains specific to EOL and EOLC that were important for students.

Nursing students as adult learners with backgrounds regarding EOL required more than knowledge provided in class for their reappraisals related to death and dying. Experience with the dying provided sources of feedback in all learning domains to change previous frames of reference that negatively influenced their views of EOLC. Even without providing physical EOLC, students were less apprehensive about providing EOLC in the future due to their immediate fears being diminished or resolved as unfounded. Participants expressed sadness to say ‘good bye' to patients or families along with more optimism about their ability to provide EOLC, especially psychosocial care. The elective group paradigm of EOLC reflected marked changes in their beliefs about EOL and EOLC based on fears of what to expect from patients and of themselves when faced with how to comfort the dying.

Most participants attributed their initial reluctance about providing EOLC to lack of knowledge despite relatively high knowledge scores at pretest. However, qualitative data revealed the types of knowledge that influenced participants' positive attitudes toward EOLC, which quantitative measures failed to detect. High scores on the FATCOD instrument did not seem to predict the impact of personal EOL experience on attitudes in the provision of EOLC. Qualities of their emotions revealed important positive changes in student knowledge, misconceptions, beliefs, values, and behaviors communicating with dying patients and family members at EOL.

**Question Five.** From focus group discussions, what attitudes, beliefs, values, and emotions about EOL care did students from the comparison group express?
Comparison group attitudes. Despite completing 172 hours of clinical practicum experience in various acute care settings, the comparison group reflected weak efficacy in various dimensions of learning specific to EOLC. Personal EOL experience before nursing school influenced beliefs about comfort at EOL, which included the absence of physical and emotional suffering. However, participants were unaware of the interdisciplinary approach of palliative care. Therefore, their efficacy beliefs about providing comprehensive comfort were negatively influenced by a lack of exposure to palliative care practices provided within an acute care environment. Participants in the comparison group needed to see dying patients in comfort and within a comforting environment to know about the alternatives to EOL in an acute care setting.

“Discomfort” was a major theme reflecting participants’ apprehension to provide EOLC without specific knowledge of what to expect physically of patients at EOL or what to do as expected of a nurse. Comparison participants also expressed comfort as a major theme from experiences that were comforting for them or for patients and families at EOL. Participants valued honoring a dying patient’s preferences at EOL, providing meticulous physical care or medications, and supporting family members as priorities of EOLC. However, subthemes related to the nurse’s role revealed essential knowledge participants needed in order to feel comfortable providing those priorities of EOLC such as knowledge about the dying process and further sources of EOL knowledge to learn about care, particularly practical experience with the dying. Due to a personal loss, some comparison participants believed that having a “close relationship” with someone dying might cause more emotional discomfort providing EOLC than having a “detached” relationship as an acquaintance. Participants’ lack of knowledge or
adequate experience for learning to provide EOLC left them more anxious than confident of their skills to care for the dying.

The sporadic experiences with EOL during practicum left students more reluctant about providing EOLC than students in the elective group who did not provide physical care to the dying but spent time being with them as hospice volunteers. The acute care setting provided limited experience with palliative or hospice care. Therefore, participants lacked specific knowledge of what to expect physically or emotionally at EOL. Comforting at EOL was generally focused on the physical dimensions of acute suffering. Their ideas of comforting were limited to administering narcotics, or antibiotics, and physical measures related to repositioning and meticulous hygiene. Only a few participants had positive EOL experiences during clinical practicum, but not enough to improve their overall attitude about EOLC or abilities to care for the dying as expected of a nurse.

Most comparison participants recalled being educated about EOLC, yet lacked knowledge of how to care for dying patients in a real practice environment. Therefore, providing EOLC in context of the nurse’s role evoked distress, especially for participants with their first EOL experience during clinical practicum. The environment influenced their reactions to providing EOLC “unexpectedly” without any previous EOL experience as a care provider. Some participants described an “educative EOLC experience” as having knowledge without practical opportunities for practice. They were naturally more apprehensive in their efficacy beliefs about providing EOLC. Providing physical care at EOL without clinical experience with dying patients had a negative effect on attitudes toward EOLC, which is supported in previous literature on lack of practice (Bassah et al., 2014; Chow et al., 2014; Gillette et al., 2015).
End-of-life care experience during practicum did not inform or assure participants about their abilities to provide EOLC within an acute care environment. Some learned from nurses about EOLC and provided care as directed during practicum, yet felt apprehensive about their own cognitive abilities in knowing what to assess. Students doubted their abilities to recognize symptoms accurately or the effects of dying on family members since they could not interpret family responses to the care they provided. Therefore, they did not know what symptoms to expect or how to support family members accordingly about declining conditions of their dying loved one. Lack of knowledge and exposure to the multidisciplinary approach of EOLC was not improved by providing EOLC during clinical practicum. Lack of feedback on the EOL care that some participants provided during practicum and their misconceptions about the expectation of nurses to provide comprehensive care at EOL were distorted by the environment, which affirmed the theoretic influence of the environment on self-efficacy to provide EOLC.

Implications. Knowledge alone did not affect student attitudes in practice, regardless of the source. These findings converged with previous literature on students’ sources of apprehension toward EOLC (Bassah et al., 2014; Cavaye & Watts, 2010; Charalambous & Kaite, 2013; Gillette et al., 2015). Rather than lack of “knowledge” in the literal sense, participants from this study needed practical experiential “knowledge.” They did not know how to clinically apply knowledge recalled from the classroom. This finding affirmed the theoretic framework emphasizing the influence of the environment for providing a place to learn the skills specific to EOLC.

According to Bandura (2012), “There is a marked difference between possessing knowledge and skills and being able to use them well under diverse circumstances, many of which contain ambiguous, unpredictable, and stressful elements. Self-efficacy plays an
influential role at the operative level” (p. 24). For comparison participants, the EOL knowledge they learned was not useful in the practical sense to provide effective nursing care to patients within the acute care setting of clinical practicum. This finding affirmed the relationship between the learning environment and the learner’s efforts for improving self-efficacy and self-appraisal about EOLC. As projected by SCT, participants relied on feedback to learn about appropriate practices specific to EOLC. Students needed to know if they were performing correctly or needed to adjust their behaviors in order to bring about a desired outcome. Inadequate feedback about effective or ineffective EOLC resulted in doubts about their abilities to care for the dying. Therefore, Bandura (2012) clarified the importance of social conditions of the environment for learning because of the practical knowledge gained from interacting within the environment and the reciprocal effects on learning in all dimensions. There is a difference between possessing knowledge or skills and being able to use them within a difficult circumstance.

