

2017

Primary Care Nursing Barriers to Identifying and Referring Patients to Palliative Care

Angela F. Rutherford

Follow this and additional works at: https://digitalcommons.gardner-webb.edu/nursing_etd



Part of the [Nursing Commons](#)

Recommended Citation

Rutherford, Angela F., "Primary Care Nursing Barriers to Identifying and Referring Patients to Palliative Care" (2017). *Nursing Theses and Capstone Projects*. 284.

https://digitalcommons.gardner-webb.edu/nursing_etd/284

This Thesis is brought to you for free and open access by the Hunt School of Nursing at Digital Commons @ Gardner-Webb University. It has been accepted for inclusion in Nursing Theses and Capstone Projects by an authorized administrator of Digital Commons @ Gardner-Webb University. For more information, please see [Copyright and Publishing Info](#).

Primary Care Nursing Barriers to Identifying and Referring Patients to Palliative Care

by

Angela F. Rutherford

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

Boiling Springs, North Carolina

2017

Submitted by:

Approved by:

Angela F. Rutherford, RN, BSN

Jill S. Parker, DNP, MSN, FNP-C

Date

Date

Abstract

Palliative care (PC) is an interdisciplinary approach that specifically focuses on improving quality of life for people living with chronic, life-limiting illnesses (Kelley & Morrison, 2015). Ideally, PC should be initiated at the time of diagnosis. Research suggest that PC referrals are often delayed until there is a clearly terminal event, leading to unnecessary suffering from preventable symptoms and poor quality of life (Wilson, Avalos, & Dowling, 2016). The aim of this MSN thesis was to determine what barriers exist in the primary care setting to identifying and/or referring patients to PC programs. A descriptive study was performed utilizing an electronic survey questionnaire that was distributed to Registered Nurses (RNs) working in primary care practices. Barriers identified were physician reluctance to communicate a terminal prognosis and physician discomfort in discussing end of life planning with their patients.

Keywords: Palliative Care, Primary Care

Acknowledgments

This MSN thesis is dedicated to the memory of my grandmother, Phoebe Poteat. Her strength and independence helped mold me into the woman I am today, and her faith inspired me to never give up on my dreams.

I would like to thank my thesis advisor, Dr. Jill Parker. I have been fortunate to have an advisor who cared about my work and offered wisdom, guidance, and advice.

I must express my sincere gratitude to my husband Mark, for his constant support and encouragement. His love and belief in my abilities helped me overcome the challenges.

Finally, I would like to thank my parents for their unwavering support throughout this journey, and my siblings and extended family for always believing in me.

©Angela F. Rutherford 2017

All Rights Reserved

Table of Contents

CHAPTER I: INTRODUCTION

Introduction.....	1
Significance.....	2
Purpose.....	4
Theoretical Framework.....	5
Thesis Question.....	6
Summary.....	6

CHAPTER II: LITERATURE REVIEW

Literature Review.....	8
Literature Related to Statement of Purpose	9
Literature Related to Theoretical Framework.....	22
Survey Tool.....	23
Strengths and Limitations of Literature	24

CHAPTER III: METHODOLOGY

Study Design.....	27
Setting and Sample	27
Design for Data Collection	28
Measurement Methods.....	29
Data Collection Procedure	30
Protection of Human Subjects	31
Data Analysis	32

CHAPTER IV: RESULTS

Sample Characteristics.....	34
Major Findings.....	38

Summary	59
CHAPTER V: DISCUSSION	
Implication of Findings.....	61
Application to Theoretical/Conceptual Framework.....	63
Limitations	64
Implications for Nursing.....	65
Recommendations.....	65
Conclusion	66
REFERENCES	67
APPENDICES	
Appendix A: Palliative Care Screening Tool.....	71
Appendix B: Attitudes about Hospice Care Questionnaire	72
Appendix C: End of Life Nursing Education Consortium Flyer	73
Appendix D: Attitudes about Palliative Care Questionnaire	74
Appendix E: Invitation to Participate in Research email.....	80
Appendix F: Follow-up Invitation to Participate in Research email	81
Appendix G: Survey/Questionnaire Permission email	82
Appendix H: Gardner-Webb IRB Approval.....	85
Appendix I: CaroMont IRB Approval.....	86

List of Figures

Figure 1: Participant Age	35
Figure 2: Participant Years of Experience	36
Figure 3: Participation in ELNEC.....	37

List of Tables

Table 1: Question 4.....	39
Table 2: Question 5.....	40
Table 3: Question 6.....	41
Table 4: Question 7.....	42
Table 5: Question 8.....	43
Table 6: Question 9.....	44
Table 7: Question 10.....	45
Table 8: Question 11.....	46
Table 9: Question 12.....	47
Table 10: Question 13.....	48
Table 11: Question 14.....	49
Table 12: Question 15.....	50
Table 13: Question 16.....	51
Table 14: Question 17.....	52
Table 15: Question 18.....	53
Table 16: Question 19.....	54
Table 17: Question 21.....	55
Table 18: Question 23.....	56
Table 19: Question 24.....	57

CHAPTER I

Introduction

There are estimates that by the year 2050 more than one quarter of the world's population will be aged 65 years and older (Wilson, Avalos, & Dowling, 2016). An aging population presents new and more complex health care needs for which health care professionals must prepare. Approximately 78% of Medicare beneficiaries have at least one chronic medical condition (Auer, 2008). Special attention must be given to elderly patients to ensure quality of life is preserved during the end stages of chronic disease.

Palliative Care (PC) is a service that can maintain or improve quality of life for patients suffering from life-limiting chronic medical conditions. PC is interdisciplinary care that includes medicine, nursing, social work, chaplaincy, and others that specifically focuses on improving quality of life for people living with serious illnesses (Kelley & Morrison, 2015). PC differs from Hospice care in that PC services can be provided for any length of time, whereas Hospice care is specifically intended for the final six months of life. PC can also be provided congruently with disease-directive and curative treatments (Kelley & Morrison, 2015). Ideally, PC should be initiated at the time of diagnosis of a chronic, life-limiting illness (Keim-Malpass, Mitchell, Blackhall, & DeGuzman, 2015).

In addition to improving patient satisfaction and quality of life, PC can also provide financial benefits to both the patient and healthcare organization. One study compared the health care costs of patients following a hospital discharge in both a PC intervention group and a control group (Smith, Brick, & Normand, 2014). The costs of the group receiving PC interventions were significantly lower than the control group,

with cost savings largely driven by a significant difference in hospital readmission costs (Smith et al., 2014). New payment models under the Patient Protection and Affordable Care Act (PPACA) now penalize hospitals for unwanted and unnecessary readmissions and mortality rates (Morrison, 2015). PC programs can help reduce financial penalties to healthcare organizations by improving quality of care in the ambulatory setting, thereby reducing hospital admissions.

