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### Knowledge Gaps: Addressing the Need for Palliative Care Education for University Nursing Students

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Knowledge Gaps: Addressing the Need for Palliative Care Education for University Nursing  
Students

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NURS797W Honors Thesis

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May 18, 2022

### **Abstract**

This study aimed to analyze undergraduate nursing students' primary palliative care knowledge to determine if there is a need for further palliative care education in undergraduate, pre-licensure curriculums. To make this determination, this study utilized the Undergraduate Nursing Palliative Care Knowledge Survey (UNPCKS), created by Dr. Andra Davis and Dr. Megan Lippe, a 27-question survey that addresses the 6 domains of holistic palliative care; i) holistic, patient-centered care (Whole person care), ii) collaborative (Interprofessional), iii) understanding of primary palliative care as a resource and how to support patients/families (Advocacy and Knowledge of Primary Palliative Care), iv) the importance of understanding patient's priorities (Goals of Care), v) the importance of informed conversations with patients and families (Communication), vi) physical care (Symptom Care) and vii) support after a loss (Bereavement). The survey was administered to students enrolled in the undergraduate nursing program at the University of New Hampshire-Durham, and the data was collected through an online survey distributed to every undergraduate nursing student. The UNPCKS scores were then analyzed to determine if there was a knowledge deficit in the primary palliative care knowledge of undergraduate nursing students, and whether those deficits correlated between participant answers and the demographic experiential questions. After the results had been examined, 3 significant correlations were extracted, the most notable of which was between the total UNPCKS score and having provided postmortem care. While we were unable to identify concrete correlations that pointed to significant gaps in nursing students primary palliative care knowledge, it is important to acknowledge the current and future need for palliative care education in nursing curriculums. This research is important and relevant because there is an aging population in the United States that requires increased healthcare for an increasing rate of complex, chronic and life-limiting disease processes for which palliative care is indicated.

## **Background and Importance**

Palliative care is specialized medical care that focuses on competent, caring and holistic healthcare to improve the quality of life of individuals with chronic, complex or life-limiting disease processes. It is intended to optimize quality of life by “anticipating, preventing and treating suffering” (Ferrell et al., 2018, p. 1685). This is achieved through systematic symptom management and is appropriate for patients of any age and at any stage in their disease process. This care varies from patient to patient, but often takes the form of relief from pain, shortness of breath, fatigue, nausea, constipation, and other symptoms that are often associated with chronic disease. The number of patients with chronic diseases that meet the indications for palliative care specialists is increasing in this country, and as a result, “the need for continuing, evidence-based nursing education on the principles and goals of palliative and end-of-life care” is paramount (Dimoula, et al., 2019). Palliative care principles and practices can be delivered by any clinician with appropriate training who is caring for the seriously ill, and in any setting, and yet there is a general lack of understanding about the benefits that palliative care can provide (Mallory, 2013). Despite this increased need, the curriculums of many undergraduate nursing, prelicensure programs do not include adequate palliative care modules to sufficiently educate nurses on how to address the concerns of their palliative care patients competently and holistically (Mallory, 2013).

Undergraduate nursing education should be providing the foundation for end-of-life nursing care, and yet nursing education consistently lacks an effective, efficient approach to educating students about the care patients need in their final days care (Desbiens, Gagnon & Fillion, 2011). A recent analysis of nursing textbooks found that of the nearly 50,000 pages of text reviewed, only 902 pages were related to the end of life (Mallory, 2013). For reference, that

is roughly 2 percent of the content. There are very few effective components in nursing education curricula for end-of-life care. The lack of time spent on death and dying can be attributed to the following: “already crowded curricula owing to a rapid increase in knowledge and technology, a lack of effective teachers qualified to teach death and dying, and an existential fear of death” (Mallory, 2013, p. 306). Studies have shown that nursing students’ attitudes toward care of the dying were improved after an educational component in palliative care (Desbiens, Gagnon & Fillion, 2011). This was consistent with previous research that showed that education has a positive effect on nurses’ attitudes toward care of the dying (Mallory, 2013). It is important to establish a foundation and framework of primary palliative care knowledge within undergraduate nursing students that can then be enhanced as they progress through their undergraduate studies and into their careers. In order to establish this framework, it is important to understand if there is a knowledge gap, in what domains this gap exists, and how we best address it. This information is significant to the nursing field because there is an increasing rate of chronic and life-limiting illnesses in this country that are not being adequately addressed, and many nurses have not received the sufficient education needed to address the concerns of their palliative care patients.