Regardless of 172 patient care hours completed, sporadic experience with EOL situations, and the overall focus of the clinical practicum were not advantageous for improving participants’ self-efficacy regarding psychosocial comfort at EOL. With or without EOLC experience, participants were apprehensive about providing psychosocial comfort. Participants did not receive the necessary feedback regarding their performance of psychosocial skills from which to judge or improve their efforts. As a result, comparison participants overall appraised themselves poorly regarding the provision of psychosocial comfort reflecting weak affective learning specific to EOLC. As predicted by SCT, participants could not judge their efforts or abilities for providing EOLC in several domains. Therefore, they were doubtful and more reluctant about their skills to provide EOLC.
Coping with emotions was the most difficult aspect of EOL for nursing students with practicum experience, which supports findings from the literature (Adesina et al., 2014; Ek et al., 2014; Mutto et al., 2010). The theoretic framework supported study findings to explain why at this formative stage of acquiring nursing practice skills, nursing students were more apprehensive about providing emotional care than physical care at EOL. Given immediate feedback from completing physical tasks as more tangible evidence for judging efficacy, students were not apprehensive about the physical care they provided. They struggled more in their abilities to provide emotional support at EOL, which was more difficult to judge without feedback from patients, family members, or the nursing staff during the practicum.

Based on the postulate that self-reflective qualities enable adult learners as active agents to attain goals (Bandura, 1989), 172 hours of patient care in acute care settings seemed to motivate students to obtain greater EOL education and experience. Addressing their fears and questions about EOLC experience during focus groups was constructive in comforting participants who had no experience during practicum. After realizing efficacy weaknesses specific to nursing care of the dying, participants suggested that EOL education and experience be required during nursing school in addition to the practicum. In reflecting about their weaknesses, they believed that EOLC education and experience would have been useful preparation for diminishing their fears of dying and what to expect at EOL prior to caring for someone dying.

**Question six.** Do students who participate in a structured EOL course including 10 hours of experience with dying patients express different attitudes, beliefs, values, and emotions about EOLC from students who do not participate in a structured EOL course but complete in 172 hours of clinical experience?
Discomfort. Discomfort about EOLC as a major theme for both groups was influenced by their respective learning environments. Although participants from both groups expressed some degree of apprehension about EOLC and the emotional aspects of care, participants from the elective group expressed more “relief” of their fears associated with EOL than participants from the comparison group. Elective participants described empathizing instead of fearing emotions expressed by patients and family members. Additional subthemes of comfort by the elective group such as “gratified and privileged,” verified their relief to know that they contributed to patient and family comfort at EOL. In contrast, participants in the comparison group were apprehensive overall about EOLC. Clinical practicum within an acute care setting provided sporadic experience with care of dying patients and family members. They received inadequate feedback on supportive skills at EOL from which to learn. Although some participants received positive feedback from patients, especially to medications administered for pain, it was not enough to influence positive self-appraisals of skills specific to psychosocial comfort of the dying. Regardless of EOLC experience gained, participants from the comparison group were apprehensive about their abilities to provide psychosocial comfort at EOL. No one from the comparison group expressed satisfaction about providing EOLC. Thus, a significant difference between groups was the degree of relief of knowing what to expect of dying patients and how to be supportive of them and their families.

Comfort. Comfort was a major theme for both groups due to feelings and actions related to EOL, but with significant differences between groups in beliefs and behaviors. Elective group participants with and without personal EOL experience before nursing school were “relieved” of many specific fears of the unknowns about death and dying such as physical features, related physical responses, and emotional responses by patients and families. Relief of these fears was
significant for making them feel more comfortable interacting with the dying. *Feeling*
comfortable influenced elective participants to engage in comforting *actions* toward the dying.
As a result, they also realized the value of *meaningful relationship* as a positive feature of EOLC.

This finding illustrated what Bandura (1999) found reliable for predicting actions people would
choose based on learning, “They do things that give them satisfaction and a sense of self-worth,
and refrain from actions that evoke self-censure” (p. 27).

Contrary findings in the comparison group seemed to affirm the opposite. Participants
within the comparison group described fewer positive feelings about EOL or providing EOLC,
regardless of EOL experience before entering nursing school or during clinical practicum. They
expressed valued priorities of EOLC such as absence of suffering according to patients’ wishes,
physical care, and support to family members. However, without EOLC experience, these
priorities seemed abstract to participants who felt incapable of achieving these priorities in a
practical way.

Most participants felt educated about EOLC from various “sources of knowledge.” However, they expressed fears of the unknown about death and dying because they lacked
“essential EOL knowledge” about the physical and psychosocial manifestations of EOL to
comfort patients and families as expected of nurses. Subsequently, comparison participants were
more apprehensive about care of the dying. Students’ attitudes about EOLC were influenced by
interactions within the learning environment. They witnessed less comfort at EOL within an
acute care setting and more comfort at EOL in a hospice setting.

*Beliefs about death.* Experiences within the elective or comparison group resulted in
different student beliefs about death in the context of EOLC. As predicted by Bandura (1999),
what participants learned about EOLC was conditioned by the imposed environments.
Experience with dying patients in a hospice setting diminished many students’ fears about “what to expect” about suffering and comfort at EOL. As a result, elective participants believed in the possibility of providing a “good death.” Experience with dying patients in an acute care setting left students feeling helpless to comfort. Several participants preferred “avoidance” regarding EOLC or even “thinking about it,” which indicated a poor self-appraisal of their abilities to provide EOLC. The idea of a “good death” never occurred to comparison participants as nursing care providers. The difference in beliefs were related to abilities in facilitating a “good” death as care providers. The imposed physical environment influenced self-efficacy as projected by the statement that “the relative strength of external and self-sanctions shape what courses of action are pursued” (Bandura, 1999). This finding is well supported in the literature on the effect of negative emotions predicting negative attitudes toward care of the dying (Charalambous & Kaite, 2013; Cooper & Barnett, 2005; King-Okoye & Arber, 2014; Parry, 2011).

**Value of interpersonal relationship.** Participants within the elective group gained “more respect for dying patients and family members” than they had before by getting to know a dying patient and family members personally. As a result of developing interpersonal relationships with hospice patients, elective participants felt more compassion than fear about communicating with the dying and their family members. In the comparison group however, no one had an opportunity to get to know someone dying personally during the practicum. Thus, participants were unaware of developing interpersonal relationships with the dying as a means of mutual comfort to patients and care providers. Comparison participants were more familiar with feelings of “detachment” toward the dead or dying to “cope with difficult EOL” situations outside of a nursing care role.
**Implications.** Natural fears of the unknown associated with death and dying can be diminished by spending time with dying patients without having to provide physical care. The hospice environment provided multiple sources of information that students wanted to know about dying, suffering, emotional responses by patients and families, the social atmosphere, and their own responses to the dying. Having knowledge of the physical and psychosocial attributes of dying patients relieved a lot of students’ fears about the unknown. With these fears relieved, future experiences with more involvement can be devoted to learning about skills for managing what they know to expect about EOLC. Without prior experience with someone dying, the first encounter with a dying patient with responsibilities to provide nursing care can be very memorable in a positive way or a negative way. All participants needed affirmation of abilities conditioned upon experience seeing a dying patient and knowing what to expect with feedback on their skills and behaviors. Otherwise, participants remained doubtful about their personal abilities to provide EOLC. Participants from the comparison group were more aware of what they did *not* know about death and dying.

