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Hospice and Palliative Care: Imperative to the Education of Nursing

Crystal Lynn Jordan

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Hospice and Palliative Care: Imperative to the Education of Nursing

By

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A thesis submitted to the faculty of
Gardner-Webb University Hunt School of Nursing
in partial fulfillment of the requirements for the
Master of Science in Nursing Degree.

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Abstract

Many advanced practice nursing programs do not have hospice and palliative care content included in their curricula. Reviewing the literature regarding the nature of hospice and palliative care content in advanced practice nursing curricula revealed few published studies. Rather than a small snapshot of what end-of-life care entails, it is vital to integrate end-of-life care into every aspect taught in advanced practice nursing school. The purpose of this thesis was ascertain the nature of hospice and palliative care content contained in advanced practice nursing curricula. A survey was sent to advanced practice nursing program directors asking for information related to the nature of hospice and palliative care content in their curricula. The results showed that while most program directors feel hospice and palliative care is important, adding the palliative care content to the current curriculum was challenging. Barriers include, curriculum being too full, faculty's on personal comfort level, lack of interest, or lack of clinical sites. Additional results revealed that while physical pain management is readily included, emotional pain is ignored/neglected in the curriculums. The more education that advanced practice nurses receive in relation to palliative care, the more prepared they feel to care for dying patients.

Keywords: hospice, palliative care, advanced practice nursing, advanced practice nursing curriculum

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I would like to first take a moment and thank my Savior, first and foremost for dying on the cross to save a wretch like me, for loving me when I don't deserve it and for allowing me such an opportunity to be where I am today. Without Jesus, this would never have been possible. You alone, Jesus, believed in me when I didn't even believe in myself.

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Table of Contents

CHAPTER I: INTRODUCTION

Significance.....	1
Purpose.....	1
Theoretical or Conceptual Framework	2
Thesis Hypothesis	5
Definition of Terms.....	5

CHAPTER II: LITERATURE REVIEW

Literature Review.....	7
------------------------	---

CHAPTER III: METHODOLOGY

Study Design.....	23
Setting and Sample	23
Design for Data Collection	23
Measurement Methods.....	23
Data Collection Procedure	24
Protection of Human Subjects	24
Data Analysis	24

CHAPTER IV: RESULTS

Sample Characteristics.....	25
Major Findings.....	25
Summary	27

CHAPTER V: DISCUSSION

Implication of Findings.....	28
------------------------------	----

Application to Theoretical/Conceptual Framework.....	29
Limitations	30
Implications for Nursing.....	31
Recommendations.....	31
Conclusion	31
REFERENCES	33

List of Figures

Figure 1: Jean Watson's Theory of Human Caring	3
Figure 2: Orem's Self-Care Deficit Theory	5

CHAPTER I

Introduction

Hospice and palliative care are often taboo terms in the field of healthcare. No one in the medical profession wants to assume that he/she can't resolve every issue a patient experiences. Unfortunately, every patient cannot be saved, but they can experience an increase in their quality of life with the provision of palliative care. Palliative care ensures that a patient has a quality life over a quantity life (Meier, 2015). This thesis will be exploring the amount and type of hospice and palliative care content included in the curriculums of advanced practice nursing programs. All nurses care for patients who are dying, so this means a basic knowledge skill set is imperative to assist patients with the utmost care and compassion.

Significance

The significance is that all advanced practice nurses will care for patients who are dying, so preparation in the delivery of this care is imperative. Knowing the nature of the hospice and palliative care, education in advanced practice nursing curricula will provide insight about what needs exist regarding inclusion of this information. Two problems exist – lack of studies describing the nature of hospice and palliative care in advanced practice nursing curriculums, and the lack of content in these programs.

Purpose

The purpose of this thesis was to ascertain the type and amount of the hospice and palliative care content that is included in advanced practice nursing curriculums. Throughout this thesis, hospice and palliative care and end-of-life care will be used interchangeably. Rather than a small snapshot of what end-of-life care entails, it is vital to integrate end-of-life care into every aspect taught in nursing school. Each nurse will

handle death and dying different, however their knowledge base will shape how they are prepared to handle any situation that should arise (Anderson, Kent, & Owens, 2015).

Theoretical or Conceptual Framework

This thesis will follow a theoretical framework following the ideology of two theories. One theory is Jean Watson's Theory of Human Caring, which puts into action 10 carative factors on how to care and deal with patients (Watson's Care Institute, 2010).

These caritas factors include:

1. Practicing loving-kindness and equanimity within context of caring consciousness.
2. Being authentically present and enabling, and sustaining the deep belief system and subjective life world of self and one-being cared for.
3. Cultivating one's own spiritual practices and transpersonal self, going beyond ego self.
4. Developing and sustaining a helping-trusting, authentic, caring relationship.
5. Being present to, and supportive of, the expression of positive and negative feelings.
6. Creatively using self and all ways of knowing as part of the caring process; engaging in artistry of caring-healing practices.
7. Engaging in genuine teaching-learning experience that attends to wholeness and meaning, attempting to stay within other's frame of reference.
8. Creating healing environment at all levels, whereby wholeness, beauty, comfort, dignity, and peace are potentiated.

9. Assisting with basic needs, with an intentional caring consciousness, administering ‘human care essentials,’ which potentiate alignment of mind-body-spirit, wholeness in all aspects of care.

10. Opening and attending to mysterious dimensions of one’s life-death
(Watson’s Care Institute, 2010, p1).

Following the framework, the thesis will show the importance of these caritas in advanced practice nursing curricula, such as how developing and sustaining a helping-trusting, authentic caring relationship is vital for nurses when caring for patients. (See Figure 1).