Early initiation of PC programs will help healthcare organizations achieve the three dimensions of the Institute of Healthcare Improvement's (IHI) Triple Aim of improving patient quality and satisfaction, improving the health of populations, and reducing the per capita cost of health care (Institute of Healthcare Improvement [IHI], 2017). Since PC has been shown to reduce cost and improve patient satisfaction, it clearly aligns with the focus of the Triple Aim. Hospitals and community organizations must work together to achieve the goals of the Triple Aim. The IHI recommends empowering individuals and families to take more active roles in the planning of their healthcare, and broadening the role and impact of primary care as effective approaches to achieving the Triple Aim (IHI, 2017).

Significance

PC serves patients with life-limiting and life-threatening chronic medical conditions and aims to address the patient's physical, psychological, social, spiritual, and end-of-life care needs (Keim-Malpass et al., 2015). PC can provide an extra layer of support for the chronically ill population, and has the potential to greatly improve quality of life if services are initiated in a timely manner. Research indicates that health care professionals often delay referrals to PC until there is a clearly terminal event, leading to

unnecessary suffering from preventable symptoms and poor quality of life (Wilson et al., 2016).

The Institute of Medicine (IOM) produced a consensus report entitled "Dying in America" in which a committee of experts investigated the quality of health care available to patients nearing end of life (IOM, 2014). The committee determined that although PC is becoming well established in many hospitals, there is an opportunity for improvement in the public and health care professionals' understanding of the role of PC (IOM, 2014). It is essential that nurses caring for older patients have adequate knowledge of PC and feel comfortable discussing end-of-life care (Wilson et al., 2016). It is recommended that PC be implemented at the time of diagnosis of a life-limiting illness. Therefore, nurses working in the primary care setting must fully understand the role of PC and how to refer patients to this service.

This researcher met with Kaye Grubaugh, RN, MSN, PC program coordinator at CaroMont Regional Medical Center (CRMC) to discuss CaroMont's PC program. Statistics at CRMC align with national PC trends in that the numbers of inpatient hospital referrals to the PC program have increased in recent years, but remain low in outpatient, primary care settings (K. Grubaugh, personal communication, June 2, 2017). Changes have been implemented in both inpatient and outpatient CRMC facilities in an attempt to increase the number of PC referrals. Quality of Life consults, which arrange for a discussion of Advanced Directives and the PC program, were added to the CRMC inpatient order sets for many chronic and life-threatening conditions including heart failure, chronic obstructive pulmonary disease, and cancer. In the outpatient primary care setting, a PC screening tool (Appendix A) was developed to assist nurses working in

primary care practices to appropriately identify patients that may benefit from a PC referral (K. Grubaugh, personal communication, June 2, 2017).

Mrs. Grubaugh indicates that the implemented changes have successfully increased the number of inpatient PC referrals. Current CRMC-generated reports indicate that approximately 12% of all CRMC hospital admissions receive PC (K. Grubaugh, personal communication, June 2, 2017). The national PC penetration rate is 4.8% of all hospital admissions (Center to Advance Palliative Care [CAPC], n.d.). This statistic indicates that CRMC has made great strides in improving inpatient PC access. The implemented changes have not however significantly impacted referral numbers from the primary care setting (K. Grubaugh, personal communication, June 2, 2017). Each CaroMont Medical Group (CMG) primary care practice employs Registered Nurse (RN) care navigators to assist with care coordination and chronic disease management for patients receiving primary care in that practice. All RN care navigators have access to the screening tool and have received training on the PC referral process. It is unknown what barriers exist to prevent primary care RN care navigators from making PC referrals (K. Grubaugh, personal communication, June 2, 2017).

Purpose

Patients with chronic illnesses often visit the primary care practice at least once every three months (Auer, 2008). This frequency of visits presents a number of opportunities for the nurse to discuss patients' wishes for end-of-life care and explore the benefits of PC. Nurses spend more time with patients than any other health care professionals, presenting nursing with the unique opportunity to clarify patients' goals

and explore treatment options (Malloy et al., 2014). The purpose of this MSN Thesis was to identify potential barriers in the PC referral process that exist in primary care nursing.

Theoretical Framework

The theoretical framework guiding this MSN Thesis was Hildegard Peplau's Nurse-Patient Relationship theory. Peplau identified the nurse-patient relationship as central to all nursing care, believing that without a relationship or connection between nurse and patient, nursing could not occur (Smith & Parker, 2015). The nurse interacts with patients as a resource and teacher. Nurses must possess intellectual, interpersonal, and social skills to fully engage in the nurse-patient relationship (Smith & Parker, 2015).

Peplau described three phases of the nurse-patient relationship: the orientation phase, the working phase, and the resolution phase. During the orientation phase, the patient expresses a need and seeks professional assistance from the nurse (Smith & Parker, 2015). The nurse and patient are unfamiliar with each other. In the orientation phase, the nurse and patient get to know each other and define their roles and expectations (Smith & Parker, 2015). The next phase of the nurse-patient relationship is the working phase. The patient focuses on exploiting resources to improve health. The nurse assumes the roles of resource person, counselor, and teacher in order to facilitate the patient's development toward well-being (Smith & Parker, 2015). During the working phase, the nurse must help the patient develop a balance between independence and dependence. This balance is essential for the patient to develop responsibility and become more equipped to face future challenges (Smith & Parker, 2015). The final phase in Peplau's nurse-patient relationship is the resolution phase. In the resolution phase the patient moves further from dependence towards independence. The patient becomes

more capable of managing their care (Smith & Parker, 2015). At the completion of the resolution phase, plans for future support are developed and new goals are established (Smith & Parker, 2015).

Nurses spend more time with patients than any other health care profession (Malloy et al., 2014). Primary care nurses have a unique opportunity to develop a long-term relationship with their patients. A large percentage of elderly patients have at least one chronic, life-limiting medical condition, making it necessary for these patients to visit a primary care provider at least every three months (Auer, 2008). The frequency of primary care visits allow the nurse time to build a trusting and therapeutic nurse-patient relationship. Primary care nurses must be knowledgeable of PC and feel comfortable identifying and referring patients that may benefit from PC services. Once a nurse-patient relationship has been established in the primary care setting, the nurse can take on the roles of resource person and educator, particularly in advocating for PC services for their elderly, chronically ill patients.

Thesis Question

This MSN Thesis answered the following thesis question: What barriers exist in the primary care setting to prevent nurses from identifying and/or referring patients to palliative care programs?

Summary

The elderly population is expected to rise tremendously in the upcoming years. The number of people aged 60 years and older is anticipated to double in proportion, with the greatest increase expected in people aged 85 years and older (Wilson et al., 2016). Approximately three quarters of Medicare beneficiaries have at least one chronic disease

(Auer, 2008). Elderly patients living with chronic illnesses present complex medical challenges for healthcare professionals. Early involvement of PC can improve the quality of the elderly patient's life through effective management of distressing symptoms and incorporating psychosocial and spiritual care, with consideration of the patient's and family's needs, values, beliefs, and culture (Morrison, 2015). Recommendations are that PC be implemented at time of diagnosis of a life-limiting or life-threatening illness, and continue across the disease trajectory (Keim-Malpass et al., 2015). Nurses working in the primary care setting have the opportunity to recognize and refer patients to PC early in the disease process. Primary care nurses have frequent interactions with their patients, and through the establishment of a therapeutic nurse-patient relationship can educate and advocate for PC services. The purpose of this MSN thesis was to identify potential barriers in the PC referral process that exist in primary care nursing.