**Final Study Conclusions**

**Knowledge.** Knowledge of palliative care principles did not affect how comfortable participants felt with someone dying in the context as nursing students. They needed basic knowledge of physical, psychosocial, and emotional processes specific to EOL. *Experiential knowledge* was more important for comfort to diminish student fears of what to expect at EOL.

Knowledge *about* EOLC alone was not enough to affect students’ beliefs about EOLC even after providing EOLC in an acute care setting. Students felt that adequate knowledge of EOLC included feedback during their experiences in order to learn which skills were appropriate and effective for producing desired outcomes at EOL. Acute care settings allowed for learning
within multiple domains, but fewer opportunities to focus on skills specific for EOLC. A few students within the acute care setting during practicum had positive EOLC learning experiences. Due to the infrequency of opportunities however, such experiences did not improve their self-efficacy with EOLC. Therefore, meaningful EOLC experiences that were infrequent had little impact on students’ overall self-appraisal regarding their abilities to provide EOLC, especially psychosocial comfort.

Cognitive knowledge about specific symptom treatments at EOL was less important to student beliefs about providing EOLC than seeing that they could effectively contribute to a dying patient’s comfort. Positive feedback from a patient or family member was the most influential factor affecting students’ positive self-appraisals. Elective participants received positive patient and family feedback regarding ways they comforted patients through their presence and interactions. Thus, students were happy to know that they could contribute to a dying patient’s comfort. Positive feedback from dying patients was less frequent for comparison participants, except for the immediate effects seen from narcotic administration. However, they received little if any feedback about psychosocial comfort provided to patients and family members and thus were more apprehensive about providing psychosocial comfort in the future.

Addressing their own discomfort regarding EOL was fundamental for students before learning more about others’ needs at EOL, which the literature supports for understanding another’s suffering (Halldorsdottir, 2007; Haraldsdottir, 2011; Saunders, 2000; Williams & Stickley, 2010). Findings reflected the priority of students to know about their own responses to death or dying, especially if negatively preconditioned by a personal EOL experience. Knowledge of their own affective limitations specific to providing EOLC were not automatically apparent to students until experiencing someone dying in their context as a nursing student.
Students underestimated the influence of preconceived ideas and emotions from past experiences on their beliefs, emotions, and behaviors toward dying patients, which collectively reflected attitudes about care of the dying. By listening to other students’ experiences with EOLC and identifying with the distress and fears of the unknown or unexpected about death and dying, students were more aware of their own feelings regarding EOL. Discussing common limitations and positive experiences with EOLC openly with peers comforted students from both groups, especially those with no experience. All students indicated the need to know how they would react emotionally to their first encounter with death or someone dying.

In summary, student knowledge and beliefs about death and dying were already shaped by cognitive, social, emotional, and behavioral frames of reference before nursing school. Most beliefs about EOLC were influenced by a past EOL experience with personal significance because of a meaningful relationship. Whether negative or positive, normal responses to death and dying were discomforing. Positive cognitive re-appraisal of death and dying for students occurred with sustained exposure to dying patients in a hospice setting. A non-threatening setting was key to learning about EOL in all domains, with a priority on their own sense of emotional well-being. Students needed to feel emotionally stable before learning in other dimensions. Emotions formed from previous experiences with EOL limited or enhanced learning about EOL and EOLC.

**Attitudes.** Attitudes toward care of the dying were influenced by limited experiential knowledge. Rather than knowledge of palliative care concepts represented on the PCQN instrument, students did not know what to expect physically, psychosocially, and emotionally from patients at EOL. Lack of foundational knowledge about physical, psychosocial, emotional,
or behavioral manifestations of dying and experience with someone dying influenced the degree
of comfort students felt to provide EOLC as nursing students.

Students never exposed to someone dying in a positive situation at EOL or in the context
as a care provider were relieved to see dying patients comforted in various dimensions of
suffering (physically, psychosocially, emotionally, spiritually, or existentially) in a hospice
setting. Even without knowledge of specific palliative care treatments, seeing dying patients
comfortable made students believe in the possibility of a “good death” and hopeful rather than
fearful. Seeing dying patients in an acute care setting left participants more apprehensive about a
comfortable death. Some students were unaware of the concept of a “good death” for patients or
family members within an acute care setting and more apprehensive about how to provide
comprehensive comfort at EOL.

Integrated EOL education did not address the sense of responsibility students in the
comparison group felt for providing comfort at EOL as nurses, regardless of the area of nursing
care they preferred or provided in clinical. Having completed 172 hours of patient care,
participants were aware of the many expected nursing responsibilities in an acute care setting.
The responsibility to comfort made them more apprehensive about providing EOLC without
basic knowledge or experience with dying patients, and not enough feedback on their ability to
provide comfort at EOL. Essential knowledge about EOL and experiential knowledge providing
EOLC were conditions related to feeling comfortable about comforting at EOL, as well as
feeling capable to meet basic responsibilities as nurses. Thus, some participants experienced
avoidance and had beliefs about detachment as responses toward care of the dying.

Given the universal responses of sadness, grief, and fear of the unknown to death and
dying, lack of opportunities to learn about EOL or care for a dying patient were disadvantages
for nursing students expected to care for the dying upon graduation. Offering EOL education as an optional elective fosters natural human tendencies to avoid discomfort. Findings from both groups verified natural responses of sadness and discomfort to death and dying, which impacted students’ emotions, beliefs, and behaviors toward care for the dying prior to their experiences. Students who did not participate in the EOL elective suggested the need to make EOL education and experience mandatory to address a common fear of the unknown about death or dying, which they know they will encounter in practice.

When learning about care as nursing students, all participants had the desire to know how to provide the best care possible to patients, whether dying or not. Every source of feedback on how to diminish patient discomfort during clinical practicum expanded students’ views of comforting at EOL. Lack of basic knowledge and limited exposure to the interdisciplinary approach to provide EOL comfort through palliative care services distorted students’ expectations of their capabilities to provide comfort at EOL within the acute care setting. Comforting in every way possible was especially important at EOL. Without knowledge of how to comfort at EOL or seeing possibilities for comforting a dying patient within the acute care setting, participants were less hopeful.

**Environments for learning.** Regardless of previous EOL experience, the environment of a first EOL experience in the context as caregivers affected nursing students’ knowledge, feelings, thoughts, beliefs, and values regarding death and care of the dying. This finding supports the literature regarding the lasting impact of a nursing student’s first encounter with someone dying. In the hospice setting, students gained knowledge of EOL and EOLC in several learning domains specific to dying patients, without having to provide physical care. The non-threatening environment of hospice provided for learning that addressed students’ primary
concerns about EOL, what to expect physically, emotionally, and socially, which diminished their fears about talking to dying patients and family members.

Expectations imposed by the learning environment influenced student learning based on priorities of the environment. First EOL experiences in an acute care setting allowed little time for obtaining feedback specific to EOLC. Participants recalled sad emotions from their EOL experience despite providing numerous other required tasks, which left them lacking in knowledge about providing EOLC. In the hospice setting, students learned about their own responses to seeing their first dying patient, without the stress of having to provide physical care or fear of doing harm. With time to observe and learn about physical symptoms of decline at EOL and at each stage closer to the time of death, participants from the elective group were more comfortable about what to expect at EOL. Therefore, they felt capable of facing care of the dying in future nursing practice.