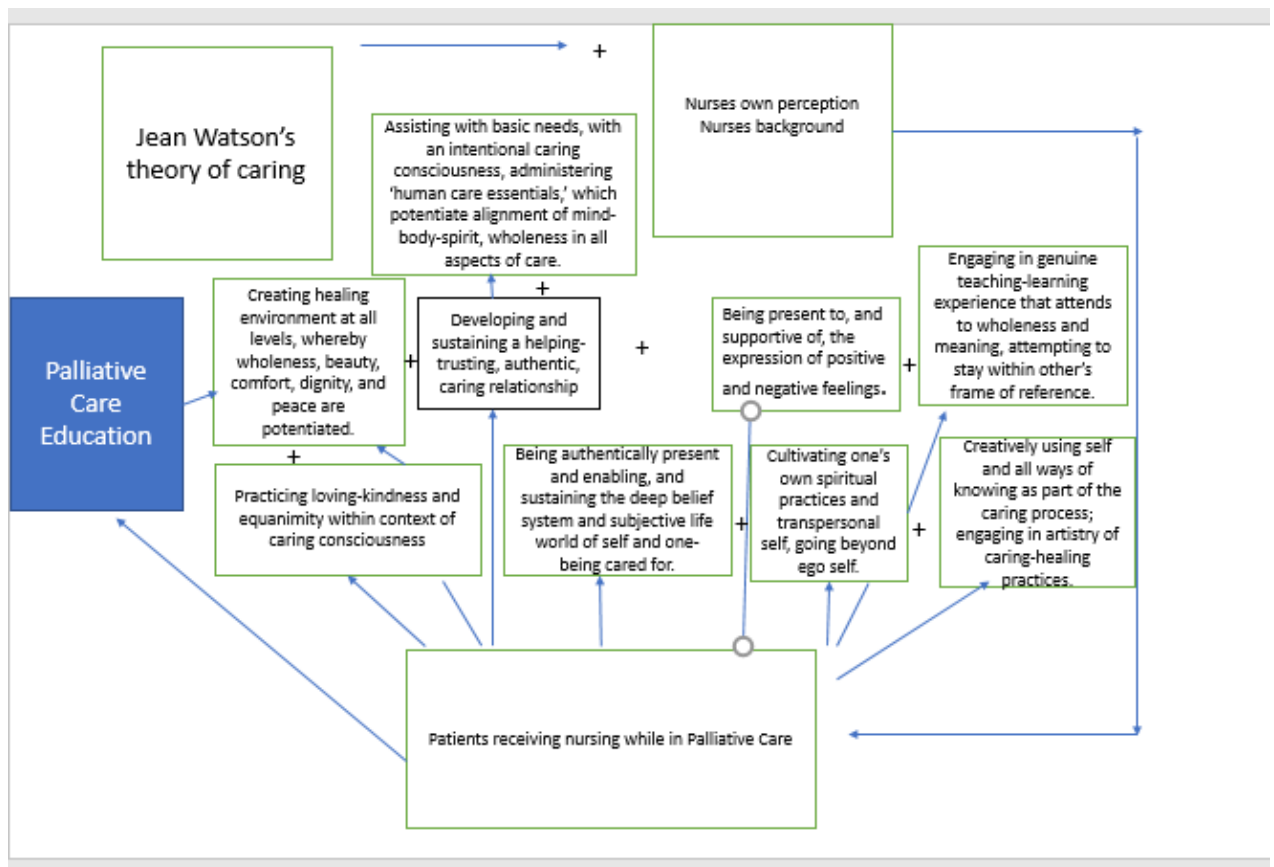


Figure 1. Jean Watson's Theory of Human Caring

Orem's Self-Care Deficit also guided this study. Orem's Self-Care Deficit theory is related to four basic principles of nursing. These principles include deliberate action, self-care, human action of arts and science, and helping others (Biggs, 2008). Throughout Orem's theory, it is noted that communication, fostering consistent care, and ensuring education for nurses are all vital components to ensure patients receive adequate care (Biggs, 2008). Laferriere (1995) discusses a connection between Orem's self-care deficit in relation to hospice care. Orem's self-care deficit theory comprises of three components which are: theory of self-care, theory of self-care deficit, and theory of nursing system. This theory directly relates to palliative care because, as the needs of a patient increase, the deficit of adequately providing their own care can also decrease, which relates to the nursing system and what is needed to provide adequate care (Laferriere, 1995). Throughout Orem's Theory of Practice, Orem's theory simply put states that we are each in control of our own healthcare (Laferriere, 1995). While nursing and caring for the physical aspects at hand, Orem's theory reiterates that end-of-life care may not just relate to the physical care received but also may include needs related to a patient's emotional wellbeing (Laferriere, 1995). This thesis was collecting information to show how much hospice and palliative care is included in advanced practice nursing curricula. (See Figure 2).