### **Theoretical Framework**

This study was guided by the Shared Theory of Palliative Care, which was identified because of its alignment with the development of the Undergraduate Nursing Palliative Care Knowledge Survey (UNPCKS) tool (Desbiens, Gagnon & Fillion, 2011). The theory asserts that competence in the provision of palliative care requires sufficient knowledge. A nurses’ competence influences their perceptions of competence and thus the performed interventions

when caring for seriously ill patients. The interventions that are provided directly translate to patient outcomes (Desbiens, Gagnon & Filion, 2011). The Shared Theory of Palliative Care is broken down into six components, the first three of which specifically concern the nurse. The first concept corresponds to palliative care nursing competence. The second concept of the shared theory is self-competence in palliative care nursing. The third concept of the shared theory corresponds to palliative care nursing interventions. Nursing competence, nursing self-competence and nursing interventions provide the theoretical basis for quality care in palliative care situations.

While the first three concepts of the Shared Theory specifically concern the nurse, the following three concepts concern patients with life-limiting illnesses receiving care. The Shared Theory clarifies the expected effects of palliative care nursing interventions in terms of self-care, health and well-being. The fourth concept of the Shared Theory refers to palliative self-care behaviors. The fifth concept of the Shared Theory represents physical and emotional symptoms of people with serious long-term illness, such as pain, fatigue and emotional distress. Finally, the sixth concept corresponds to quality of life for people who have life-limiting illness or are at the end of life.

The Shared Theory of Palliative Care “applies the concept of nursing agency to the context of palliative care. This theory delineates the therapeutic relationship between nurses and patients who have life-limiting illness. It provides a framework for developing palliative care nursing competence and enhancing care quality in palliative care situations” (Desbiens, Gagnon & Filion, 2011, p. 2117). More specifically, this shared theory could be used as a framework to evaluate the impact of palliative care training programs on improvements to nursing care and patient outcomes (Desbiens, Gagnon & Filion, 2011).

### **Specific Aims**

This study aimed to assess the primary palliative care knowledge of undergraduate, prelicensure nursing students to determine if there is a need for further palliative care education in the undergraduate curriculum.

### **Methodology**

Researchers in this study utilized a quantitative survey methodology for collecting information from a pool of respondents. A cross-sectional quantitative design was proposed to elicit current knowledge and exposure to palliative care content in undergraduate students. The sample included 82 undergraduate students enrolled in an undergraduate nursing program. While 153 students submitted responses to the survey, 71 responses appeared to end after the participant completed the consent form, and were marked with “*This question was not displayed to the respondent*”. This resulted in a total sample of 82 participants that had provided complete or nearly complete survey responses deemed appropriate for data collection. The survey was administered via computer and asked demographic and palliative care knowledge questions. This study utilized the Undergraduate Nursing Palliative Care Knowledge Survey (UNPCKS) tool to analyze the primary palliative care knowledge of undergraduate nursing students at the University of New Hampshire-Durham (UNH). Using the Shared Theory of Palliative Care framework, the researchers behind the creation of UNPCKS were able to devise a tool that comprehensively addresses critical aspects of palliative care practice, which can then be used to analyze primary palliative care knowledge in undergraduate, prelicensure students. Through this survey, researchers in this study were able to assess for a gap in primary palliative care

knowledge to determine the need for further palliative care education in the undergraduate curriculum.

### **Study Procedures**

This survey sampled the students in the undergraduate nursing program at the University of New Hampshire-Durham. Roughly 315 students were eligible to participate in this study. This survey sample was chosen because it is a large sample size at a major public university, and all participants are undergraduate, prelicensure nursing students, which this study pertains to. All students who chose to participate were given the same 27 question UNPCKS survey, and all responses from students who answered at least 24 of the 27 questions were counted. Each participant was then asked a series of 8 demographic and palliative care experience questions after they completed the UNPCKS survey.

This survey was anonymous to protect respondents' privacy and all undergraduate nursing students at the University of New Hampshire were eligible to participate. There were minimal risks posed to the students who participated in this survey. This survey was intended to be as straightforward and stress-free as possible by allowing students to start and stop as they saw fit, and they were not timed. There was a risk that questions posed to the students could have provoked memories of past experiences that may have been difficult to handle. Participants were encouraged to connect with researchers if they were feeling distressed during or after completion of the survey, and were referred to the appropriate counseling services if desired.

## Measures

***The Undergraduate Nursing Palliative Care Knowledge Survey (UNPCKS)***. The UNPCKS survey tool is a 27-item measure that comprehensively addresses critical aspects of palliative care practice. The UNPCKS has demonstrated reliability and validity for use with undergraduate students and can be appropriately utilized to analyze the primary palliative care knowledge of undergraduate nursing students at the University of New Hampshire. The marker of reliability in this descriptive survey tool was an overall alpha coefficient of a 0.70 Cronbach score, with some questions individually scoring a much higher Cronbach score. The researchers who designed the UNPCKS tool meticulously developed the measure by subjecting it to pilot testing, multiple rounds of revision and use of the ELNEC-Kat knowledge revision measure, which evidence suggests has reliability and validity in measuring knowledge (Davis, Lippe, Burduli, & Barbosa-Leiker, 2020). The sample for psychometric testing of the new survey tool included undergraduate students from three universities across the United States: a public university in the Pacific Northwest, a public state university in the South, and a health-science center in the Southeast.