As theoretically projected about all dimensions for effecting lasting change, self-efficacy with EOLC required exposure to dying patients in a non-stressful environment. Given the lasting effect of personal EOL experiences prior to nursing school, 10 hours extended over one semester with dying patients and family members in a hospice setting were enough to address previous social, cognitive, affective, and behavioral influences that shaped their responses to death and dying. Given the findings and conclusions from this study, the following recommendations are proposed.

**Recommendations for Nursing Student Educators**

**Environments for developing EOLC competencies.** Nursing undergraduate educators should require all students to have experience with dying patients in addition to foundational EOL knowledge before graduating. Findings from this study indicated that natural fears about
death and dying were due to negative memories of EOL or lack of experience with a dying person enough to know what to expect. Experience with a dying person under hospice conditions provided students with various types of learning not limited to the affective domain. Students learned about physical symptoms of dying, emotional responses by patients and family members, all of which enabled them to overcome the fears of “being with” a dying patient.

In consideration of concerns about packing nursing curricula with more content, several strategies are described for providing required EOL education within the curriculum.

**Required EOL education by module.** End-of-life content should be taught to students in a separate course, which may not be feasible for all programs due to limited facilities or qualified faculty. However, foundational EOL content could be provided to students through required EOL modules. Various EOL concepts can be learned through self-study modules accessed online at students’ convenience. Each modular concept should include learning goals with objectives to be completed during hospice volunteer hours. Completed objectives should be submitted as written assignments. For example, a module on basic physiology at EOL should include a written profile of physical characteristics observed in one or more hospice patients. The written assignments would be submitted to faculty teaching either Health Assessment or Adult Health. An assignment from the module on psychosocial responses could be completed and submitted to faculty teaching a Mental Health course. A module assignment on the interdisciplinary approach in EOL care can be submitted to a Community Health or Leadership course instructor. Thus, foundational knowledge of EOL can be provided with the potential for application during normally scheduled clinical experiences during the semester. In this way, students gain crucial EOL knowledge and experience with dying patients in a gradual process alongside their regular clinical experiences. In addition to self-study modules, at least four hours
of hospice volunteer time should be required during the same semester for completing module assignments. The volunteer time could be divided into two visits without expectations to provide physical care.

In addition to module assignments, students with completed assignments and volunteer time should discuss their hospice visit experiences during post-conference of one normally scheduled clinical during the semester. Findings from this study revealed students’ comfort just from “talking about death and dying openly” with peers, which supports positive findings in the literature about sharing in a smaller group (Brien et al., 2011). The non-judgmental atmosphere to confidentially express their positive and negative experiences with peers allowed students to learn how to acknowledge and manage emotional distress instead of the natural tendency to avoid them in EOL situations. This way of sharing is particularly necessary for students with no previous history of EOL experience, such as traditional nursing students who are typically younger.

**Hospice volunteer hours.** As a separate course, EOL education can be required in conjunction with at least 10 hours of supportive caregiver experience as hospice volunteers within a hospice setting, which might be especially beneficial for younger traditional nursing students. The course can be taken in the second or third semester before a senior practicum course for traditional students, and between the start and end of the program for accelerated nursing students who have a shorter educational time frame. Hospice volunteer time of two hour intervals without expectations to provide physical care allows students to focus on dying patients and become gradually accustomed to seeing symptoms in dying patients. Students can also see alternatives to EOLC within the community or free-standing hospice agencies partnered with larger acute care organizations.
Peaceful end-of-life hours. Given the infrequent or sporadic exposure to dying patients out of 172 hours required by the senior practicum course, 10 hours should be devoted to experience with dying patients in peaceful environments. Findings from this study indicated that students would benefit from learning specifically about alternatives to dying in acute care settings. The potential for exposure to a difficult death and dying situation within the acute care setting as a first and only EOL experience can negatively impact student beliefs and attitudes toward EOLC. Counterbalancing such negative experiences with positive EOL situations may diminish their impact on attitudes about EOLC.

Senior nursing students can begin accumulating “peaceful EOL hours” with dying patients at the start of the senior semester before qualifying for clinical practicum placements. The first few weeks allotted for studying drug calculations and practicing competency skills to qualify for clinical practicum placements would be appropriate for two hour intervals of supportive caregiver experience with dying patients.

Findings from this study revealed the value of extended but shorter intervals for consistent exposure to dying patients. Seeing patients at EOL who were comfortable had a positive impact on students’ views of EOLC and attitudes for facilitating a peaceful death. Students can self-schedule two hour visits for a total of eight to 10 hours to counterbalance the remaining acute care focus during clinical practicum experiences. In addition, EOL specific education can be provided through self-study modules of fundamental EOL content, which students complete in conjunction with their “peaceful death” hours to combine knowledge with experience.

Immersion experience. Another strategy for balancing the acute care focus of clinical practicum is to devote the first clinical practicum shift, typically eight or 12 hours, to an
immersion experience on a dedicated palliative care unit with a preceptor. Students can gain required “peaceful death” hours in one area for exposure to the interdisciplinary approach at EOL before the rest of the required practicum hours. Such an experience would allow students to view the interdisciplinary palliative care approach outside of the acute care setting and within an environment focused on comprehensive comfort of the patient and family. Providing this immersion experience in the clinical practicum course supports the holistic approach as the paradigm for nursing care.

**Experiences targeting affective learning.** Requirements demonstrating affective learning should be more explicit in nursing curricula. Required exposure to dying patients in various hospice or palliative care settings is suggested as a means for developing and demonstrating students’ affective learning. Less resistance is expected from students if they are not expected to provide physical nursing care. This requirement specifically addresses affective skills students from this study were unaware of as barriers to their own professional growth for facing difficulties. In this study, coping with emotions by family members at EOL was the most difficult aspect of EOLC for some participants in the comparison group. They may continue as nurses to avoid EOLC situations emotionally and physically. Therefore, students not exposed to dying patients in their nursing education miss the benefits from such experience.

**Recommendations for Practice**

**On ‘standby’ for increased experience.** A recommendation for practicing nurse leaders is to allow nursing students to come in and experience an actual EOL event on an inpatient palliative care or oncology unit within an acute care setting during their senior practicum. Findings from this study indicated the infrequency of such opportunities with the guidance of a supportive staff member. Even on an oncology unit, a comparison participant had one
meaningful opportunity out of her 13-week practicum to participate in a post-mortem washing ritual. Although beneficial for the participant, one out of 13 weeks of practicum was not enough to positively influence the participant’s overall self-efficacy beliefs about her ability to provide EOLC. Lack of EOL self-efficacy was also true for another comparison participant who did not feel supported by staff members for post-mortem care during her only EOLC experience during clinical practicum.