CHAPTER II

Literature Review

The number of elderly persons living in the United States is expected to see tremendous growth in the upcoming years. Advances in technology and medical practices have increased the life expectancy for people with chronic medical conditions. It is estimated that the proportion of people over age 60 years will double by 2050, with the greatest percentage increase expected to be among people aged 85 years and older (Wilson et al., 2016). This increase in the aging population presents new and complex challenges for healthcare professionals. Early implementation of palliative care (PC) services can benefit elderly patients living with life-limiting medical conditions. PC works alongside primary care and aims to relieve suffering through early identification and treatment of pain and other physical, psychosocial, and spiritual problems (Hughes & Smith, 2014).

PC is a relatively new concept that has experienced rapid growth in the United States in recent years, particularly in the hospital setting. In 2000, 25% of hospitals in the United States with at least 50 beds offered a palliative care program (Hughes & Smith, 2014). By 2010, this number had significantly increased, with two-thirds of hospitals offering palliative care (Hughes & Smith, 2014). Research indicates that community-based, end-of-life care has been primarily limited to dying patients under Hospice care (Morrison, 2015). Newer models of PC now offer services to patients in the community through ambulatory clinics and interdisciplinary, home-based care (Morrison, 2015). Although community-based PC programs are growing in the United States, there continue to be missed opportunities to provide PC services to the elderly living with life-

limiting medical conditions. In the 2014 Institute of Medicine's (IOM) "Dying in America" consensus report, the committee determined that although PC is becoming well established in many hospitals, the greatest opportunity for improvement is in the public and health care professionals' understanding of the role of PC (IOM, 2014).

The purpose of this MSN thesis was to identify potential barriers in the PC referral process that exist for nurses in the primary care setting. A search of the literature was conducted to review the current state of PC programs in the United States, best practices regarding PC, current primary care PC delivery models, and identified barriers that exist to implementing PC in the primary care setting. Available studies on PC and Hildegard Peplau's nurse-patient relationship theory were also reviewed. Sources utilized for searching the literature included Cumulative Index for Nursing and Allied Health Literature (CINAHL), Google Scholar, and the National Institutes of Health (NIH). Keywords used during the literature review included end of life planning, end of life planning and primary care, palliative care in the United States, palliative care and primary care, palliative care and nursing, and barriers to palliative care in the United States. Search results ranged from 240 to 6,422 results, depending on keywords selected. All results were limited to geography of the United States. Abstracts were reviewed to determine relevance to this MSN thesis. Studies that were not related to the purpose of this MSN thesis were eliminated. Duplicate studies were also eliminated.

Literature Related to Statement of Purpose

Background and History of Palliative Care in the United States

The passage of the Patient Protection and Affordable Care Act (PPACA) of 2010 provided opportunities for new models of PC in the United States. PC has evolved from

care focused solely on comfort into a broader, interdisciplinary specialty that addresses needs of all seriously ill patients and their families (Morrison, 2015). PC in the United States was developed in the early 1990s based on the determination that hospice care core principles should be applied to all patients with serious illness, regardless of prognosis (Morrison, 2015). PC programs have been implemented at many hospitals throughout the United States. Currently 85% of mid to large size hospitals have PC teams, and over 6,000 physicians are certified in PC by the American Board of Medical Specialties (Morrison, 2015). PC is now expanding into the outpatient community setting. New payment models in the PPACA penalize hospitals for unnecessary hospital readmissions. Outpatient models of PC can help reduce hospital readmissions through the use of interdisciplinary home-based care (Morrison, 2015).

A review article by Kelley and Morrison (2015) discussed core concepts and components of PC, models of PC delivery, expanding access to PC, and barriers to PC delivery. PC is defined as interdisciplinary care, including nursing, medicine, social work, and chaplaincy focused on improving quality of life for patients living with serious, life-limiting illnesses, regardless of the patient's age or expected length of life (Kelley & Morrison, 2015). Ideally, PC should be initiated at the time of diagnosis and can be provided concordantly with curative treatments (Kelley & Morrison, 2015). Identified core components of PC include the assessment and treatment of physical and psychological symptoms, support for spiritual distress, establishment of goals and assistance with complex medical decision making, and coordination of care (Kelley & Morrison, 2015). The authors indicate that appropriate timing of PC referrals continues to be defined by empirical research, but current recommendations are to initiate PC

referrals at the time of diagnosis for patients with advanced cancer, neurologic disease, those with multiple coexisting conditions, frailty, and advanced cognitive impairment (Kelley & Morrison, 2015). The authors identified knowledge and perception of PC as the greatest barrier to implementing PC services. Perceptions among physicians are that PC is appropriate only at the end of life, that PC is synonymous with hospice, and that patients will lose hope if a PC referral is discussed (Kelley & Morrison, 2015). The authors referenced a recent study that indicated 90% of adults in the United States have limited knowledge on PC, but when read a definition of PC more than 90% of survey respondents indicated that they would want PC for themselves or a family member (Kelley & Morrison, 2015). The physicians' perceptions of PC discussed in this article must be addressed if PC services are to be implemented at time of diagnosis.

PC is one of the most rapidly growing fields in healthcare in the United States. PC provides an extra layer of support for patients living with chronic, life-limiting medical conditions. The need for PC services continues to rise with an increase in the aging population. One study determined that nearly 25% of patients with at least one chronic disease reported limitations in their activities of daily living (Hughes & Smith, 2014). Reports from the Centers for Disease Control and Prevention (CDC) Surveillance System indicated that in 2012, 17% of Americans rated their health status as "fair" or "poor" (Hughes & Smith, 2014). In 2005, approximately 70% of deaths were from chronic diseases (Hughes & Smith, 2014). Clinical benefits of PC are improvement of quality of life, better quality of care with less aggressive end-of-life care, less emotional distress, and economical and financial benefits including more equitable resource utilization, decreased hospitalizations, and reduced use of the intensive care unit (Hughes

& Smith, 2014). The authors presented several pilot models of PC that have shown success in achieving the goals of better quality, improved access, and lower costs.

Although the field of PC has grown exponentially in recent years, knowledge limitations remain. Research shows that there are deficiencies in clinical knowledge about PC among primary care providers (Hughes & Smith, 2014). Knowledge deficiencies must be addressed in order to increase PC referrals in the primary care setting.