Through this survey, researchers were able to assess for a gap in primary palliative care knowledge, which was intended to illuminate a need for further palliative care education in the undergraduate curriculum. The UNPCKS tool is also intended to support faculty as they integrate primary palliative care knowledge into their curricula. The UNPCKS survey encompasses key components of palliative care, such as symptom management, interprofessional collaboration, advocacy and knowledge of primary palliative care. UNPCKS has been tested with baccalaureate completion and traditional baccalaureate student samples who were evenly dispersed between the junior and senior years of their program. Because the majority of students who took

UNPCKS as it underwent validity testing had not taken the ELNEC (End-of-Life Nursing Education Consortium) palliative care modules, the collected data demonstrates primary palliative care knowledge as reflected in the general nursing curricula.

It is important to note that ethics and culture, while being competencies in palliative care modules in other learning tools, were not “directly evaluated with dedicated questions in the knowledge measure” (Dimoula et al., 2019, p. 50). They are, however, threaded through questions in the UNPCKS survey that are dedicated to other competencies. It is also important to note that past experiences with palliative care or hospice can and do impact the scores and performance of participants on the UNPCKS survey.

### **Demographic & Experience Items**

This study utilized the Undergraduate Nursing Palliative Care Knowledge Survey (UNPCKS), which is a 27-question survey tool designed to analyze the primary palliative care knowledge of undergraduate nursing students at the University of New Hampshire. After the 27 items that students answered during the survey, they then encountered 8 demographic questions designed to assess their general background, palliative care background, personal experiences, and knowledge of being a primary caregiver. Questions that were included were “What year are you in your undergraduate degree?” “How old are you?” “Have you ever had a loved one with a complex, chronic or life-limiting illness?” “Have you ever been the primary caregiver to a loved one?” “Are you a Licensed Nursing Assistant (LNA)?” “Have you ever seen someone die?” “Have you ever provided postmortem care (care after someone has passed) to a body?” and “Have you ever taken the UNH course “Death and Dying”?”.

**Data Collection and Method of Analysis**

The Undergraduate Nursing Palliative Care Knowledge Survey (UNPCKS) tool was utilized to collect data to determine if there is a gap in primary palliative care knowledge of undergraduate nursing students that could be addressed through palliative care education in the curriculum. The survey was distributed via student Outlook emails so that all undergraduate nursing students with a valid UNH email could participate. This survey came with an answer key that allowed researchers to grade student survey responses, allowing the participant's knowledge of primary palliative care knowledge to be gauged. Data was analyzed using Microsoft Excel and descriptive statistics were used to analyze the sample demographic characteristics, knowledge questions and perceived knowledge.

## Results

**Figure 1: Demographic Results and UNPCKS Scores**

Table 1		
<i>Participant Demographics (N=?)</i>		
	Range (M)	n (%)
Loved one with a chronic illness		62 (76%)
Have you been a primary caregiver		11 (13%)
Are you an LNA		50 (61%)
Have you seen someone pass		53 (65%)
Have you provided post-mortem care		33 (40%)
Have you taken the UNH course “Death and Dying”		30 (37%)
Year in Undergraduate Degree		
Freshmen	16 (20%)	
Sophomore	23 (28%)	
Junior	10 (12%)	
Senior	33 (40%)	
Total UNPCKS Score	12-27 (21)	
Spirituality and Grief Score	2-8 (6)	
Principles of Primary Palliative Care	3-7 (6)	
Communication	0-5 (4)	
Pain and Symptom Management	3-5 (5)	

**Figure 2: Correlation Table of Total UNPCKS Score and Subscales with Experience Questions**

Correlation Table of Total UNPCKS Score and Subscales with Experience Questions					
	Loved One with a Chronic Illness	Been a Primary Caregiver	Are an LNA	Have Seen Someone Pass	Have Provided Post Mortem Care
<b>Total:</b>	0.135	-0.085	0.048	0.019	<b>.237*</b>
<b>Principles of Primary Palliative Care</b>	0.040	<b>-.254*</b>	-0.086	-0.106	-0.091
<b>Pain &amp; Symptom Management</b>	0.041	0.083	-0.045	-0.032	0.208
<b>Communication</b>	0.089	-0.018	0.022	-0.003	0.185
<b>Spirituality and Grief</b>	0.155	-0.053	0.158	0.121	<b>.267*</b>
* indicates p value <.05					

**Figure 3: Correlation Values**

Strength of Correlation	Range of Absolute Correlation Coefficient ( <i>r</i> )
Very strong	0.8–1.0
Strong	0.6–0.79
Moderate	0.4–0.59
Weak	0.2–0.39
Very weak	0–0.19

As is shown in figure 1, a total of 82 participants filled out the survey to completion (n=82). The participant sample included 16 freshmen (20%), 23 sophomores (28%), 10 juniors (12%) and 33 seniors (40%). Three quarters of (n=62, 76%) participants have or have had a loved one with a chronic illness (ex: COPD, Diabetes, Dementia, etc.). Few participants (n=11, 13%) are or have been the primary caregiver to someone with a chronic illness. The majority (n=50, 61%) are currently LNAs or CNAs, and have seen someone pass away (n=53, 65%). More than a third (n=33, 40%) have provided postmortem care (care to a body after a person has passed), and have previously taken the UNH elective course “Death and Dying” (n=30, 37%).