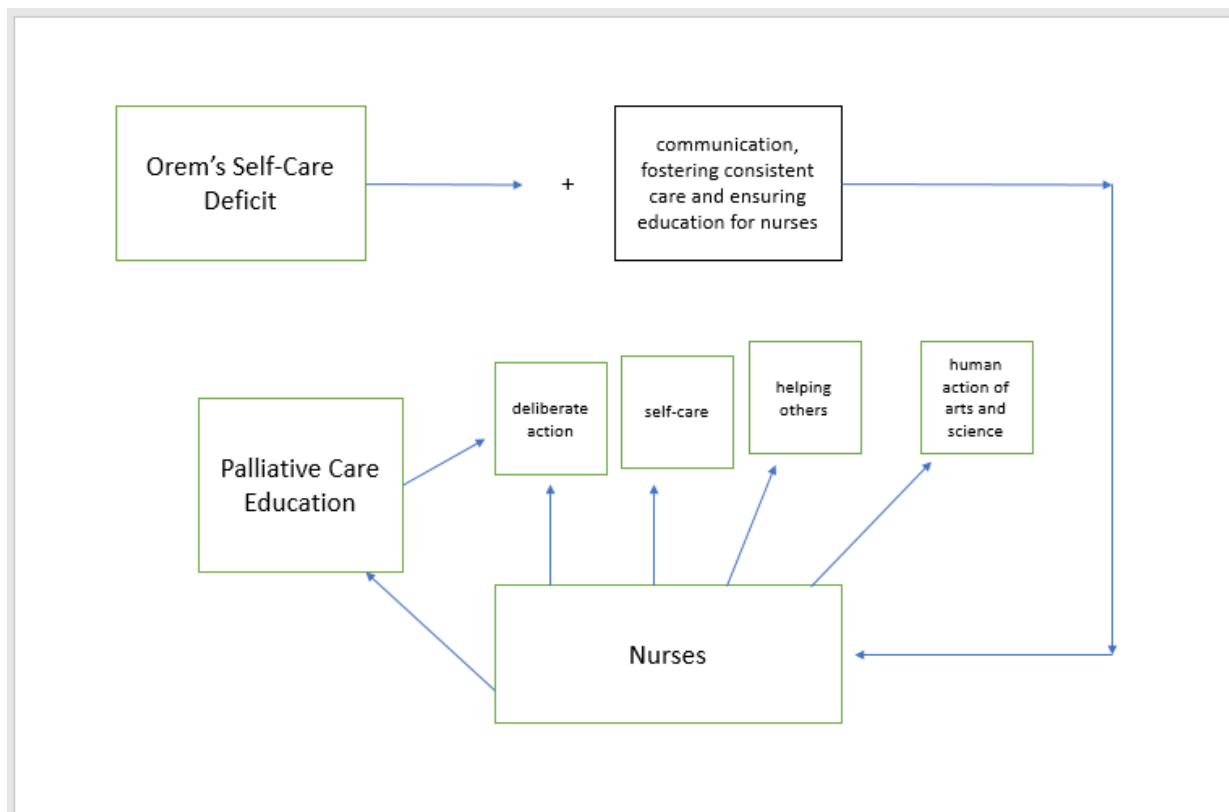


Figure 2. Orem's Self-Care Deficit

Thesis Hypothesis

This study will ascertain the type and amount of hospice and palliative care content that is contained in advanced practice nursing curricula.

Definition of Terms

Hospice - care of a patient whose focus is on caring, not curing. "(Hospice) is the model for quality, compassionate care for people facing a life-limiting illness or injury; hospice care involves a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's loved ones as well. At the center of hospice and palliative care is the belief that each of us has the right to die pain-free and with dignity,

and that our families will receive the necessary support to allow us to do so” (National Hospice & Palliative Care Organization [NHPCO], 2016, p1).

Palliative care- “Patients and family- centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information and choice” (NHPCO, 2016).

In conclusion, the purpose of this thesis was to ascertain the type and amount of hospice and palliative care content in the advanced practice nursing curriculum in the United States.

CHAPTER II

Literature Review

It is imperative that hospice and palliative care content be included in the curriculum for nursing students in advanced practice programs. However, only one study was found that provided information about the nature of hospice and palliative care content in advanced practice nursing curriculums. Due to this lack of existing studies, information regarding the inclusion of this content in undergraduate nursing and medical school curriculums will be included in this literature review.

Robinson, (2004), a reviewed journal article from Medline, discussed the importance of including hospice and palliative care in the undergraduate nursing curricula. Per Robinson, (2004) there were multiple gaps in the education of nurses about hospice and palliative care; therefore, a project, the End-of-Life Nursing Education Consortium, was started to help bridge this gap. This project has led to the education of over 1,000 nurses on end-of-life care (Robinson, 2004). This project grouped the education into several categories of learning, including: pain management, symptom management, ethical and legal issues, cultural considerations in end-of-life care, communication, grief loss and bereavement, achieving quality care at the end of life, and preparation and care for the end of life (Robinson, 2004). Assisting 1,000 nurses to receive this education ensures that these nurses are doing everything within their power to ensure that the patient's death is as peaceful as possible. According to Robinson (2004) nursing organizations are advocating to add end-of-life care to the NCLEX-RN examination to ensure a basic knowledge for all nurses' (Robinson, 2004).

Throughout the text, the article discusses several ways to combat this gap in knowledge about end-of-life care, hospice, and palliative care. To address this learning need, a tool kit was developed for use by nurse educators to teach hospice and palliative care concepts. This tool kit can be provided to nurse educators with different modules for the educators to use to assist in filling the gap that is left by current textbooks. These modules include “comfort, connections, ethics, grief, wellbeing, and impact” (Robinson, 2004). This kit will consist of overviews, resources, exam questions, and case studies to help nursing students learn all they can about end of life care (Robinson, 2004). This kit has been available to nursing students since 2001, as a gift from the Robert Wood Johnson foundation. (Robinson, 2004).

Wallace et al. (2009) reported that studies showed nurses spend most of their time with patients, with that it is imperative that nurses feel prepared to handle any situation that may arise. Over half of all patient deaths will occur in hospitals (Wallace et al., 2009). To review current knowledge, they collected data from 111 undergraduate students (61 sophomores and 50 seniors) (Wallace et al., 2009). Students were made aware that participating in the study would have no effect on their grade (Wallace et al., 2009). These students were given a multiple-choice test with 50 questions to test their basic knowledge about end-of-life care (Wallace et al., 2009). These questions were derived from the 109 questions pulling knowledge from all 9 modules within the ELNEC Curriculum. Of those tested, seniors pretested higher than sophomores, with the seniors having a mean of 83.26 and the sophomores having a mean of 60.98 (Wallace et al., 2009). After the baseline knowledge was determined the students were introduced to the ELNEC Curriculum as it was integrated into current palliative care practices (Wallace et

al., 2009). The students were then questioned on their understanding of palliative care after this implementation and it was clear that the education was a vital part in increasing knowledge on palliative care for all patients (Wallace et al., 2009). Reviewing students' knowledge post curriculum integration several themes were present, including 35% of all seniors reporting there was for specific need for education and experience in palliative care (Wallace et al., 2009). This result concluded that to increase nurses' knowledge of end-of-life care it is vital to provide them with more education (Wallace et al., 2009).

Bush & Shahwan-Akl (2013) raised the question, does palliative education influence future practices? To answer this question a questionnaire was sent to third year nursing students at Victory University who had recently completed an oncology and palliative course (Bush & Shawan-Akl, 2013). This oncology course was comprised of 70% of the data referring directly to palliative care (Bush & Shahwan-Akl, 2013). This questionnaire was created using the Likert scale with area for qualifying comments (Bush & Shahwan-Akl, 2013). This beginning questionnaire asked questions such as how students perceived their own ability to care for patients with life threatening diseases, it also asked whether students would be willing to work in palliative care setting (Bush & Shahwan-Akl, 2013). After the completion of this questionnaire, a secondary study was completed which selected students of this same group to be a part of a focus group discussion about effective ways to each about palliative care (Bush & Shahwan-Akl, 2013). This focus group comprised of 70 students who were randomly selected from total of 109 students enrolled (Bush & Shahwan-Akl, 2013). Of those 70 students 51 returned their survey (Bush & Shahwan-Akl, 2013). These 51 students were made up of 44 females and 7 males which was a direct reflection of the cohort (Bush & Shahwan-Akl,

2013). One hundred percent of students surveyed indicated that the course had shaped their perceived competence level concerning palliative care and oncology (Bush et al, 2013). No student surveyed stated that the course decreased their perceived competence level (Bush et al, 2013). The conclusion drawn from this study is that nurses feel a course in palliative care is imperative to help lead them to better can take care of palliative care patients (Bush et al, 2013).