The Role of Primary Care in Palliative Care

Auer (2008) outlined a patient case and described the primary care provider's role during stages of illness. The stages of illness discussed were stable chronic illness, worsening condition, and end-stage disease. Primary care providers must incorporate end-of-life planning into routine visits (Auer, 2008). The frequency of primary care visits for patients with chronic illnesses presents numerous opportunities for discussions on end-of-life planning and PC. The author suggested that during the stable chronic illness stage providers should introduce these discussions and then allow the patient time to think about it prior to the next visit (Auer, 2008). When conditions begin to worsen, providers must feel comfortable discussing with the patient that their illness is not reversible. A national study of internists found that physicians found prognostication stressful and felt it was more difficult to make an accurate prognosis than an accurate diagnosis (Christakis & Iwashyna, 1998). The author of this case study includes criteria indicating worsening prognosis in selected chronic diseases for reference as well as an outline of primary care visit tasks for end-of-life planning. The tasks include telling the patient the diagnosis, determining the patient's treatment goals, discussing advanced directives, and explaining options for end-of-life care (Auer, 2008). This article

emphasizes the importance of primary care in the PC referral process. Nurses working in the primary care setting have multiple opportunities to educate and advocate for PC services.

Patients with established primary care providers have fewer emergency department visits and hospitalizations, lower healthcare costs, and better provider communication, indicating that primary care providers play an important role in coordinating care for their patients at the end of life (Kim & Tarn, 2016). Kim and Tarn (2016) performed a literature review study in order to assess the relationship of primary care involvement in end of life care on patient outcomes. The outcomes examined in the study were discharge or death with supportive care, emergency department or hospital admission, resource utilization, hospital length of stay and cost, symptom management, and survival rate (Kim & Tarn, 2016). The study showed mixed results. The literature review demonstrated that patients with greater primary care involvement at the end of life were more likely to die outside of the hospital, but showed no clear influence on the rate of emergency department or hospital utilization (Kim & Tarn, 2016). The authors stated that additional research is needed and discussed a number of limitations to the study. A majority of patients express desires to die in the home and the study by Kim and Tarn (2016) suggested that primary care involvement at the end of life may help patients achieve this goal.

McCormick, Chai, and Meier (2012) reviewed the benefits of PC interventions, discussed the shared goals of primary care and PC, and outlined recommendations for incorporating PC into primary care practice. Primary care providers play an important role in ensuring good PC for their patients, but limited access to training and resources

and restrictions in time can make referring and incorporating PC challenging (McCormick et al., 2012). A randomized trial of 238 in-home PC patients with congestive heart failure, chronic obstructive pulmonary disease, and cancer found that PC intervention early in the disease course improved patient and family satisfaction, reduced medical costs, and increased the percentage of patients dying in the home (McCormick et al., 2012). Both primary care and PC goals are to treat the patient, not just the disease, addressing the physical, psychological, social, and spiritual needs of the patient and family (McCormick et al., 2012). Aligning goals of care allow for seamless integration of PC from the primary care setting. Primary care providers have long-standing and trusting relationships with their patients allowing for opportunities to discuss the difficult topic of advanced care planning. Primary care providers have the ability to identify patients who may benefit from early PC consults (McCormick et al., 2012). Early referral to PC programs can improve symptom management and quality of life for patients with chronic illnesses. Primary care providers play an important role in identifying and referring patients to PC programs.

Crosby and Yelamanchi (2013), conducted an informal survey of an interdisciplinary end-of-life care team comprised of long term care nurses, clergy, and community leaders to determine their thoughts on how primary care providers could improve in providing PC. A clear theme in the responses received was that primary care providers should initiate PC earlier in the disease process (Crosby & Yelamanchi, 2013). The authors published an article with a goal of encouraging early implementation of PC by primary care providers, and suggested steps and tools to assist with implementation. One tool suggested was to utilize the PEACE mnemonic to guide care and facilitate

patient dialogue. PEACE stands for physical, emotional, autonomy, closure/caretaker, and existential/economic (Crosby & Yelamanchi, 2013). Primary care providers play a vital role in initiating the discussions of end of life care and referring to PC programs when appropriate. Primary care providers must have adequate knowledge of PC and the available resources.

Existing Barriers to Palliative Care in Primary Care

Underutilization of PC has been associated with primary care providers' reluctance to make referrals, misunderstanding on what constitutes PC, lack of training, lack of knowledge of advance directives, and a fear that suggesting PC could cause a loss of hope (Snyder, Hazelett, Allen, & Radwany, 2012). Snyder et al. (2012), conducted a survey to evaluate primary care provider knowledge, attitude, experience, and utilization of advanced care planning, PC, and hospice. Survey results were as follows: 44% of physicians felt that advanced planning discussions take too much time, 65% of physicians felt comfortable communicating a prognosis to patients, and 29% of physicians believed that PC and hospice are the same (Snyder et al., 2012). These survey results indicated that additional education on PC is needed in the primary care setting.

Wilson et al. (2016) performed a cross-sectional study utilizing two questionnaires, the palliative care quiz for nursing (PCQN) and the thanatophobia scale, to determine the PC knowledge and attitudes towards caring for the dying of nurses working in elderly care settings. Results demonstrated that nurses had a moderate level of PC knowledge. Nurses who had attended a formal end of life care training course had higher PCQN scores, indicating increased knowledge of PC, than those nurses who had attended an informational session within their unit (Wilson et al., 2016). There was also a

significant correlation between PCQN score and years working as a registered nurse, showing that the nurse's knowledge of PC improved the longer they had been registered (Wilson et al., 2016). The authors concluded that younger, inexperienced nurses would benefit from working with older, more experienced nurses in regards to PC (Wilson et al., 2016). Nurses play an important role in identifying patients and advocating for PC services. It is essential that nurses have knowledge of PC and feel comfortable caring for patients at the end of life.

A study by Wharton, Manu, and Vitale (2015), integrated a pilot project aimed at expanding patient access to PC through three objectives: to enhance interdisciplinary teams' PC knowledge through education, to improve identification of patients with PC needs by use of a validated assessment tool, and to build working relationships between primary care and the PC consult team. To achieve these objectives, team members completed the End of Life Nursing Education Consortium (ELNEC) national PC education curriculum, and the PPS PC assessment tool was added to the electronic medical record as part of the nursing assessment (Wharton et al., 2015). Results of the study demonstrated that ELNEC training was well received by participants and final course evaluations showed substantial improvement in the participant's self-reported knowledge when compared to the pre-course evaluation (Wharton et al., 2015). Nurses reported that the new PPS screening tool was not burdensome and did not disrupt their workflow. During the pilot period, 77% of patients were screened for PC (Wharton et al., 2015). A limitation of this study is that PC referrals were not measured. Further study was needed to determine if increased screenings led to increased PC referrals. Overall, this study demonstrated the vital role nurses play in screening and identifying appropriate

patients for PC, and that formalized training programs such as ELNEC increase nursing knowledge of PC.