As far as survey results are concerned, the 82 participant’s scores on the 27 questions of the overall UNPCKS survey tool ranged from 12-27, which an average score of 21 out of 27 questions correct. Scores in each of the subsections are important to note as well. In the Spirituality and Grief subsection, there were 8 questions and scores ranged from 2-8, with 6 as the average score. In the Principles of Primary Palliative Care subsection, there were 7 questions and scores ranged from 3-7, with 6 as the average score. In the Communication subsection, there were 5 questions and scores ranged from 0-5, with 4 as the average score. Finally, in the Pain and Symptom Management subsection, there were 7 questions and scores ranged from 3-7, with 5 as the average score.

As is shown in figure 2, the collected data was analyzed, and correlations were extracted from the overall UNPCKS scores and the UNPCKS subsection scores when compared to how the participants answered the demographic experience questions at the end of the survey. Correlation strength interpretations were drawn from figure 3, which establishes a range of absolute correlation coefficients ( $r$ ) (Pearson, 2019). There were 3 significant correlations of note that were extracted. Firstly, there is a weak correlation between *the principles of primary*

*palliative care subcategory* and *having been a primary caregiver* that is significant. Secondly, there is a weak correlation between *the total UNPCKS score* and *having provided postmortem care* that is significant. Lastly, there is a weak correlation between *the spirituality and grief subcategory* and *having provided postmortem care* that is significant.

### **Discussion**

The average UNPCKS survey score was 77%. Past studies that have utilized the UNPCKS survey tool have had similar participant scores prior to palliative care education, so this range is in line with previous studies. However, it is important to note that the correlations that were significant were different than what the researchers expected. Most notably, it was an unexpected finding that having provided postmortem care was correlated to a higher UNPCKS score and higher score in the spirituality and grief subcategory. It is unclear why this specific experience makes a participant statistically more likely to score higher overall on the UNPCKS survey tool. Because of this unexpected finding, this opens the door for future research endeavors that could elaborate on the postmortem care aspect of palliative care. On top of that, future research endeavors could be utilized to further demonstrate the importance and relevance for nursing students to provide postmortem care before graduation.

Some proposed education experiences that could build upon palliative care knowledge could be simulation experiences and the ELNEC modules. In the past, sophomore nursing students within the University of New Hampshire nursing program have undergone a four-week simulation experience in which they guide a patient with a chronic, terminal illness through the last weeks of their life, culminating in their passing and the provision of postmortem care. This

could be a valuable exercise to reintroduce for nursing students and is a potential intervention to broaden student's understanding of both postmortem care and primary palliative care. Another valuable educational experience that could be integrated into the curriculum is the ELNEC modules, which stands for End-of-Life Nursing Education Consortium. ELNEC includes the following modules: Nursing Care at the End of Life; Pain Management; Symptom Management; Ethical and Legal Issues; Cultural and Spiritual Considerations; Communication; Loss, Grief, Bereavement; and Final Hours/Days. These modules come as part of a national education initiative to improve palliative care and could be integrated into an undergraduate nursing palliative care course.

As mentioned above, the results were unexpected. We had hoped this study would have turned up concrete, irrefutable correlations that pointed to significant gaps in nursing students primary palliative care knowledge. That would've made it easy to point to the data as a major indicator for the need for a required palliative care course as part of the undergraduate nursing program here at UNH. But it is important to understand that the need for a palliative care course within the undergraduate nursing curriculum has already been firmly established. Generally incurable and ongoing, chronic diseases affect approximately 157 million Americans, representing more than 40% of the total population of this country (CDC, 2020), and this number is only increasing. Palliative care is the key to ensuring that these patients have their symptoms managed, their pain properly controlled, and their health goals met. Palliative care optimizes quality of life by "anticipating, preventing and treating suffering" (Ferrell et al., 2018, 1685), and puts decision-making power in the hands of the patient. These interventions let patients dictate what care they do and do not want for themselves and help direct healthcare providers as to how best to manage their conditions. It is essential that undergraduate nursing students receive the

foundational primary palliative care education they need in order to be able to best serve their patients upon graduation.

### **Limitations**

There are several key limitations to this study that are important to note. This study was completed using a sample of undergraduate nursing students at the University of New Hampshire, a relatively limited participant pool. While there are roughly 350 undergraduate nursing students at this university, we received 82 completed submissions, an even more narrow sample. While we technically received 153 submissions, 71 responses appeared to end after the participant completed the consent form, and were marked with *“This question was not displayed to the respondent”*. One possibility for this hole in responses is that these 71 responses were incomplete, and as a result Qualtrics prevented them from being utilized in data analysis. It is possible that 71 participants started the survey and stopped partway through, or that participants stopped and started the survey multiple times, and each of these times was counted as a separate response. As a result, a total sample of 82 survey responses could be included in the data.