The ‘standby’ strategy would allow students more opportunities to experience EOL events with a supportive staff member. However, the strategy depends on close collaboration between a nursing program and specific units within a facility. Designated nurse leaders on those units such as the manager or resource nurse familiar with all patients’ conditions can project when such events may occur. If deaths are anticipated within a day or two, nurse leaders can call from a list of nursing students prepared to be available on “standby” for specific EOL experiences. Expected EOL events often anticipated within a few days include post-mortem washing rituals for viewing for family, a family palliative care team meeting, the process of admitting and transitioning a patient to hospice care services, or the process of discontinuing a patient from life sustaining ventilation. Students approved for clinical within the facility can sign up to be available for “standby” dates and specific shifts projected by nurse leaders. In this way, students can experience an actual EOL event guided by a supportive nurse or staff member for that experience. Students can experience EOL events that occur outside of their scheduled clinical preceptorship to increase the likelihood of obtaining such experience, especially with supportive feedback. Guiding a student through a single event may also be less burdensome for nursing staff than guiding a nursing student for 172 hours of clinical practicum.
Freestanding hospice or palliative care facilities can also call students on a “standby” list. Patients in such facilities from out of state or who have no family members can be provided nursing students as temporary hospice companions or “sitters” to be present with the patient for short intervals of time closer to the time of death. These are options that would allow students to be included as participants in actual EOL experiences to learn about the interdisciplinary approach of palliative care before being expected to care for someone dying without a supportive staff member.

**Preparing preceptors.** Providing nursing preceptors within acute care settings with specific objectives for teaching nursing students about EOLC is recommended. Given multiple tasks expected within an acute care setting, preceptors need to know about nursing students’ weaknesses specific to providing EOL care. Objectives can include recognizing physical, psychosocial, cognitive, behavioral, and spiritual manifestations specific to EOL. Patients with chronic conditions within an acute care setting often exhibit symptoms characteristic of EOL, whether terminally ill or not. Clinical faculty can remind preceptors during site visits to seek out opportunities for teaching students specifically about EOLC in patients diagnosed as terminally ill or in the end-stages of an incurable chronic condition for which palliative care principles apply. Another objective can include learning about palliative care services available in the facility, which may be unknown to the preceptor. This objective would serve a dual purpose to update seasoned nurses about EOLC competencies now included in nursing education. Due to the mechanisms of self-efficacy and self-appraisal, preceptors need to know how vital their personal feedback is to nursing students for shaping their attitudes toward EOLC as practicing nurses.
Assigning dying patients to students during clinical practicum would also increase EOLC experience. However, findings from comparison participants in this study revealed the variability of supportive nursing staff to guide them during EOLC experiences in acute care settings. Providing specific EOLC objectives for the preceptor and student during clinical practicum may serve to diminish differences in learning about EOLC affected by varying staff resources, especially supportive nurses.

**Recommendations for Further Research**

**Controlled studies.** Controlled research is recommended regarding students’ emotions in their experiences of extended time in the supportive caregiver role with dying patients. In this study, higher attitude scores at pretest by the elective group seemed to reflect the bias of self-selection and an ADN nurse with hospice care experience, which confounded quantitative results of knowledge and attitudes. However, qualitative findings revealed credible changes in student emotions and beliefs about EOLC after spending 10 hours with dying patients as hospice volunteers in a supportive role. More qualitative data are needed from students who normally would not choose the EOL elective, but complete 10 hours of extended experience with dying patients as non-caregivers.

**Outcome research.** More research is recommended for studying student behaviors and responses when caring for dying patients. Observation studies of behavioral expressions such as body language, facial expressions, and communication patterns with dying patients may be helpful for verifying student responses while directly within the experience. Such responses may reveal natural changes in emotions and beliefs toward EOLC. Behaviors may be easier to detect for purposes of assessing affective learning. Findings from qualitative data in this study revealed specific behavioral responses observed by the researcher consistently across students to certain
beliefs and experiences with dying patients, such as smiling when describing patients who were comforted. Observation studies followed by focus groups may further clarify students’ emotions and thoughts at the time of their experiences to reveal distinct patterns of behavior indicating changes in learning and attitude.

**Improving affective learning.** More research is recommended to examine ways that enhance affective nursing skills. Although time spent with dying patients in a hospice setting was feasible for elective students in this study sample, the experience may not be viable in other nursing programs due to location of available hospice facilities. A practical strategy may be to facilitate students in class to revisit past personal experiences that have significance for them. Findings from this study revealed that memorable qualities from a past meaningful relationship were applicable in getting to know dying patients, which comforted nursing students. They found the time with dying patients meaningful because of the mutual comfort from the relationship. Guiding students in accessing positive emotions from past relationships may help them identify similar qualities with dying patients in the context of the nurse-patient relationship. Findings from elective participants revealed comfort and relief from the discomfort associated with getting emotionally close to someone dying, which is supported in the literature. Bailey et al. (2011) found that by investing more time in the nurse-patient relationship mentally and emotionally at EOL, nurses in an emergency room setting learned to manage their emotions and as a result found EOL care more rewarding.

**Emotional work.** More research is recommended to assess students’ affective skills because of the misunderstanding between *avoiding* and *working through* emotions at EOL. Participants in this study underestimated the effect of past emotions and misconceptions about EOL on their attitudes toward dying patients. One participant who felt comforted and competent
from providing physical care at EOL did not equally improve in other skills or feel comforted in providing psychosocial care. Although most participants were relieved to talk openly about dying patients and their fears of the unknown about death, some still preferred to avoid EOLC because of distressing experiences at EOL. This finding indicates the possible misconception of avoidance as working through difficult emotions. The literature reveals that nursing students often seek to do psychomotor tasks rather than face the emotional work of confronting their own fears of dying patients (Adesina et al., 2014; Edo-Gual et al., 2014).

**Measurement.** A practical recommendation concerning measurement is to assess emotions related to a personal EOL experience. Evoking abstract qualities such as empathy, helplessness, or vulnerability from students may be easier if relevant to a loss with personal significance. Students’ outward expressions of grief and sadness also varied because of personal meaning attached. The number of items for assessing grief on written instruments should increase to account for differences in personal responses, which should statistically increase its sensitivity to detect differences across respondents.

Although less sensitive than qualitative data, increasing the number of items related to personal EOL events on an instrument may improve results and decrease attrition rates for data collection. A longer instrument may appear too burdensome to students, which may decrease the likelihood of participation. However, written instruments may be less threatening and time consuming if offered as an alternative to attending a focus group, especially if scheduled in proximity to an exam or assignment due dates.

**Clinical staff.** More research is recommended for assessing attitudes toward care of the dying among the staff of specific acute care units rather than assume they can model affective behaviors during EOLC. Qualitative findings from this study indicated that providing physical
EOL care within an acute care setting did not enhance student learning about affective skills. The literature reveals practicing nurses equally apprehensive about EOLC for the same reasons students are reluctant about the topic (Arantzamendi et al., 2012). Findings from the literature do not support increased years of nursing experience as related to positive attitudes toward care of the dying unless working directly with dying patients (Brazil et al., 2012; Hughes et al., 2006). Students are not likely to learn affective qualities from nurses with less aptitude in affective skills, despite years of practice.