Chronically ill patients at the end of life report that honest communication is extremely important (Boyd, Merkh, Rutledge, & Randall, 2011). Communication regarding prognosis is necessary for appropriate discussions about treatment options such as PC, and has been associated with fewer aggressive medical interventions near death, and enhanced quality of life (Boyd et al., 2011). Nurses are ideally positioned to begin end of life planning discussions. Boyd et al. (2011) performed a descriptive, correlational survey study aimed at characterizing nurses' attitudes toward end of life care and their experiences in caring for terminally ill patients. Most commonly reported barriers were patient denial, misperception or fear of hospice care, physician not ready to give up (feels PC/Hospice is failure), nurse not sure of the treatment plan, and physician reluctance to communicate a terminal prognosis (Boyd et al., 2011). The authors suggested that strategies should be developed to enable nurses to have a stronger voice during the advanced care planning process (Boyd et al., 2011).

Consensus statements suggested that PC should be implemented at the time of a cancer diagnosis and continue across the disease trajectory and through bereavement (Keim-Malpass et al., 2015). The authors employed a cross-sectional qualitative study design using interviews from key stakeholders at an academic National Cancer Institute to investigate barriers to integration of PC for cancer patients. Major themes describing barriers were fragmentation of services, unclear pathways and triggers for referrals, demand exceeding available practitioners, and inadequate/insufficient education for patients and providers (Keim-Malpass et al., 2015). A common misconception that PC

and hospice services are synonymous emerged in the surveys. This study suggested that additional education for providers could increase the number of referrals to PC services.

Integrating PC into routine oncology services has shown positive outcomes for patients with advanced cancer (Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010). Advanced practice oncology nurses are prepared and capable of helping patients explore treatment goals and preferences through advanced care planning discussions. Zhou et al. (2010) conducted a study to investigate oncology nurses' knowledge, attitudes, and practice behaviors regarding advanced care planning, and to identify barriers to having advanced care planning discussions. Study results demonstrated that oncology nurses had moderate knowledge and fairly positive attitudes toward advanced care planning. They felt comfortable discussing advanced care planning with their patients (Zhou et al., 2010). The study participants indicated that advanced care planning discussions were incorporated into their routine patient care. Most commonly reported barriers for advanced care planning discussions were reluctance from patients and families, followed by physicians (Zhou et al., 2010). This study indicated that incorporating end of life planning into the nurse's typical patient care routine may increase the number of advanced planning discussions.

Opportunities to Increase Implementation of Palliative Care

Nurses spend more time with patients than any other health care professionals, presenting numerous opportunities to have conversations with patients and their families to clarify goals of care at the end of life, and to explain different treatment options (Malloy et al., 2014). This unique role of nursing prompted nursing researchers to investigate the lack of education nursing students receive regarding end-of-life care.

Research found that very little information was embedded in the nursing curriculum, and that nursing textbooks had less than 2% of information related to end of life care (Malloy et al., 2014). This lack of information resulted in the City of Hope in California and the American Association of Colleges of Nursing (AACN) partnering together to create the End of Life Nursing Education Consortium (ELNEC)-Core curriculum. In 2000, a Robert Wood Johnson Foundation grant was received to develop the ELNEC-Core curriculum and to provide nursing education for undergraduate nursing faculty, continuing education providers, and staff development educators (Malloy et al., 2014). Since the introduction of ELNEC-Core curriculum, more than 17,500 nurses, physicians, social workers, chaplains, and other health care professionals have attended an ELNEC course (Malloy et al., 2014). ELNEC courses are offered around the world and have been translated into a number of languages. As nurses increase their education of end of life care, the care of the terminally ill will improve (Malloy et al., 2014).

A model of PC described in a study by Van der Plas et al. (2015), utilized nurses with expertise in PC as case managers. The case managers employed the patient advocacy model of case management, which offers multidimensional coordination of care aimed at quality of care (Van der Plas et al., 2015). The authors of the study used questionnaires to investigate the reasons patients were referred to case managers and the characteristics of those patients. The results of the study showed that the majority of the patients referred to case managers were older (mean age of 71 years old), had a majority of treatment aims, and were almost exclusively cancer patients (Van der Plas et al., 2015). The study results also suggested that patients are referred to case managers relatively early in their disease process (Van der Plas et al., 2015). Further exploration is

needed to determine reasons chronic illnesses other than cancer are not referred to PC case managers. The referrals were received early in the disease process suggesting that the PC case manager model may be effective in early implementation of PC services.

A large, population-based study showed that poverty was associated with increased pain severity, with a trend toward similar patterns for depression and shortness of breath (Beyea, Fischer, Schenck, & Hanson, 2013). PC services are often underutilized by low-income patients. These disparities in access to PC worsen symptom burden and reduce quality of life at the end of life (Beyea et al., 2013). The authors developed a project designed to develop and evaluate a systems intervention to improve communication about advanced care planning and symptom distress, and to facilitate PC referrals (Beyea et al., 2013). Specific objectives were to deliver statewide training on topics in advanced care planning and PC to case managers, to implement a PC quality improvement toolkit, and to link case managers to regional hospice, PC, and supportive care resources for the patients they serve (Beyea et al., 2013). The intervention targeted 510 case managers caring for seriously ill Medicaid patients. Interventions were measured with participant surveys and tracking of key quality measures (Beyea et al., 2013). The study demonstrated that educational and quality improvement initiatives were effective to increase case management communication about advanced care planning and symptom distress, and to increase PC referrals (Beyea et al., 2013).

Research related to end of life care demonstrates that it is often substandard, with 7-9% of elderly patients with cancer utilizing an emergency department at least once in the last year of life (Owens et al., 2012). The authors investigated a Primary Palliative Care Pilot Project to determine if patients with a life-limiting illness receiving care from a

nurse practitioner (NP)-directed PC clinic would have improved symptom management and decreased emergency department utilization (Owens et al., 2012). The study was conducted at a 415-bed academic medical center and included patients with a life-limiting illness and no primary care provider. Patients were provided with 24-hour access to a PC specialist (Owens et al., 2012). Results of the study showed a significant decrease in the number of emergency department visits, while symptom trajectories varied substantially, depending on the patient characteristics (Owens et al., 2012). Further research is needed on symptom management, but the reduction in emergency department visits suggested that continuity of care is effective in improving quality of life at the end of life. Continuity of care can be achieved through establishment of a primary care provider and routine visits to that provider.

Knowledge of end-of-life care has been recognized as an area needing additional education and attention. Organizations are attempting to address the knowledge deficit and encourage providers to complete advanced care planning discussions. Beginning in January of 2016, the Centers for Medicare and Medicaid Services began offering reimbursement for physicians, nurse practitioners, and physician assistants for talking to patients about preferences for end of life care (Sheldon, 2015). As of 2015, the Association of American Medical Colleges reported that 136 medical schools now include end of life care as a required course, and 94 schools offer it as an elective course (Sheldon, 2015). The average total end-of-life curriculum in baccalaureate nursing programs has risen to 15 hours, and national educational programs such as ELNEC have trained more than 19,000 nurses in all 50 states (Sheldon, 2015). Nurses must take

initiative to increase their knowledge of end of life care in order to appropriately educate and advocate for their patients.