Another limitation is that 30 participants have already taken the UNH course “Death and Dying” and 33 of the respondents were seniors. While there were technically no significant correlations between either of these factors and the overall UNPCKS scores or scores in any of the subsections, both factors could inflate knowledge scores on account of these participants having received more education. Another limitation is that participants have all had different experiences with death and dying. Such personal experiences have the potential to negatively impact their scores and their willingness to participate fully in the survey, or participate at all.

Another limitation is that the survey is 27 questions long, followed by 8 demographic questions. The length of the survey may have dissuaded active participation from respondents. On top of the number of questions, this was a voluntary survey with no incentive beyond helping the researchers broaden their data. This survey was not attached to any course and participants had nothing to gain personally from completion. Essentially there is minimal incentive for participants to spend roughly 15 minutes of their time completing this survey.

### **Conclusion**

In today's society, people are living longer than ever – even those facing serious chronic illnesses often enjoy a much longer lifespan thanks to advancement in the treatment of diseases including cancer, heart disease, diabetes, and COPD (Crossroads Hospice, 2019). While these patients may be living longer lives, both the disease and treatment can cause distressing symptoms that can impair their quality of life. Palliative care is important because it gives patients an option for pain and symptom management and improved quality of life while still pursuing curative measures. This care should be available to all patients with serious illness regardless of age, prognosis, disease stage, or treatment choice, and ideally is provided early and throughout the illness, beginning at diagnosis, together with life-prolonging or curative treatments. In other words, “patients don't have to choose between treatment for their illness and palliative care; they can have both” (Shmerling, 2019, p. 2).

The demand for palliative care is increasing rapidly as the number of aging Americans continues to climb (Harwell, 2019). This increased need for palliative care calls for healthcare professionals to be knowledgeable and competent palliative care providers. It is imperative to

nursing education that palliative care concepts be integrated into undergraduate nursing curriculums to adequately educate future nurses. Ultimately, patients are at the heart of primary palliative care, and this population deserves students and nurses who are knowledgeable and confident in the care they provide (Harwell, 2019). Ensuring adequate knowledge about palliative care and “positive attitudes towards death and dying are crucial educational aspects when preparing undergraduate nursing students to respond effectively to the complexities of care for people affected by a progressive, life-limiting illness” (Harwell, 2019, p. 53). Specific attention should be paid to misconceptions and biases towards death and dying and the management of chronic illnesses to prepare student nurses adequately to be able to improve the quality of life of their patients and ensure their patients meet their health goals on their terms.

It is important to establish a foundation and framework of primary palliative care knowledge within undergraduate nursing students so that nurses possess the appropriate education to be able to address the concerns of their palliative care patients competently and holistically. The AACN recommends integrating the End-of-Life Nursing Education Consortium (ELNEC) modules into undergraduate nursing curriculums in order to prepare nurses to deliver quality palliative care. Students must be taught that palliative care is essential at the time of diagnosis of any serious illness or event and be provided with the knowledge they need to be able to provide this quality care regardless of their work settings (AACN, 2017). Going forward, palliative care needs to become a mainstream component of nursing education and needs to be prioritized by healthcare providers when caring for patients with chronic and life-limiting illness across the country. Palliative care is the key to optimizing quality of life, managing distressing symptoms, and eliciting goals of care to best match the care we provide with the care our patients would like us to provide.

## Undergraduate Nursing Palliative Care Knowledge Survey (UNPCKS)

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### Start of Block: Block 2

Consent to Participate in this Survey:

Thank you for considering taking the Undergraduate Nursing Palliative Care Knowledge Survey (UNPCKS) (IRB-FY2022-230). This study is being conducted by Odin Bickford, an undergraduate nursing student at the University of New Hampshire under the guidance of Professor Michele Lovell. This consent form describes the research study and helps you to decide if you want to participate. It provides important information about what you will be asked to do in the study, about the risks and benefits of participating in the study, and about your rights as a research participant.

You should:

1. Read the information in this document carefully, and ask the research personnel any questions, particularly if you do not understand something.
2. Not agree to participate until all your questions have been answered, or until you are sure that you want to.
3. Understand that your participation in this study involves you answering some questions about death and your understanding of the care given at the time of death, as well as personal experiences you may have had with death. Participation is comprised of an online survey that is estimated to take 15 minutes to complete.
4. Understand that the potential risks of participating in this study are minimal but could include encountering memories of past experiences that may be difficult to handle.

The purpose of this research is to assess the primary palliative care knowledge of undergraduate, prelicensure nursing students to determine if there is a need for further palliative care education in the undergraduate curriculum. This information is significant to the nursing field because there is an increasing rate of chronic and life-limiting illness in this country that are not being adequately addressed, and many nurses have not received sufficient education as to how to address the concerns of their palliative care patients competently and holistically.