**Summary**

This chapter presented conclusions to study findings from mixed sources of data on BSN students’ knowledge and attitudes toward care of the dying. Based on gaps in the literature regarding EOL education among nursing students and their avoidant attitudes toward EOL care, students from one nursing program with different amounts of EOL education and exposure to dying patients were assessed for one semester. With lack of knowledge and attitudes associated with avoidant behaviors towards the dying, underlying aims of the study were to examine the possible effects of different amounts of EOL education and intentional experience ‘being with’ dying patients on student knowledge and attitudes about EOL care, more specifically outcomes indicating decreased apprehension and avoidance toward nursing care of dying patients.

Guided by social cognitive theory of learning (Bandura, 1989, 1999), conclusions were interpreted in view of theoretic relationships incorporating different dimensions of human learning and the environment for improving self-efficacy and self-appraisal. Conclusions were presented with references to previous literature related to the study. Specific conclusions reflected the theoretic framework in consideration of the methodology to clarify cognitive, social, emotional, and behavioral dimensions of human learning corresponding to domains of
learning encompassed by knowledge and attitudes. Theoretically, cognitive, social, emotional, and behavioral dimensions of human learning are inseparable, especially within complex situations at EOL.

Recommendations were provided for nursing education, nursing practice, and nursing research focused on measures addressing attitudes about death and dying shaped by previous frames of reference before nursing school, improving affective skills of nursing students, making EOLC education required rather than elective, and providing foundational knowledge of EOL through experience with dying patients in comforting patient care environments before experience providing physical care in an acute care setting.
References


doi:10.1177/0269216313477176


Carson, S. (2010). Do student nurses within an undergraduate child health programme feel that the curriculum prepares them to deal with the death of a child? *Journal of Child Health*
Care: For Professionals Working with Children in the Hospital and Community, 14(4), 367-374. doi:10.1177/1367493510374066


doi: 10.1111/j.1365-2648.2006.03660.x


Pope, A. (2013). *Palliative care knowledge among bachelors of Science nursing students.* Retrieved from DigitalCommons@Kennesaw State University. Paper 596.


doi:10.1016/j.profnurs.2008.10.005


doi:10.1080/1369857021000016641


doi:10.1191/0269216305pm1015oa


APPENDIX A

Palliative Care Quiz for Nursing (PCQN)

ANSWER BY CIRCLING ONLY ONE: T= TRUE, F= FALSE, or IDK= I DON’T KNOW

1. Palliative care is appropriate only in situations where there is evidence of a downhill trajectory or deterioration.
   T  F  IDK

2. Morphine is the standard used to compare the analgesic effect of other opioids.
   T  F  IDK

   T  F  IDK

4. Adjuvant therapies are important in managing pain.
   T  F  IDK

5. It is crucial for family members to remain at the bedside until death occurs.
   T  F  IDK

6. During the last days of life, the drowsiness associated with electrolyte imbalance may decrease the need for sedation.
   T  F  IDK

7. Drug addiction is a major problem when morphine is used on a long-term basis for the management of pain.
   T  F  IDK

8. Individuals who are taking opioids should also follow a bowel regime.
   T  F  IDK

9. The provision of palliative care requires emotional detachment.
   T  F  IDK

10. During the terminal stages of an illness, drugs that can cause respiratory depression are appropriate for the treatment for severe dyspnea.
    T  F  IDK

11. Men generally reconcile their grief more quickly than women.
    T  F  IDK

12. The philosophy of palliative care is compatible with that of aggressive treatment.
    T  F  IDK

13. The use of placebos is appropriate in the treatment of some types of pain.
    T  F  IDK

14. In high doses, codeine causes more nausea and vomiting than morphine.
    T  F  IDK

15. Suffering and physical pain are synonymous.
    T  F  IDK

16. Demerol is not an effective analgesic in the control of chronic pain.
    T  F  IDK

17. The accumulation of losses renders burnout inevitable for those who seek work in palliative care.
    T  F  IDK

18. Manifestations of chronic pain are different from those of acute pain.
    T  F  IDK

19. The loss of a distant or contentious relationship is easier to resolve than the loss of one that is close or intimate.
    T  F  IDK

20. The pain threshold is lowered by anxiety or fatigue.
    T  F  IDK
APPENDIX B

Side 1: Questions 1-15

Frommelt Attitude Toward Care of the Dying (FATCOD, Form B)

All statements concern the giving of care to the dying person and/or his/her family. Where there is reference to a dying patient, assume it to refer to a person who is considered to be terminally ill and to have six months or less to live. Please circle the statement that corresponds to your own personal feelings about the attitude or situation presented. Please respond to all 30 statements on the scale.

1. Giving care to the dying person is a worthwhile experience.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

2. Death is not the worst thing that can happen to a person.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

3. I would be uncomfortable talking about impending death with the dying person.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

4. Caring for the patient’s family should continue throughout the period of grief and bereavement.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

5. I would not want to care for a dying person.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

6. The nonfamily caregivers should not be the one to talk about death with the dying person.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

7. The length of time required giving care to a dying person would frustrate me.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

8. I would be upset when the dying person I was caring for gave up hope of getting better.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

9. It is difficult to form a close relationship with the dying person.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

10. There are times when the dying person welcomes death.
    - Strongly disagree
    - Disagree
    - Uncertain
    - Agree
    - Strongly agree

11. When a patient asks, “Am I dying?” I think it is best to change the subject to something cheerful.
    - Strongly disagree
    - Disagree
    - Uncertain
    - Agree
    - Strongly agree

12. The family should be involved in the physical care of the dying person.
    - Strongly disagree
    - Disagree
    - Uncertain
    - Agree
    - Strongly agree

13. I would hope the person I’m caring for dies when I am not present.
    - Strongly disagree
    - Disagree
    - Uncertain
    - Agree
    - Strongly agree

14. I am afraid to become friends with a dying person.
    - Strongly disagree
    - Disagree
    - Uncertain
    - Agree
    - Strongly agree

15. I would feel like running away when the person actually died.
    - Strongly disagree
    - Disagree
    - Uncertain
    - Agree
    - Strongly agree

Permission authorized for use 8.19.15
APPENDIX B

Side 2: Questions 16-30

Frommelt Attitude Toward Care of the Dying (FATCOD, Form B)

All statements concern the giving of care to the dying person and/or his/her family. Where there is reference to a dying patient, assume it to refer to a person who is considered to be terminally ill and to have six months or less to live. Please circle the statement that corresponds to your own personal feelings about the attitude or situation presented. Please respond to all 30 statements on the scale.