Literature Related to Theoretical Framework

The nurse-patient relationship is considered the foundation for all nursing care (Hagerty & Patusky, 2003). This is the basis for Hildegard Peplau's Nurse-Patient Relationship theory. An essential element of the nurse-patient relationship is establishment of trust. Trust is developed during the first phase of the relationship, the orientation phase. The establishment of trust is necessary before patients are able to identify problems they wish to work on with nurses, and in turn divulge information and cooperate with health care advice to accomplish established health care goals (Hagerty & Patusky, 2003). Nurses in the primary care setting have increased interactions with their patients over a longer period of time, allowing for the development of a trusting nurse-patient relationship.

Marchese (2006), utilized Peplau's nurse-patient relationship theory to help guide education for patient's undergoing a urinary procedure. Successful nurse-patient relationships require unbiased encounters that focus on addressing and meeting the needs of the patient (Marchese, 2006). Peplau discussed that interventions can only be successful if the patient is valued and accepted by the nurse. Patients must be active participants in the development of the goals for the interventions (Marchese, 2006). Patient-centered care is now common practice in the primary care setting. Primary care nurses must frequently discuss treatment goals with their patients and modify care plans as needed. The patient-centered care mentality now engrained in primary care aligns well with the nurse-patient relationship theory. Primary care nurses can transition from the

orientation phase to the working phase in the nurse-patient relationship over a longer duration of time when compared to nurses working in acute care settings. The frequency of primary care visits by patients with life-limiting illnesses allows for the development of a trusting nurse-patient relationship. The primary nurse must feel comfortable discussing end-of-life care and understand the patient's goals for care. The working phase of the nurse-patient relationship in the primary care setting involves the nurse fulfilling the roles of teacher and counselor. A primary care nurse who is knowledgeable in PC and comfortable having end-of-life discussions can advocate for PC services, and in turn improved quality of life, during this phase of the nurse-patient relationship.

Survey Tool

The survey tool utilized in the Boyd et al. (2011) study was an adaptation of the Attitudes about Hospice Care questionnaire. This tool was originally developed by Bradley et al. (2001), who developed the tool to study the palliative care practices by nurses caring for terminally ill patients in the acute care setting. The tool was later expanded in a study by the authors to evaluate the influence of modifiable factors on nurses' tendency to discuss hospice care with patients and families in the acute care setting (Cramer, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2003). The questionnaire evaluates several areas of potential barriers to initiating hospice care or PC. Areas of evaluation include knowledge of caring for patients at end-of-life, comfort level in end-of-life discussions, added benefits of hospice/PC, perceived physician comfort and responsibility, patient perceptions of care and prognosis, results of hospice/PC, facilitation of end-of-life care for nurses, and physician and nurse turf issues (Cramer et al., 2003). The survey utilized a Likart scale; rating responses on a range of 1 (strongly

agree) to 5 (strongly disagree). The questionnaire explored a number of perceived barriers to initiating hospice/PC, is easily administered, and required a short amount of the nurse's time to complete the survey (Appendix B).

Strengths and Limitations of Literature

PC interventions are associated with greater patient and family satisfaction, decreased health care expenditures, and improved quality of life at the end of life (Snyder et al., 2012). Recommendations are to initiate PC early in the disease trajectory, preferably at time of diagnosis of a life-limiting disease (Keim-Malpass et al., 2015). A review of literature demonstrated that barriers exist to implementing PC services. A variety of survey tools were used to evaluate physician and nurse knowledge and attitudes towards PC and advanced care planning. Many of the nursing studies were performed in the acute care setting. Several studies indicated that the use of case managers with additional training on end of life care has been effective in identifying appropriate patients for and initiating PC services. Research also suggested that formalized end of life training, such as ELNEC, has been successful in improving nurse and physician comfort level in discussing end of life care.

Limitations from the literature review were identified. This author was unable to find research on primary care nursing in end of life care utilizing Peplau's nurse-patient relationship theory. Studies demonstrated the usefulness of applying Peplau's theory in patient education and patient-centered care planning, but these were not specific to advanced care planning and initiating PC. Another limitation identified was that a number of studies introduced a nursing PC screening tool as an intervention to increase PC referrals, but no studies were found that investigated any barriers to using the tool.

There were also limited studies on nursing knowledge and attitudes of PC in the primary care setting versus the acute care setting.

Application of Literature Review to the MSN Thesis

CaroMont Regional Medical Center (CRMC) utilizes Registered Nurses (RNs) as care navigators in the primary care setting. Each CaroMont-owned primary care practice employs a RN care navigator to provide additional education and care coordination for patients within their assigned practice. The RN care navigators have multiple interactions with their patients, both face-to-face and via weekly telephone contacts. The frequency of interactions provides opportunities to build a strong nurse-patient relationship. The role of the nurse in the nurse-patient relationship evolves over the course of time, with the nurse assuming the roles of teacher and counselor. RN care navigators must feel comfortable discussing end of life with their patients. They must have knowledge of PC and know when to initiate referrals to PC programs. A PC screening tool is currently in place to assist the RN care navigators with identifying and referring patients that may benefit from PC services. CRMC also offers the ELNEC-Core training program several times a year at no cost to employees (Appendix C). The aim of this MSN Thesis was to discover any barriers that exist to prevent RN care navigators from referring patients to PC services.

CHAPTER III

Methodology

The purpose of this MSN Thesis was to understand potential barriers to initiating Palliative Care (PC) referrals within the primary care setting. Older patients with life-limiting illnesses have complex medical needs that must be addressed. Early integration of PC is being increasingly recommended in the literature based on the improved quality of life PC services can achieve (Wilson et al., 2016). Nurses spend more time with patients than any other healthcare workers. Primary care nurses are ideally positioned to facilitate PC referrals and support communication between patients and families and their healthcare physicians (Boyd et al., 2011). Research indicated that PC referrals are often delayed until a clear terminal event occurs (Wilson et al., 2016).

Early involvement of PC can improve the quality of the elderly patient's life through effective management of distressing symptoms and incorporating psychosocial and spiritual care, with consideration of the patient's and family's needs, values, beliefs, and culture (Morrison, 2015). Suggested barriers to initiating PC services include primary care providers' reluctance to make referrals, misunderstanding on what constitutes PC, lack of training, lack of knowledge of advance directives, and a fear that suggesting PC could cause a loss of hope (Snyder et al., 2012). Nurses working in the primary care setting have frequent interactions with patients, often seeing patients with chronic, life-limiting illnesses every three months. Primary care nurses have an opportunity to establish a trusting nurse-patient relationship and serve as both an educator and advocate for PC services. It is important to understand the primary care nurse's

knowledge of PC and any barriers to facilitating PC services that exist in the primary care setting.