Any use of the internet poses minimal risk of a breach of confidentiality. In order to protect your confidentiality, your survey answers will be protected on an encrypted platform and no IP addresses or personally identifiable information will be collected to protect your anonymity. All of your survey data will be downloaded regularly into a UNH Box file that is password protected and will only be accessed by the research personnel using password protected computers. Data collected in this study will be combined and reported in a student-completed research project that will result in a poster and podium presentation and potentially a peer-reviewed journal article. Data may be shared with other faculty within the nursing department once analysis is complete; however, all data will remain entirely anonymous and will only be used for advancement of the curriculum.

Taking part in this study is completely voluntary. You may choose not to take part at all. If you decide not to participate, you will not be penalized in any way. If you agree to participate in this study and you then change your mind, you may refuse to answer any question or choose to stop participating at any time. Any data collected as part of your participation will remain part of the study records. If you decide to stop participating at any time, you will not be penalized in any way.

If you have any questions pertaining to the research you can contact Odin Bickford at [Odin.Bickford@unh.edu](mailto:Odin.Bickford@unh.edu), or my faculty advisor, Professor Michele Lovell at [Michele.Lovell@unh.edu](mailto:Michele.Lovell@unh.edu) to discuss them. If you have questions about your rights as a research subject you can contact Melissa McGee in UNH Research Integrity Services, 603/862-2005 or [melissa.mcgee@unh.edu](mailto:melissa.mcgee@unh.edu).

Thank you for participating!

Q0 Please indicate if you give consent to participate in this research study.

- Click here if you consent to participate in the research study. (1)
- Click here if you decline to participate in the research study. (2)

Q1 The nurse is orienting a new staff member on a unit that cares for many patients at the end of life. Which of the following comments by the nurse correctly reflects a principle of palliative care?

- "We're busy because most people prefer to die in a hospital rather than at home where they would be a burden" (1)
  - "Death and dying are not discussed much here in order to maintain hope for patients and families" (2)
  - "Because our patients are often uncomfortable, they need physical care more than psychological or spiritual care" (3)
  - "Patients are eligible for palliative care even though they are also receiving curative treatment" (4)
- 

Q2 The nurse's 68 year old patient is in the last hours of life after a lengthy illness. The patient has been receiving opioids for pain management. In assessing the patient as death approaches, the nurse knows that the opioid dose may need to be:

- Increased or decreased to maintain pain control (1)
  - Given only if requested by the patient (2)
  - Monitored as neuropathic pain increases as death approaches (3)
  - Discontinued due to diminished consciousness and altered mental state (4)
- 

Q3 An 84-year-old widow with diabetes and end-stage renal disease has been sent to the hospital from a nursing home. She has gangrene of the left foot with multiple, open infected wounds. Surgery is recommended, but the client does not want any invasive procedures. She wants to go back to the nursing home. She is alert, oriented, and has good decision-making capacity. Her

children are emotionally distraught and pull the nurse aside to say, “We want the surgery. We want to do everything that can be done.” What should the nurse do first?

- Ensure the client and family understand the treatment options and risks. (1)
  - Ask the hospital ethics committee to consider this case as soon as possible. (2)
  - Offer to discuss the children’s preferences with the physicians. (3)
  - Encourage the children to talk their mother into having the surgery. (4)
- 

Q4 Ethical issues abound in palliative care. Which of the following statements most accurately describes the nurse’s role in addressing ethical issues in palliative care?

- Consider patient decisions according to the nurse’s own values and beliefs (1)
  - Help the patient/family understand all options and their consequences (2)
  - Refer patient care ethical issues to ethics experts within the health care system (3)
  - Determine when patients are no longer competent to make their own decisions (4)
- 

Q5 The nurse is caring for a client from Cambodia who has terminal lung cancer. The client is reluctant to discuss the illness. Which of the following actions should the nurse take?

- Remind the client that it is important to talk about the illness (1)
  - Allow the client to remain in denial by not discussing the cancer (2)
  - Ask the family about their beliefs regarding full disclosure (3)
  - Refer the client to a mental health professional for evaluation (4)
-

Q6 The nurse is orienting to palliative care, and is identifying necessary learning activities. In order to provide culturally sensitive care to those at the end of life, one of the nurse's earliest orientation tasks should be to:

- Evaluate the cultural beliefs of co-workers (1)
  - Identify one's own cultural background and values (2)
  - Learn to predict how various races deal with end-of-life issues (3)
  - Become informed about state laws concerning end-of-life care (4)
- 

Q7 An 85-year-old client with end-stage heart disease arrives unconscious at the emergency department after sustaining her third myocardial infarction. The physician has told the daughter that without resuscitation, her mother could die today. The nurse finds the daughter crying by the client's bedside. Which of the following interventions by the nurse is most appropriate in communicating with this family member?