Hendricks-Ferguson, Akard, Madden, Peters-Herron, and Levy (2015) stated that while there has been a significant amount of improvements in the past decade, it is estimated that some children will still inevitably succumb to their illness. This journal article from Medline stated that while DNP nursing education primarily focuses the most inventive and up-to-date information to provide care to patients, it does not include a major focus on end-of-life care (Hendricks-Ferguson et al., 2015). By obtaining this education while in school, the nurse would have more of a chance of providing more holistic care for end-of-life pediatric patients (Hendricks-Ferguson et al., 2015). By providing holistic care for end-of-life pediatric patients, early referrals can lead to fewer hospitalizations and a cost-savings for the patient. (Hendricks-Ferguson et al., 2015). By providing more education on palliative care and decreasing hospital admission stays, costs to health care systems would decrease (Hendricks-Ferguson et al., 2015). By being able to be well-positioned during end-of-life care conversations, families will feel more at ease to make the tough decisions in the care of their loved ones (Hendricks-Ferguson et al., 2015). It is imperative that end-of-life education is included in all advanced practice education programs.

Throughout this journal article retrieved from Medline, one of the most important ideologies nurses will learn throughout their education is how to work in teams (Hermann, Head, Black, & Singleton, 2016). However, “adding interprofessional education (IPE) has proven to be difficult in an already crowded curriculum” (Hermann et al., 2016). Teamwork among nurses sets a foundation for better patient outcomes, more confident nurses, and an overall better morale (Hermann et al., 2016). The focus when preparing nurses adequately is communication, collaboration, and teamwork (Hermann et al., 2016). This communication is even more vital in a specialty situations, such as end-of-life care or palliative care (Hermann et al., 2016). The idea of Hospice began in the late 1960s, and decades later has grown into the present-day palliative care, also known as end-of-life care (Hermann et al., 2016). With the boom of this palliative care movement, nurses felt increasingly more of the responsibility to provide the care, the education, the shoulder to lean on, and show the experience about the patients’ health (Hermann et al., 2016). With the need in place for more expertise, how to gain this expertise became the primary focus. The World Health Assembly then integrated the policies and budgets of hospice and palliative care to be included in the curriculum for all health care professionals (Hermann et al., 2016). Palliative care is an essential part of the education nurses must receive to adequately take care of every growing population of individuals.

Is it vital for nurses to have education on hospice and palliative care? If yes, then the next question is, how? To answer these questions, nurses began to brainstorm by completing a list of situations within palliative care that a nurse may face. This list included speaking with a family member through meetings, assisting them with the

changing health of patients and their feelings surrounding it, and assisting families in what is to come. (Hermann et al., 2016.) So, to complete this task, a framework was chosen and developed by the National Consensus of Quality Palliative Care. After lengthy discussions, a framework was set into place which included: the ability for nurses to perform multiple tasks at once, and being able to care for the patient as well as the family in all unique psychological, spiritual, social, and cultural resources and needs (Hermann et al., 2016).

To accomplish the goal of education of palliative care and end-of-life care is imperative for all nurses (Hermann et al., 2016). To make health care a better place, and to help nurses feel more adequately prepared, changes must happen to encourage education and provide avenues to new ideas of healthcare (Hermann et al., 2016).

Most deaths in society happen in some type of health care environment (Ramjan, Costa, Hickman, Kerns, & Phillips, 2010). Ramjan et al. (2010) completed a key word search for the following terms: undergraduate, curriculum, multidisciplinary, palliative care, education, and nursing. Using these key words, a journal article was written that states 50-70% of all deaths occur in an acute care setting (Ramjan et al., 2010).

Regardless of in what area a death occurs, it is inevitable that a nurse will be assisting in the stages of the terminal condition, and will be dealing with the family also (Ramjan et al., 2010). While this is the case, only a few nurses have the certification needed to provide essential palliative care (Ramjan et al., 2010). Undergraduate nursing education must include education about palliative and end-of-life care to “prepare graduates to achieve the core capabilities required to deliver the best evidenced based care” (Ramjan et al., 2010, p 85). Comfort and dignity are at the forefront of the palliative care

approach through early detection, assessment, and ease of pain (Ramjan et al., 2010). In addition to taking care of the physical symptoms, it is also crucial that a nurse can recognize the patients' psychological and/or spiritual concerns (Ramjan et al., 2010). To be able to achieve this, nursing graduates need to be prepared with the knowledge and foundation of palliative care to be able to sufficiently provide care to both patients and families (Ramjan et al., 2010). During difficult times, often the most difficult questions arise. When patients and families are uncertain what the future holds for their health, they will likely ask questions to try to have a better understanding of what is needed (Ramjan et al., 2010). Nurses who don't have the proper education and confidence level will not be able to provide the care needed to these patients (Ramjan et al., 2010).

Even though great strides have been made in relation to the integration of palliative care, there have been barriers that have also presented themselves (Ramjan et al., 2010). Having a limited number of placements that have a palliative care specialty for nurses to gain hands-on experience creates a limit which is often difficult to overcome (Ramjan et al., 2010). To alleviate this, the Australian government funded the palliative care curriculum for undergraduates (Ramjan et al., 2010). This program was designed to focus on "Principles of palliative care, communicating with people with life-limiting illness, palliative assessment and intervention, and optimizing function in palliative care" (Ramjan et al., 2010). Nursing students who can gain knowledge through education gain the skill set needed to provide excellent care (Ramjan et al., 2010). The evidence that Australia found concluded that it is vital to include palliative care and end-of-life care to the nursing curriculum; this will allow for increased customer expectations and deliver top-of-the-line nurses in an ever-competitive field (Ramjan et al., 2010). In this case

study, it is expected that nursing students will have a basic knowledge and skill set and will be able to apply that skill set and use it throughout a palliative care setting (Ramjan et al., 2010). In relation to specific data, it was noted throughout Ramjan's et al. (2010) article that not much research exists to be able to pull data. However, despite the limited amount of research, Ramjan et al. (2010) could identify that nursing students have general anxiety regarding death, dying, and caring for dying patients.