This MSN thesis answered the following thesis question: What barriers exist in the primary care setting to prevent nurses from identifying and/or referring patients to palliative care programs?

Study Design

The design of this MSN thesis research was a descriptive study. Questionnaire surveys were utilized to evaluate primary care nurses' attitudes about PC. Demographic questions were asked to determine the nurse's age, years of nursing experience, and participation in formal end-of-life nursing education, such as End of Life Nursing Education Consortium (ELNEC). The demographic questions were used for case sample descriptive purposes only.

Setting and Sample

The research for this MSN thesis was conducted in 18 primary care practices affiliated with CaroMont Regional Medical Center (CRMC). CRMC primary care practices that only serve pediatric populations were excluded from the study. Each CRMC primary care practice employs a Registered Nurse (RN) care navigator. The RN care navigator works with patients in the primary care practice to assist with care coordination, collaboration between providers, chronic disease education, patient self-management, and advocating for therapies or services to improve the quality of care and the patient's quality of life. The role of the RN care navigator also includes early identification and referral of qualifying patients to PC services through the use of the PC

Screening Tool (Appendix A). RN care navigators at each of the 18 CRMC primary care practices selected for the study were invited to participate in this MSN thesis research.

Design for Data Collection

Data for this MSN thesis was collected through an anonymous electronic survey. A single questionnaire was distributed to the 18 RN care navigators working in the CRMC primary care practices via the online survey site Survey Monkey. The survey was divided into three sections: demographic questions, the attitudes about PC survey, and an open-ended question regarding the nurse's perceived barriers to initiating PC referrals (Appendix D). Each RN care navigator received an email invitation to participate in the study that included a link to complete the online survey questionnaire (Appendix E). A follow up email was sent to the RN care navigators one week after the initial invitation to remind them to complete the survey (Appendix F). RN care navigators were given a total of two weeks to participate in the study. To encourage participation in the survey, participants were entered into a drawing for a \$25 Visa gift card. A separate survey page was available for the RN care navigator to enter their email address as to keep survey responses anonymous.

Participant survey information was imported into the IBM SPSS Version 23 software program. The demographic variables imported were the nurse's age, years of nursing experience, and participation in ELNEC or other formal end-of-life education. Other variables were the responses to the Attitudes about PC survey. Descriptive statistics were used to describe frequencies and measures of central tendencies. Demographic information was used only to describe the case sample. Each question on the Attitudes about PC survey was evaluated individually. Each question received a

score of 1 (strongly disagree) through 5 (strongly agree). In some questions a score of 1 indicated nursing discomfort, while a score of 5 indicated nursing discomfort for other questions. All questions with scores indicating nursing discomfort were considered barriers to initiating PC. The final open-ended question was used to identify any PC barriers perceived by the primary care nurse that were not addressed in the Attitudes about PC survey.

Measurement Methods

The data collection tool utilized for this MSN Thesis project included the following three sections: demographic questions, the Attitudes about PC survey, and an open-ended question regarding the nurse's perceived barriers to initiating PC referrals (Appendix D). The data collection tool was based on the Attitudes about Hospice survey developed by Crammer et al. (2003). The authors of the Attitudes about Hospice survey were contacted and gave permission to use the survey in this MSN thesis.

The Attitudes about PC survey tool was modified with the author's permission from the original Attitudes about Hospice survey developed by Cramer et al. (2003). The Attitudes about Hospice survey was used to evaluate the influence of modifiable factors on nurses' tendency to discuss hospice care with patients and families in the acute care setting (Cramer et al., 2003). Areas of evaluation include knowledge of caring for patients at end-of-life, comfort level in end-of-life discussions, added benefits of hospice/PC, perceived physician comfort and responsibility, patient perceptions of care and prognosis, results of hospice/PC, facilitation of end-of-life care for nurses, and physician and nurse turf issues (Cramer et al., 2003). This tool has been utilized in a number of studies. This researcher has received permission from the authors to modify

the tool to evaluate Attitudes about PC. All questions regarding Hospice were modified to PC (Appendix G).

The demographic questions were used for descriptive purposes only and do not affect the reliability or validity of the Attitudes about PC survey tool. The final open-ended question was not used for statistical evaluations. This question was used to identify any additional barriers to PC in the primary care setting that were not evaluated by the survey tool. This question was used to identify needs for future studies.

Data Collection Procedure

Data for this MSN thesis was collected via online surveys. Participants completed an online survey that included three sections: demographic questions, the Attitudes about PC survey, and an open-ended question regarding the nurse's perceived barriers to initiating PC referrals (Appendix D). Demographic questions were the nurse's age, years of nursing experience, and participation in ELNEC or other formal end-of-life education. The researcher sent the email requests to participate in the survey and was responsible for collecting the data. Invited participants had a total of two weeks to participate in the study. At the end of the two weeks, all responses to the electronic survey were entered into the IBM SPSS Version 23 software program for data analysis.

Eighteen RN care navigators working in CRMC primary care practices were invited to participate in the survey. The Population Health/Care Navigator Supervisor Suzanne Howell, MSN, RN was contacted to request permission to invite the RN care navigators to participate in the survey and to obtain email addresses for each RN care navigator. Each RN care navigator received an email invitation to participate in the study with an explanation of the purpose of the research (Appendix E). The email also

included a link to the online survey tool. The survey was open for completion for a total of two weeks. One week after the emailed invitation, a reminder to participate in the research survey email was sent to the RN care navigators. Since the survey was anonymous, the researcher did not know who had completed the survey and who had not. Therefore, all invited participants received the follow up email. The survey closed two weeks after the initial emailed invitation.

Protection of Human Subjects

Permission to conduct research for this MSN Thesis was obtained from both the the University and CaroMont Regional Medical Center Institutional Review Boards (IRBs) (Appendix H and I). Participants completed the survey anonymously via the online survey tool Survey Monkey. No names or other personal identifiers were collected at any point in the research. Participants were not asked to provide information regarding the specific primary practice in which they were employed. Demographic information was used for descriptive purposes only and did not affect the confidentiality of the participant. Participation in the survey was voluntary and there were no consequences for refusing to participate. An incentive was offered to participants to encourage participation in the survey. Each RN care navigator that completed the survey was entered into a drawing for a \$25 Visa gift card. A separate survey page within Survey Monkey was available for the RN care navigator to enter their email address as to keep survey responses anonymous. There were no identified risks to participants associated with involvement in this MSN Thesis research.

Data Analysis

At the completion of the two-week open survey period, this researcher reviewed all surveys submitted. Information obtained in the surveys was imported into the IBM SPSS Version 23 software program. The variables imported were the nurse's age, years of nursing experience, participation in ELNEC or other formal end-of-life education, and the Attitudes about PC survey responses. The demographic variables of the nurse's age, years of nursing experience, and participation in ELNEC or other formal end-of-life education were used for case sample descriptive purposes only.