- Ask the daughter if she would like to reconsider treatment (1)
  - Talk to the physician about moving the client to a unit with more privacy (2)
  - Remain present with the daughter, using silence to impart comfort (3)
  - Assure the daughter that she doesn't need to stay with her mother (4)
- 

Q8 The hospice nurse is caring for the family of a man who died several days ago after a long illness. His wife is concerned that their 9 year old son has become withdrawn and is easily angered. Which of the following actions is most appropriate for the nurse?

- Recommend the boy be referred to a specialist for complicated grief reaction (1)
- Suggest to the mother that the boy be excused from his usual activities (2)
- Give permission and opportunities for the boy to express feelings of loss (3)
- Provide information about death to the boy by telling stories rather than giving facts (4)

Q9 The nurse may experience feelings of anxiety and grief when caring for clients and families facing death and the dying process. In order for the nurse to be able to continue to provide quality care, it is important to obtain personal support by:

- Seeking out the assistance of team members whenever necessary (1)
  - Periodic transfer to another unit to avoid caring for dying patients (2)
  - Maintaining an emotional distance from clients and families (3)
  - Scheduling counseling at regular intervals to deal with loss issues (4)
- 

Q10 The nurse is caring for a terminally ill client who wishes to be discharged so that he can die at home. When planning for the discharge of this client with the interdisciplinary team, it is important to consider costs of care. The nurse understands that for a family caring for a dying patient at home:

- Costs of care can exhaust a family's financial resources (1)
  - Medicare will cover all the older client's medical expenses (2)
  - Services are readily available to allow the client to stay at home (3)
  - Medicaid will be the primary provider of services (4)
- 

Q11 The nurse is developing the content for an interdisciplinary discussion on the concept of healing. Which of the following statements should be included?

- Healing is a medical outcome and is most appropriately directed by physicians (1)
- Healing can occur only after the client's spiritual issues have been resolved with a chaplain (2)
- Healing is possible if attention is paid to the multiple dimensions that influence a person's quality of life (3)
- Healing occurs when the patient and family realize and accept when cure is not possible (4)

Q12 The nurse is caring for a 48-year-old woman recently diagnosed with breast cancer. The client is married and has 3 small children. Which of the following is the best time to begin a spiritual assessment?

- When the patient enters the health care system (1)
  - After chemotherapy is initiated (2)
  - Once the patient asks for spiritual support (3)
  - As soon as the client begins to deteriorate (4)
- 

Q13 Mr. F has advanced prostate cancer with bone metastases. He is unresponsive, and is being cared for at home by his daughter. The home health nurse is teaching the daughter about assessing her father's pain. Which of the following statements by the daughter indicates understanding of her father's pain status?

- "If he is not moaning, he's probably not experiencing pain." (1)
  - "I'll have to guess when he is in pain since he can't tell me." (2)
  - "Now that he's unable to communicate, we can stop his pain medication." (3)
  - "Since he was in pain when he was conscious, I assume he's still in pain." (4)
- 

Q14 As the patient's nurse, you should advocate for which of the following patients to get a palliative care referral?

- A 32-year-old female newly diagnosed with breast cancer (1)
  - A 65-year-old male with kidney stones (2)
  - A 49-year-old male with fibromyalgia (3)
  - A 10-year-old female with a broken leg (4)
-

Q15 Jack is a 6 year old who just died at home with hospice from an aggressive type of brain cancer. His parents and his 12 year old sister are having a very difficult time dealing with this terrible loss. Which of the following will be a help to them after Jack's death?

- Hospice bereavement care (1)
  - The American Cancer Society (2)
  - The hospital's child life worker (3)
  - The pediatric oncologist (4)
- 

Q16 Which of the following describe palliative care's philosophy and delivery?

- The care is provided by one healthcare provider, usually a nurse (1)
  - Palliative care is offered when the patient is no longer wanting treatment for his disease (2)
  - It supports the patient and family's hope for quality of life and dignity (3)
  - The focus is only on the final six months of life (4)
- 

Q17 What should drive decision-making in palliative care?

- Finding a cure for the illness (1)
  - The patient's goals of care (2)
  - The need for end-of- life care (3)
  - The wishes of the interdisciplinary team (4)
-

Q18 You are working with Mr. T. who has just been told his heart failure is getting worse. You go into his room to see how he is doing after the team has shared this information with him. He is staring out the window, looking sad. How do you start your conversation?

- "Isn't it a beautiful day today Mr. T.?" (1)
  - "I saw that the team was just here, can you tell me about their conversation with you?" (2)
  - "Are you feeling ok?" (3)
  - "I heard you just got bad news- but I know of someone just like you who lived for three more years." (4)
- 

Q19 John tells you that he doesn't want his wife to know that he has cancer. You sit down to talk about this with him. You begin this conversation with:

- "Why not tell her John?; she probably already suspects it since you have been so sick." (1)
  - "It is your right not to tell her, it would probably just upset her anyway." (2)
  - "Maybe we could have the doctor tell her so you don't have to." (3)
  - "Can you tell me what it is about your wife knowing about the cancer that is bothering you?" (4)
- 

Q20 During your assessment, you notice Robert, who has a diagnosis of dementia, rubbing his right shoulder. What should you do next?