Per the Paice, Ferrell, Coyle, and Callaway (2007) journal article derived from Medline, 50 million people die each year many without proper access to adequate pain control or palliative end-of-life care. One major reason for this lack of care is that nurses do not have the education needed to be able to provide adequate care (Paice et al., 2007). Palliative care is not just for cancer patients; palliative care also covers a variety of other illnesses, including HIV/AIDS, advanced cardiovascular disease, end stage renal disease, hepatic disease, upper motor neuron disease, and end-stage dementia (Paice et al., 2007). To test that palliative care is effective in assisting a range of different patients, Paice et al. (2007) collected a convenience sample of 38 nurses from 14 different countries and collected data using Likert scales and open-ended questions. Several questions were asked to collect the data, such as the value of palliative care, and what they felt the conference could add in relation to the palliative care of patients (Paice et al., 2007). Conclusions were formed, that nurses need a lot more education on the area of palliative care and hospice, and extensive support tools must be provided to nurses assisting with this population of patients (Paice et al., 2007). Throughout the article, it was stressed that well-trained professionals are vital in addition to educational materials and training programs to assist with the ideology of palliative care (Paice et al., 2007).

End-of-life nursing education consortium (ELNEC) was used to adapt their current curriculum to fit the needs of nurses on a larger spectrum (Paice et al., 2007). This project began in 2000 and was initially funded by the Robert Wood Johnson Foundation, and additional funding then came in from the National Cancer Institute, the Aetna foundation, the Arch Stone Foundation, and the California Healthcare Foundation (Paice et al., 2007). By using the ELNEC, the international end-of-life nursing educational program could expand the core curriculum for nurses to include vital information about palliative care (Paice et al., 2007). This project now expands to graduate nurse educators, pediatric nurses, oncology nurses, and critical care nurses (Paice et al., 2007). To date, approximately 3,000 nurses, including several from each US state, have received training (Paice et al., 2007).

The results of this training concluded that nurses greatly valued the professional level of education, they could foster interactions, and learn to network amongst participants that will assist them with their own practice when returning to their home country (Paice et al., 2007). By providing this opportunity to all nurses regardless of region, it will ensure that a certified nurse will be available doing the same type of care in every part of the world; therefore, a continuity of care will be established (Paice et al., 2007). The conclusion of this study was that it is imperative to improve care for patients who are gravely ill (Paice et al., 2007). The goal was for patients to have an improved sense of the quality of their life, and to feel holistically cared for from the nurses providing the care (Paice, et al., 2007).

Each day the population of the United States is aging, with 13% of the population being 65 years of age or older (Seaman & Herbert, 2016). This demographic is constantly

changing, and every year it slightly increases. With the increase of age also comes the increase of the complexity of illness, with two-thirds of all beneficiaries of Medicare having at least two chronic illnesses. (Seaman & Herbert, 2016). With Americans living longer, this also means that nurses are responsible for caring for patients longer, and the patients themselves are sicker than before (Seaman & Herbert, 2016).

Palliative care is not only an education on providing for physical needs; palliative end-of-life care also provides for psychological and spiritual suffering. Nurses report they feel unprepared to provide this type of care to patients and families, in part because of the lack of education they have received (Seaman & Herbert, 2016). To test this fact, Seaman surveyed 376 nurse practitioner programs (Seaman & Herbert, 2016). The survey delivered was meant to parallel the education and content being taught (Seaman & Herbert, 2016). An introductory email was sent to everyone who would be surveyed, making them aware of the study. Alongside the survey, a follow-up email was sent in seven days, reminding participants of the timeframe to complete the survey (Seaman & Herbert, 2016). The results were: 101 offered both nursing practitioner (NP) and Doctorate of Nursing (DNP) programs, while 45 offered one and the other program but not both (Seaman & Herbert, 2016). Education clinical experiences were provided in a variety of settings, including hospitals at 66%, hospices at 60%, nursing homes at 15%, and patients home at 29% (Seaman & Herbert, 2016). Each of these programs used nurses as instructors, and only a small percentage of them used a multidisciplinary team of educators such as physicians, and clergy (Seaman & Herbert, 2016). Half of the programs offered less than 10 hours of palliative care instruction (Seaman & Herbert, 2016). Only 11% of the programs surveyed report 20 hours of instruction (Seaman &

Herbert, 2016). Of everyone surveyed, 83% viewed palliative care education as either extremely or very important, 15% thought it was moderately important, and 2% viewed palliative care as slightly important (Seaman & Herbert, 2016). Forty-six percent of the barriers reported were that the curriculum is already too full, and 24 % stated lack of clinical sites as a barrier (Seaman & Herbert, 2016). In conclusion, it was determined that while some of the schools do provide graduate level palliative care, most do not feel what they are teaching is adequate to fulfill the ever increased need throughout the community (Seaman & Herbert, 2016). Therefore, it is imperative to change the graduate curriculum to include palliative care as the needs are evolving and the future of sicker patients are in the hands of nurses of the future (Seaman & Herbert, 2016).

Current standards do not meet all needs of families in relation to palliative care. (Kelly, Ersek, Virani, Malloy, & Ferrell, 2008). The 2006 California Healthcare Foundation, by using a convenience sample of 1,778 Californians asking about their concerns related to death and dying, stated that only 58% of all families feel their loved one experienced a “good death” (Kelly et al., 2008). When reviewing evaluation data from the 2007 pilot ELNEC training program and then comparing it to data received from a follow-up evaluation (Kelly et al., 2008), it was found that only two of 72 chapters from three different gerontology books were devoted to end-of-life care and that overall, less than 2% of all texts books relate to palliative care (Kelly et al., 2008). To respond to this gap in education, an initiative was born to improve care, and the end-of-life consortium was launched as an educational opportunity to assist with bridging the gap with all curriculum deficits (Kelly et al., 2008). The primary goal of this consortium was to first educate nurses while also providing them the proper tools to not only teach themselves

and coworkers, but also to be able to provide information to families (Kelly et al., 2008) What they could find by implementing this consortium was that the training provides an excellent framework for nurses to gain knowledge and skills needed to complete their jobs effectively (Kelly et al., 2008).