16. Families need emotional support to accept the behavior changes of the dying person.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

17. As a patient nears death, the nonfamily caregiver should withdraw from his/her involvement with the patient.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

18. Families should be concerned about helping their dying member make the best of his/her remaining life.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

19. The dying person should not be allowed to make decisions about his/her physical care.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

20. Families should maintain as normal an environment as possible for their dying member.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

21. It is beneficial for the dying person to verbalize his/her feelings.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

22. Care should extend to the family of the dying person.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

23. Caregivers should permit dying persons to have flexible visiting schedules.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

24. The dying person and his/her family should be the in-charge decision-makers.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

25. Addiction to pain relieving medication should not be a concern when dealing with a dying person.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

26. I would be uncomfortable if I entered the room of a terminally ill person and found him/her crying.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

27. Dying persons should be given honest answers about their condition.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

28. Educating families about death and dying is not a nonfamily caregiver responsibility.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

29. Family members who stay close to a dying person often interfere with the professional’s job with the patient.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

30. It is possible for nonfamily caregivers to help patients prepare for death.
   - Strongly disagree
   - Disagree
   - Uncertain
   - Agree
   - Strongly agree

Permission authorized for use 8.19.15.
Demographic Data Questionnaire

Please write the last four numbers of a cell phone easy for you to remember: ABOVE THE DATE.

Age: __________
Sex: _______ Male _______ Female

Highest degree of education completed:
- ___ High School Diploma, or equivalent like a General Education Development (GED).
- ___ Associate Degree
- ___ Bachelor Degree
- ___ Master’s Degree
- ___ Education beyond Masters

1. Previous **education** on death and dying.
   - I have taken a course on death, and/or dying at this University: ____ Yes or ____ No.
   - I have heard topics related specifically to death, and/or dying in other courses at this University: ____ Yes or ____ No.

2. Previous experience **with care** for a terminally ill patient, with or without family members present.
   - I have had previous experience caring for one or more terminally ill patients: ____ Yes or ____ No.
   - If ‘Yes,’ approximately how many total hours have you spent caring for someone terminally ill:
     - ____ Less than 10 hrs.
     - ____ About 10 hrs.
     - ____ More than 10 hrs.

3. Previous experience **with the death** of someone close.
   - ____ I have had previous experience with the death of someone close to me: ____ Yes or ____ No.
   - If Yes, please specify the deceased, ie: spouse, parent, child, sibling, friend, and number of months or years since the death. You may list more than one.

<table>
<thead>
<tr>
<th>The deceased:</th>
<th>Months or years since the death.</th>
</tr>
</thead>
<tbody>
<tr>
<td>ie: mother, sister…</td>
<td>6 mo.</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. Present experience with death. At present, I anticipate the death of someone close to me within a year or less: ____ Yes or ____ No.
APPENDIX D

Focus Group Questions

Today’s Date _______ _______ _______. Circle participant group: (Elective NURS4440 or Practicum NUR4417) Total # in focus group: ___________ Participant numbers: ___________, ___________.

Announcement: This discussion is being audio-taped and anything that you say will be kept confidential. Individuals will not be identified from transcripts. You’ll only be known as “student 001, 002, or 003”

BEFORE entering this course:

* Indicates prompt that may be used to clarify the question or probe for further meaning of their answers.

1. What do you believe/think about end of life care? * Talk about your thoughts or beliefs before entering this course?
2. What was your attitude toward dying persons and their families? * Tell me more about that?
3. Describe an encounter that you have had with a dying person and/or his/her family? No matter how brief or extensive the encounter was.
4. What values were important during the time you thought about or sought to care for a person/persons near the end of life? * Dignity, respect, humanity, etc?
5. Recall how you felt at that time. What emotions did you have? * ie: Emotions, feelings, or reactions about end of life care...negative...positive...neither?
6. Where do you think those came from? (emotions, feelings, reactions) * ie: Something you heard, read, saw, influences, experiences, people,?
7. Is there anything else you would like to add?

NOW that you have completed this course:

2. What do you believe/think about end of life care now? * Go on...Talk more about that?
3. What is your attitude toward dying persons and their families? * Tell me more about that?
4. Describe an encounter that you have had with a dying person and/or his/her family during this semester? * No matter how brief or extensive the encounter was during the course, what was it like? Go on.
5. What values were important during the time you thought about or sought to care for a person/persons near the end of life? * What does that represent to you? Dignity, respect, humanity, etc?
6. Recall how you felt at that time. What emotions did you have? * ie: Emotions, feelings, or reactions about end of life care...negative...positive...neither?
8. What changes, if any, have you experienced over this semester with regard to end of life care?
9. Is there anything else you would like to add?
Title of Research Study: 16-064: Nursing Students’ Knowledge and Attitudes Toward Care of the Dying
Researcher's Contact Information: Elizabeth N. Ward, the principal investigator, or ‘PI’, (c): 770-568-7698, Email: eward@kennesaw.edu.

Introduction: You are being invited to take part in a research study conducted by Elizabeth N. Ward, of Kennesaw State University, WellStar School of Nursing, in Kennesaw GA. Before you decide to participate in this study, you should read this form and ask questions about anything that you do not understand.

Description of Project: As a professional health care provider, there is always the potential of encountering a life and/or death situation. As a nurse, you will be expected to provide quality end-of-life (EOL) care to patients who are dying, regardless of the patient’s age, diagnosis, or mental and functional status. During nursing education, experience with terminally ill patients may vary. So it is important to assess what nursing students know about EOL care, how they learn about it, and how they feel about such care during their educational development. The purpose of this study is to assess (EOL) knowledge and attitudes toward care of the dying among Bachelor of Science in Nursing (BSN) students. Because you are a nursing student enrolled in a BSN program, you are being asked to participate in this research by completing two questionnaire, one about EOL care, and another about your attitudes toward care of the dying. No preparation is necessary and these will not be graded. Study participation or non-participation will not affect your grades in this course. Your thoughts, attitudes, beliefs, values, and emotions toward EOL care are especially important in this research. So you are also being asked to share them in a small focus group discussion that will be conducted toward the end of the semester and audio-recorded.

Explanation of Procedures: The PI or a facilitator, who is a faculty member not associated with instructing in this course, will introduce the study on the orientation day for the course, explain and administer instruments and a demographic page, collect completed forms, and provide a schedule for students to sign up for a focus group. This will be repeated toward the end of the semester. The PI, who instructs in the palliative and elective course, will not be present in this group at any time while the study is being introduced, instruments are being explained, administered, and collected, or when participants are signing up for a focus group. Signed consents will not be accessible to the PI.

You are being asked to fill out two paper questionnaire instruments and a one-page demographic form, once before this course begins and then again toward the end of the course. One instrument has 20 questions that you will answer by circling: “True, False, or I Don’t Know. Another questionnaire has 30-questions that you will answer by circling one rated response from 1-strongly disagree to 5-strongly agree. For confidentiality, in the top right corner of each sheet please put the last four digits of a cell phone number easy for you to remember. After completing the forms and returning them to the facilitator or PI who will check questionnaires for completeness and four digit identifiers, you will be asked to use your four digit number to sign up for a focus group to share your thoughts, attitudes, beliefs, values, and emotions toward EOL care. Pizza and soda will be provided in the focus groups that will be scheduled on campus near the end of the semester and in a location convenient to your last classes for the semester.