- Ask Robert if he is in pain (1)
  - Give Robert pain medication (2)
  - Contact Robert's healthcare provider (3)
  - You do not need to do anything at this point (4)
-

Q21 What is the only contraindication to opioid use?

- Respiratory depression (1)
  - Constipation (2)
  - Allergic reaction (3)
  - Heart failure (4)
- 

Q22 Symptom management in older adults with serious illness is complicated because:

- They never take their medications correctly (1)
  - Many have multiple comorbidities (2)
  - They tend to ignore their symptoms (3)
  - They like to over-report the severity of their symptoms (4)
- 

Q23 Mrs. F., a 78 year-old Italian woman, is caring for her husband who has end stage COPD and is experiencing anorexia and cachexia. She tells you that she is so upset that he won't eat her pasta anymore. "It was always his favorite" and she cannot understand why he doesn't like it anymore. Which of the following is your best response?

- "I don't know why he wouldn't eat it, you have brought some to our unit and it is wonderful." (1)
  - "Don't take it personally Mrs. F - maybe you should stop pushing him to try to eat." (2)
  - "Maybe you should change your recipe and try making it a little more bland for him." (3)
  - "Food is such an important way that we show we care; it must be so hard for you that he doesn't feel like eating. (4)
-

Q24 Which of the following demonstrates good self-care that may help you in preventing compassion fatigue and burnout when taking care of many patients with serious illness and their families?

- Establish healthy eating, sleeping and exercise habits especially when rotating shifts (1)
  - Volunteer for extra shifts to cover your overworked colleagues (2)
  - Ask to take care of all the very ill patients and families because you have the expertise many of your colleagues don't have (3)
  - Make sure you go to every funeral and service for all the deceased patients you have cared for (4)
- 

Q25 John is a 70 year-old whose wife died from COPD 2 months ago. They were very close, married for 52 years and had no children. He comes by the nursing unit to bring you all candy and a thank you note for all the times you cared for her the past year. He tells you he is struggling to want to eat since she always was the cook, and is just not ready to go out to dinner with his buddies- even though they keep asking him. Your assessment is that John is:

- Experiencing normal grief after his wife died 2 months ago (1)
  - Depressed because he doesn't want to go out with his buddies (2)
  - At high risk for complicated grief because his wife died in the hospital (3)
  - Is doing poorly alone at home because he is not eating well and needs counseling (4)
- 

Q26 You are caring for an 85-year- old man who is dying. He has been comatose for several days. His respirations are now shallow and rattling. His adult children at the bedside state, "We don't want our father to suffocate." Which action should you take?

- Use a suction machine to suction secretions from the mouth and the throat (1)
- Percuss the patient's back to facilitate loosening of congestion (2)
- Reassure the family that terminal secretions are normal and try repositioning the patient (3)
- Request an order for humidified oxygen to decrease the patient's air hunger (4)

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Q27 Mrs. Smith has suffered with terrible bone pain from metastatic breast cancer for the past three admissions to your unit. She is now nearing the end of life. Her family requests that you not give her any pain medications because they are afraid it will hasten her death. What should you do?

- Honor the family's wishes so that they will be more comfortable with her plan of care (1)
- Offer to get the doctor to make the pain medications only as needed rather than around the clock (2)
- Tell the family that she probably won't need her pain medications much longer because she is intermittently unresponsive (3)
- Educate the family about the importance of keeping her comfortable and that the pain medication will not hasten her death (4)

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Page Break

Q28 What year are you in your undergraduate degree?

- Freshman (1)
- Sophomore (2)
- Junior (3)
- Senior (4)

Q29 How old are you?

- 17 (1)
  - 18 (2)
  - 19 (3)
  - 20 (4)
  - 21 (5)
  - 22+ (6)
- 

Q30 Have you ever had a loved one with a complex, chronic, or life-limiting illness? (examples: COPD, type II diabetes, congestive heart failure, cancer)

- Yes (1)
  - No (2)
  - Maybe/unsure (3)
- 

Q31 Have you ever been the primary caregiver to someone else? (examples: parent, child, loved one, friend)

- Yes (1)
  - No (2)
  - Maybe/unsure (3)
-

Q32 Are you a Licensed Nursing Assistant? (LNA or CNA)

- Yes (1)
  - No/not planning on it (2)
  - Planning on it but not currently (3)
- 

Q33 Have you ever seen someone pass away?

- Yes (1)
  - No (2)
  - Maybe/unsure (3)
- 

Q34 Have you ever provided postmortem care (care after someone has passed) to a body?

- Yes (1)
  - No (2)
  - Maybe/unsure (3)
- 

Q35 Have you taken the UNH course "Death and Dying"?

- Yes (1)
- No (2)

**End of Block: Default Question Block**

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