Adriaansen, Achterberg, and Borm (2005) described a study that looked at the results of a post qualification exam and how the course increased nurses' knowledge of palliative care and promoted self-efficacy among nurses (Adriaansen et al., 2005). A post qualification exam is an exam that is given after education is completed to gauge how prepared students are for board exams. These results were then put together and tested using two different instruments, including a comprehensive variant of palliative care and domain-specific tools for palliative care (Adriaansen et al., 2005). By completing this research, they derived that educational courses are helpful for nurses attempting to provide palliative care (Adriaansen et al., 2005). Registered Nurses (RNs) state they do not often feel they have adequate amounts of education surrounding the subject of palliative care (Adriaansen et al., 2005). Palliative care is care for the patient in the final stages of their life (Adriaansen et al., 2005). This care not only focuses on the physical symptoms but also includes any side effect symptoms which may invade their quality of life (Adriaansen et al., 2005). Also, palliative care patients feel that symptom relief is not their only need during this period; patients also have a desire to be listened to and given time to reflect (Adriaansen et al., 2005). Patients in this stage of life not only need assistance with pain control, they also need to be given time; time to reflect and discuss the meaning of life and how they feel (Adriaansen et al., 2005). They also need to have any fears they may have addressed (Adriaansen et al., 2005). Many health care workers

reported they feel inadequate with their lack of knowledge in these areas (Adriaansen et al., 2005). To test this knowledge, this study conducted a course consisting of an array of different subjects, including how to deal with palliative care with the inclusion of pain and symptom management, and care following death of a patient (Adriaansen et al., 2005). During this time, students worked on specifically aimed assignments to help reflection on the nurses' personal feelings regarding death and dying (Adriaansen et al., 2005). The results of the study indicated that the RNs felt more competent after completion of the course, and RNs also felt a better sense of achievement (Adriaansen et al., 2005). Evidence-based practice shows that nurses with education on palliative care feel more competent at delivering care (Adriaansen et al., 2005). The results they could derive were of the 57 RNs they administered the test to, data from 19 of them was considered unusable due to the fact they were not tested a second time (Adriaansen et al., 2005). In addition to the RNs tested, 50 (Licensed practical Nurses) LPNs were also tested in the first study, and 37 who took part in the entire study (Adriaansen et al., 2005). The mean age of the RNs was 37.6 years while the mean age of the LPNs was 37.1 (Adriaansen et al., 2005). RNs had an average working of experience slightly higher than that of LPNs. RNs' average was 8.7 while LPNs' average was 8.1 (Adriaansen et al., 2005). Reviewing the amount of education the nurse received directly correlated to how their knowledge base of palliative care. (Adriaansen et al., 2005).

With the lack of research available on nurses in relation to palliative care, it was imperative to branch out and further consider other medical areas to see if the same gaps also existed. Physicians and medicals students reported that they felt their education on palliative care and education was lacking (Chiu, Lao, & McDonald, 2015). New Zealand

stated that close to half of all patients in the hospital will die during their stay (Chiu et al., 2015). With this amount of deaths occurring in a medical facility, it is vital that doctors have the adequate education to provide care to these members and families (Chiu et al., 2015). This leaves medical students to be the liaison between the patients and the physicians. One study stated that only 19% of all medical students received palliative care education prior to graduation (Chiu et al., 2015). Nearly 75% of all medical students reported they could greatly benefit from some palliative care education. (Chiu et al., 2015). To improve this, it is vital that standardization of palliative care (Chiu et al., 2015). Being able to establish definitive guidelines on care to ensure that all medical students receive the same type of education and can provide standardized care to patients.

Death and dying can affect any branch of medicine (Dibiaso, 2016). Dibiaso explained that not all medical students feel preparative to deal with patients with life threatening illnesses (Dibiaso, 2016). A few of these symptoms include pain, nausea, shortness of breath, and anxiety (Dibiaso, 2016). Feeling they are not adequately prepared to deal with these types of patients can lead to hesitation in caring for these patients (Dibiaso, 2016). To review the medical students' feelings toward palliative care, Dibiaso completed a cross-sectional, web-administered survey of 457 students (2016). Dibiaso's study found that less than half of students had experience working with a dying patient, but of the medical students who have, 87.5% found this interaction to be rewarding (Dibiaso, 2016). Dibiaso's study also found that more than half of students felt somewhat prepared to discuss do not resuscitate orders (Dibiaso, 2016). Surprisingly, of the 457 students surveyed, only a minute number of students report they felt adequate to break the news to family that comfort only measures should begin

(Dibiaso, 2016). This information was very alarming, because it means that almost all medical students do not feel prepared for these situations and may not transition the patient to comfort-only care as quickly, which would result in more unneeded tests being performed on the patient, and more health care costs incurred for the health care agency (Dibiaso, 2016).

It was noted that with inexperienced medical students, inclusion of family was not likely (Dibiaso, 2016). Not recognizing the family as a part of the patient unit can create barriers and lead to less-effective communication of patients (Dibiaso, 2016). With the aging society, chronic disease is steadily increasing; therefore, the need for more adequate training in palliative care is essential to ensure that clinicians can not only provide basic needs, but can also react to situations with compassion and understanding to all patients. (Dibiaso, 2016).

Wilson, Goodwin, and Hewitt, (2011) conducted a survey about how much end-of-life education was provided to undergraduate nursing programs across Canada. Of the 35 universities studied, 29 of them responded to the survey (Wilson et al., 2011). Of the 29 schools who responded, all but one school reported they were providing some type of education on death and dying (Wilson et al., 2011). In Canada, since 2004, they have had a certification process for any nurses wanting to work with hospice or palliative care (Wilson et al., 2011). The study suggested that this certification has reinforced the push for more education on the subject and has brought to light the importance of understanding how to deal with death (Wilson et al., 2011). Of the schools who responded to the survey, an average of 24.5 classroom hours and 36.25 clinical hours was spent on death and dying process (Wilson et al., 2011). This means of the average two-

year course, only 24.5 hours are spent on this subject. This study could show the importance of full inclusion of hospice and palliative care, and how integrating it into the curriculum can provide positive feedback for the nurse providing the care (Wilson et al, 2011).