Time Required: The study questionnaires should take 25 to 30 minutes of your time to complete. The instruments are brief with responses that you simply circle. Signing up for a focus group may take 5 minutes of your time at the beginning. Participation in a focus group toward the end of the semester should take 60 minutes of your time depending on discussion dynamics and time to enjoy pizza and soda.

IRB Appvd for study# 16-064: 9.11.15
APPENDIX E
CONSENT FORM p. 2 of 2

Risks or Discomforts: Discussing death or dying may cause you to process unpleasant experiences with dying patients and/or unpleasant memories of the loss of a patient, family member, or friend that might make you sad. Participation is voluntary and you have the right not to answer any questions that make you feel uncomfortable. If at any time you have further questions or feel the need for additional counseling, please contact the Principle Investigator for answers or appropriate referral to a licensed counselor.

Benefits: Although not guaranteed, participants may gain greater knowledge about EOL care and/or greater insight and self-awareness of improved personal attitudes toward care of the dying. Participants in small focus groups may experience a sense of relief or support from sharing and/or listening to peers with similar emotions or responses toward EOL care.

Compensation: No monetary compensation or course credit will be given for participation. Regardless of participation, candy will be available to all students while instruments are being explained, administered, and collected. Pizza and soda will be provided to focus group participants toward the end of the semester while questions are asked to prompt responses on attitudes, beliefs, values, and emotions toward care of the dying.

Confidentiality: Results from completed instruments will be kept confidential and will not reveal the names of any individual because instruments will be labeled with four numbers known only by the participant. Because focus groups involve interaction with others, complete confidentiality is not possible to those in the same group. However, participants in focus groups will remain confidential by the focus group conductor and participants are asked not to divulge names of or comments by other participants in their group. On transcription of audio-recorded discussions, individuals will not be identified but referred to only as “student 001, student 002, et.” Any results of data will be presented in aggregate form. All signed consents will remain in sealed envelopes and locked in storage inaccessible to the PI.

Inclusion Criteria for Participation: All participants receiving this consent must be an adult at least 18 years old or above and enrolled in the nursing program. Participants must be able to read and comprehend English.

Signed Consent: I agree and give my consent to participate in this research project. I understand that participation is voluntary and that I may withdraw my consent at any time without penalty.

Signature of Participant,______________________________________ Date __________________________

[Signature]

Signature of Investigator, Date ________________________________

PLEASE SIGN BOTH COPIES OF THIS FORM. KEEP ONE AND RETURN THE OTHER TO THE FACILITATOR.

Research at Kennesaw State University that involves human participants is carried out under the oversight of an Institutional Review Board. Questions or problems regarding these activities should be addressed to the Institutional Review Board, Kennesaw State University, 585 Cobb Avenue, KH3403, Kennesaw, GA 30144-5591, (470) 578-2268.

IRB Appvd for study# 16-064: 9.11.15
ADDENDUM 1
Authorization for use of PCQN

August 18, 2015

To: Dr. Frances Fothergill-Bourbonnais, RN PhD Emeritus Professor
   School of Nursing, University of Ottawa
   451 Smyth Road Ottawa, Ont. K1H 8M5
   fbourbon@uottawa.ca
   (613) 562-5800 ext 8423

From: Elizabeth N. Ward, RN MSN (Betsy)
   Clinical Faculty, Wellstar School of Nursing, Kennesaw State University
   1000 Chastain Rd.
   Kennesaw, Georgia 30144
   Work Email: eward@kennesaw.edu
   Personal Email: betsyyyy2003@gmail.com
   Personal Phone: (770) 568-7698

Re: Request for Permission to Use the Palliative Care Quiz for Nurses

Dear Dr. Fothergill-Bourbonnais,

I am a doctoral student from Kennesaw State University, in Kennesaw, Georgia and I am working on my research proposal titled: Nursing Students’ Knowledge and Attitudes Toward Care of the Dying,’ under the direction of my dissertation committee, chaired by Dr. Tommie P. Nelms, RN PhD. I wanted to ask permission to print and use the Palliative Care Quiz for Nurses (PCQN) for my study. When researching Dr. Margaret M. Ross to obtain permission, I found your information from documents by Amy Pope, who also used the PCQN. I would like to use the PCQN under the following conditions that:

1. I will use this instrument only for purposes of my research study and will not sell or use it with any compensated or curriculum development activities.
2. I will include the copyright statement on all copies of the instrument.
3. I will send my research study and any reports or articles that make use of the questionnaire and results from it to you.

If these are acceptable conditions, please let me know by signing one copy of this letter and returning it to me either through postal mail or my work email. I would greatly appreciate it.

Postal Mail: 513 Walkers Ridge Ct., Woodstock, Ga. 30189
Work email: eward@kennesaw.edu

Sincerely,
Elizabeth N. Ward, “Betsy”

Agreed to and accepted: [Signature]
Date: Aug 19, 2015
KNOWLEDGE AND ATTITUDES TOWARD CARE OF THE DYING

ADDENDUM 2

Authorization for use of FATCOD

On Aug 18, 2015, at 3:50 PM, Elizabeth (Betsy) Ward <eward@kennesaw.edu> wrote:

August 18, 2015

To: Katherine H. Murray Frommelt, PhD, RN, FT
ELNEC-Pediatric Palliative Care
Clarke College
Dubuque, IA
kay.frommelt@clarke.edu
kay.frommelt@gmail.com

From: Elizabeth N. Ward, RN MSN (Betsy)
Clinical Faculty, Wellstar School of Nursing, Kennesaw State University
1000 Chastain Rd.
Kennesaw, Georgia 30144
Work Email: eward@kennesaw.edu
Personal Email: betsyyyy2003@gmail.com
Personal Phone: (770) 568-7698

Re: Request for permission to use the Frommelt Attitude Toward Care of the Dying Scale.

Dear Dr. Frommelt,
I am a doctoral student from Kennesaw State University, in Kennesaw, Georgia and I am working on my research proposal titled: Nursing Students’ Knowledge And Attitudes Toward Care of the Dying,’ under the direction of my dissertation committee, chaired by Dr. Tommie P. Nelms, RN PhD. I wanted to ask your permission to print and use your Frommelt Attitude Toward Care of the Dying Scale, Form-B (FATCOD) for my study under the following conditions:
1. I will use this instrument only for purposes of my research study and will not sell or use it with any compensated or curriculum development activities.
2. I will include the copyright statement on all copies of the instrument.
3. I will send my research study and any reports or articles that make use of the scale and results from it to you.

If these are acceptable conditions, please let me know by signing one copy of the letter attached to this email and returning it to me either through postal mail or my work email. I would greatly appreciate it.

Postal Mail: 513 Walkers Ridge Ct., Woodstock, Ga. 30189 (Home address)
Work email: eward@kennesaw.edu

Respectfully,
Elizabeth N. Ward, “Betsy”

Agreed to and accepted:

Katherine H Frommelt, PhD., R.N., PDE, CGC, FT
Date: August 19, 2015

FATCOD Letter requesting permission to use.docx