In summary, using both education and experience has been proven to allow students the opportunity to gain the knowledge needed to feel confident to handle death and dying experiences in the future. That is why it is imperative to include death and dying instruction for every nursing student in the future.

CHAPTER III

Methodology

The purpose of this thesis was to ascertain the nature of hospice and palliative care content contained in advanced practice nursing curricula. Advanced practice nurses play a vital role in ensuring that patients at the end of life receive quality hospice and palliative care. Inclusion of this content in the advanced practice nursing curricula could help nurses feel more confident in providing this care.

Study Design

This thesis followed a descriptive design. The variables or subjects that were involved in the study were unable to be controlled, manipulated, or altered.

Setting and Sample

Subjects were directors of advanced practice nursing programs in North Carolina, South Carolina, Virginia, and Tennessee. Directors of online advanced practice nursing programs were also included. The sampling frame was 56. The sample was obtained by accessing the programs' websites and retrieving the email addresses of the program directors.

Design for Data Collection

The survey was sent to all advanced practice nursing program directors. The directors were given seven days to complete the survey. After seven days, a reminder email was sent to remind directors to complete the survey.

Measurement Methods

The survey was developed by an advanced practice nurse who is a faculty member and who is a hospice and palliative care practitioner. The survey was reviewed

by a second faculty member with expertise in curriculum development. The survey asked advanced practice nursing program directors to provide information regarding the nature of hospice and palliative care content contained in their curricula. Items in the survey were chosen to provide the specific information regarding this content.

Data Collection Procedure

Directors of advanced practice nursing programs were asked to complete a survey in order to provide information regarding the nature of hospice and palliative care content contained in their curricula. An email was sent out which explained the purpose of the study and asked for their participation. The survey was distributed online via Survey Monkey. Participants were given seven days to complete the survey. After seven days, each program director received a second follow up email. All data was collected and analyzed via Survey Monkey.

Protection of Human Subjects

The surveys were completed anonymously. No identifying information was collected on the survey and no identifying information was in the results. This study posed minimal risks to participants. Subjects were informed that they had the choice to complete the survey or not. The data collected was stored on a password protected computer and then handed in to the sponsoring University and will be stored in a locked cabinet for three years.

Data Analysis

Responses to survey questions were obtained through Survey Monkey. Data was described using descriptive statistics.

CHAPTER IV

Results

The purpose of this thesis was to ascertain the nature of hospice and palliative care content contained in advanced practice nursing curricula. The need for palliative care content in advanced nursing curricula is ever-evolving, and institutions must evolve to adapt to the changes in the population.

Sample Characteristics

The final sample size was 10 (18%) with seven respondents and three withdrawals. Not all questions were answered by all respondents, some questions were skipped.

Major Findings

Characteristics of Advanced Practice Nursing Programs

Roughly half 57.14% (4/7) of all programs directors who responded were from a private institution, while 42.66% (3/7) were from a public institution. Of those institutions, 28.57% (2/7) had 0-50 students enrolled, 28.57% (2/7) had 51-100 students, and 28.57% (2/7) had 101-150 students enrolled. Only 14.29% (2/7) institutions reported having 151 students or more enrolled. 14.29% (1/7) of the institutions resided in North Carolina, 14.29% (1/7) resided in Virginia, 14.29% (1/7) resided in South Carolina, while 57.14% (4/7) resided in a state other than those listed. Three of the seven programs or 42.86%, offered both the master of science of nursing practitioner program and the doctor of nursing practitioner program. In addition, 42.86% (3/7) offered the master of science of nursing practitioner program alone and 14.29% (1/7) offered the doctor of nursing practitioner program alone. Of the nursing practitioner program directors who responded: 85.71% (6/7) reported having a specialty of family nurse practitioner, while 28.57% (2/7)

offered either adult- gerontology primary care nurse practitioner or psychiatric-mental health nurse practitioner. In addition to these specialties, another 14.29% (1/7) reported offering adult-gerontology acute care nurse practitioner or pediatric primary care nurse practitioner. None of the program directors surveyed (0) % reported a sub specialty nurse practitioner certification. Most palliative care (80% [4/7]) were taught through a course offering, while 40% (2/7) reported only including lectures embedded throughout their curriculum. 80% (4/7) required palliative care as a part of their curriculum while 20% (1/7) have it listed as an elective. 100% (7/7) of instruction provided came from an instructor with a nursing background.

Palliative Care Content

Survey results revealed that most programs 83.33 % (5/7) had some type of palliative care content; however, zero of the programs were didactic courses with a primary focus in palliative care. 60% (3/5) of the programs reported three to four hours of content devoted to palliative care, while 40% (2/5) only devoted one to two hours. Only 40% (2/7) offered clinical experiences. These experiences occur mainly in acute care facility (50%) (2/4) settings, while the other 50% (2/4) reported their experiences as an option. While not every program reported to have the same type of palliative care content, 100% of those who responded report their curriculum includes more palliative care than five years ago. The most prevalent palliative care topic discussed throughout the current curriculum is pain management (100%) (7/7), while the topic of communication with patients and families was included in 40% (2/7) of curriculums responded. Only 10% (1/7) discussed topics of non-pain symptom management, cultural or spiritual care for patients and families or bereavement and grief.

Attitudes about Palliative Care

Of the total seven program directors who responded, 57.14% (4/7) percent viewed palliative care as extremely important, while 28.57% (2/7) viewed palliative care as very important and 14.29% (1/7) viewed it as moderately important. 100% (7/7) of program directors who responded feel that the current amount of palliative care content is not adequate. Program directors indicted that the most frequent barriers to inclusion consist of the curriculum being too full (42.86% [3/7]), faculty not experienced in palliative care (42.86%) [3/7]), faculty perception that current instruction was adequate (14.29% [1/7]), lack of interest by faculty (14.29% [1/7]), and lack of clinical sites (28.57% [2/7]). Four of the seven respondents responded to the item regarding support for requiring palliative care education. Three of the four (75%) indicated they were extremely supportive of requiring palliative care education while one of the four (25%) was very supportive. Three of the four (75%) of the institutions report that palliative care is included in the future curriculum at their school, while one of the four (25%) report it is not included.

Summary

Survey results were analyzed via survey monkey responses. All the schools sampled had some variance of palliative care content in their advanced practice nursing curriculum. Of 10 respondents seven completed the survey and that they provided information regarding the characteristics of their programs, the content included and attitudes regarding the inclusion of hospice and palliative care content in the curricula.

CHAPTER V

Discussion

The purpose of this thesis was to ascertain the nature of hospice and palliative care content contained in advanced practice nursing curricula. The need for palliative care content in advanced nursing curricula is ever-evolving, and institutions must evolve to adapt to the changes in the population.

Implication of Findings

Many program directors reported that current palliative care curriculum was not adequate. Barriers to including palliative care into the curriculum were reported. They included lack of interest from faculty and lack of exposure to palliative care by faculty. This survey revealed that the deficient has been present dating back to the education of the current faculty. While strides have been made to include more palliative care than in previous years, there are many reasons that more content has not been included. A few reasons given for palliative care not being included were the curriculum was too full, the faculty is not experienced in palliative care, faculties' perception that the current instruction was adequate, lack of interest by faculty, and lack of clinical sites.

Pain management was the topic most programs included in their curricula. Per Duke, Haas, Yarbrough, and Northam (2010) one way to combat the barrier of not adequately addressing pain management, was to ensure all nursing students have adequate education about the pain assessment. By having this knowledge, nurses may be able to quicker identify pain and address it as needed (Duke et al., 2010). Cultural or spiritual care for patients and families was not often discussed. A small majority discussed bereavement and grief. Palliative care curriculum instruction is currently

provided strictly by nursing. More investigation is needed as to if other topics in relation to palliative care would be discussed if a social worker or clerical instructor was included in the palliative care programs. One such university has been able to address the barrier of discussing bereavement and grief by also including social workers and clergyman as instructors throughout their curriculum (California State University [CSU], 2017).

Application to Theoretical/Conceptual Framework

The study was led by the theoretical frameworks of Dr. Jean Watson and Dr. Dorothea Orem. Jean Watson's Theory of Human Caring includes 10 carative factors about how to care for patients (Watson's Care Institute, 2010). Following the framework, the thesis showed the importance of these caritas in advanced practice nursing curricula, developing and sustaining a helping-trusting, authentic caring relationship is vital for nurses when caring for patients. Using these Caritas as a framework of advanced practice nursing curriculum allows for a holistic approach to palliative care

A second theoretical frame work, Orem's Self-Care Deficit theory, led the study. Orem's principles included deliberate action, self-care, human action of arts and science, and helping others (Biggs, 2008). Throughout Orem's theory, it was noted that communication, fostering consistent care and ensuring education for nurses are all vital components to ensure patients receive adequate care (Biggs, 2008).

Results revealed one thing lacking from many programs is the holistic approach. To improve this deficit advanced practice nursing curriculum could include hospice and palliative care and also gain expertise of other disciplines such as clergy and social workers. Two topics revealed in the results with little instruction included bereavement and grief. Without instruction in these areas, nurses may not feel prepared to handle those

situations. In relation to this ideology, it again also leans toward the premise of holistic care. Reviewing the results, it was found that some faculty have little interest or comfort around palliative care; this reiterates the importance of further education in this area.

Limitations

This study had several limitations. The survey response rate was 18% with 10 respondents, and seven respondents completed the survey. The limitation was that this is just a snapshot of some programs' content and that information from more schools is needed. An additional limitation is the number of schools that currently offer advanced practice education in relation to palliative care. Currently, there are “six established APRN palliative nursing fellowships as opposed to some 140 palliative medicine fellowships for physicians.” (Dahlin, Coyne, & Cassel, 2016). This limitation alone reiterates the need for more palliative care education for advanced practice nurses to help bridge the gap. Another limitation is that this survey included a variety of schools from different states in the south; however, other states on the west coast and midwest were not included in this study. Some variation in nursing care is expected depending on the region. For example, one west coast school, California State University, has overcome the deficit of palliative care by offering a standalone palliative care education program (CSU, 2017, P 1). This program offers the opportunity to “explore evidence-based approaches to advance practice palliative nursing, improve patient outcomes, help patients identify and achieve their care goals, and implement pain and symptom management strategies to reduce patient's illness burden and suffering” (CSU, 2017, P1). Lastly, one barrier expressed was the fact that faculty expressed little interest in palliative care, however there isn't further information to conclude if this was structural or

personal. More information is needed to address if faculty have personal beliefs that lead to little interest in palliative care, or does the current structure of the curriculum, not leave room to branch out subjects such as palliative care.

Implications for Nursing

Including palliative care content into advanced nursing curriculum is imperative to nursing education. By addressing the nurses' own beliefs, comforts, and fears and then addressing them, adding a knowledge base of holistic palliative care could lead to nurses who feel more prepared to care for patients who need this type of care.

Recommendations

Recommendations for further study on the importance of inclusion of hospice and palliative care content would be outreaching to schools in the west coast, in addition to those on the east coast and the midwest. By comparing more institutions in both the private and public sector, trends are noted of what topics are being taught and what topics are left out. This information would help formulate a curriculum that would be more adaptable throughout the US.

Conclusion

Nursing is forever changing and will never be stagnant. Noting this, the curriculum will also have to evolve and include different topics. Looking at the results of the survey, physical pain management is readily discussed, however emotional pain is ignored/neglected in the curriculum, institutions must work to include topics such as emotional pain, bereavement, grief, depression and anxiety, and holistic care of the patient and family. Only 20% (1/7) currently teach these areas. While inclusion of all areas may not be feasible, inclusion of hospice & palliative care content is imperative to

the health of America. Further research is needed on the way to include hospice & palliative care content most effectively in order to provide optimum care to these patients. The more education that advanced practice nurses receive in relation to palliative care, the more prepared they feel to care for dying patients. With a basic knowledge skill set, advanced practice nurses are armed with the education needed to ensure patients feel empowered and can make the difficult decisions related to their health. It is vital to review the barriers in relation to hospice & palliative care, such as the curriculum being to full, or faculty who are not experienced, and create ways to overcome these barriers. To combat this, advanced practice institutions must include broader education to include the emotional aspect of palliative care. This competency could improve the quality of care for patients and could lead to more positive outcomes.

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