Each question on the Attitudes about PC survey was individually evaluated. A descriptive statistics analysis was utilized to identify frequencies in primary care nurses' attitudes about PC based on the Attitudes about PC survey responses. This was performed using the Descriptive Statistics function within the IBM SPSS software program. Survey answers with frequencies of responses indicating nursing discomfort were identified as barriers to PC referrals in the primary care setting.

CHAPTER IV

Results

The purpose of this MSN thesis was to determine what nursing barriers exist in the primary care setting to initiating palliative care (PC) services. PC is an interdisciplinary approach that specifically focuses on improving quality of life for people living with life-limiting chronic medical conditions (Kelly & Morrison, 2015). The interdisciplinary team includes nursing, social work, medicine, and chaplaincy. Research indicates that PC should be initiated at the time of diagnosis of a life-limiting, chronic illness (Keim-Malpass et al., 2015), but referrals are often delayed until there is a clearly terminal event, leading to unnecessary suffering from preventable symptoms and poor quality of life (Wilson et al., 2016).

A review of the literature discovered common themes in the reported barriers to initiating PC. These barriers included patient denial, misperception or fear of PC, physician not ready to give up (feels like PC is failure), nurses were unaware of the treatment plan, and physician reluctance to communicate a terminal prognosis (Boyd et al., 2011). Other studies have indicated a lack of knowledge of PC and unclear triggers for referrals limits initiation of PC services (Keim-Malpass et al., 2015). A study by Malloy et al. (2014) demonstrated positive results with increased PC knowledge and comfort in end-of-life discussions by offering End of Life Nursing Education Consortium (ELNEC) programs.

Nurses working in the primary care setting are ideally positioned to discuss end-of-life planning with their patients and initiate PC referrals if appropriate. Nurses spend more time with patients than any other healthcare profession (Malloy et al., 2014). This

is especially true in the primary care setting where older adults with chronic illnesses visit their primary care providers as often as every three months (Auer, 2008). Primary care nurses must be knowledgeable of PC and feel comfortable discussing end of life planning with their patients. Nurses in the primary care setting must be able to build trusting relationships with their patients and utilize the nurse-patient relationship to guide patients toward appropriate care plans.

This MSN thesis answered the following question: What barriers exist in the primary care setting to prevent nurses from identifying/referring patients to palliative care programs?

Sample Characteristics

An anonymous survey was emailed to 18 Registered Nurse (RN) care navigators working in CaroMont affiliated primary care practices serving adult patients. Twelve RNs responded to the survey (n = 12). The age of the participants ranged from brackets of 25 to 34 up to 55 to 64. The largest percentage of participants was in the 35 to 44 years of age bracket, with 33% of participants falling into that category. The participant ages are displayed below (Figure 1).

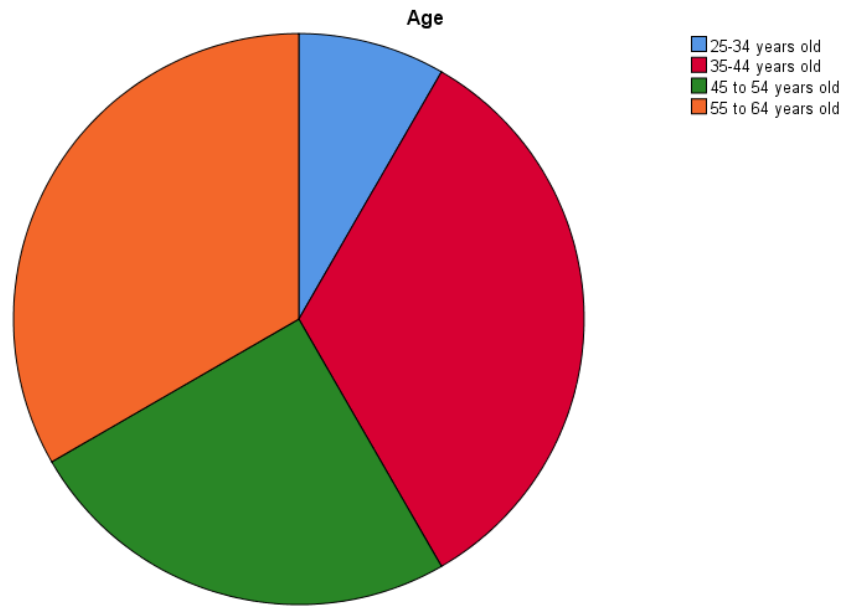


Figure 1: Participant Age

Participants were asked how long they have been working as a nurse. The largest bracket of experience was 10 to 20 years of experience, with 50% of survey respondents falling into that bracket (Figure 2). Twenty-five percent of participants reported that they had more than 30 years of nursing experience (Figure 2).

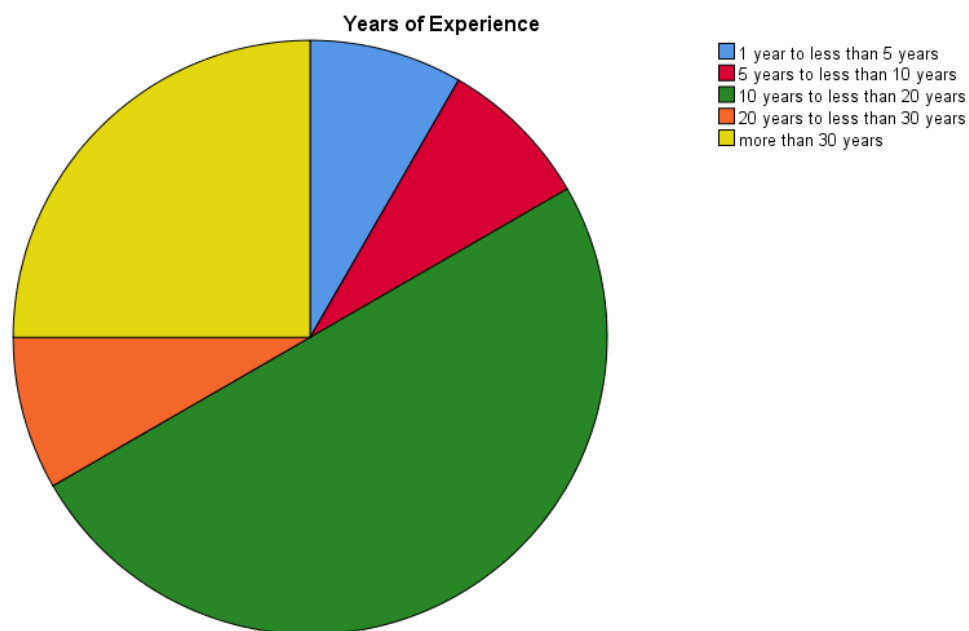


Figure 2: Participant Years of Experience

The final demographic question in the survey asked if the participant had participated in the End of Life Nursing Education Consortium (ELNEC) program or other formal end-of-life education. Eighty-three percent of participants indicated that they had not completed the ELNEC program (Figure 3).

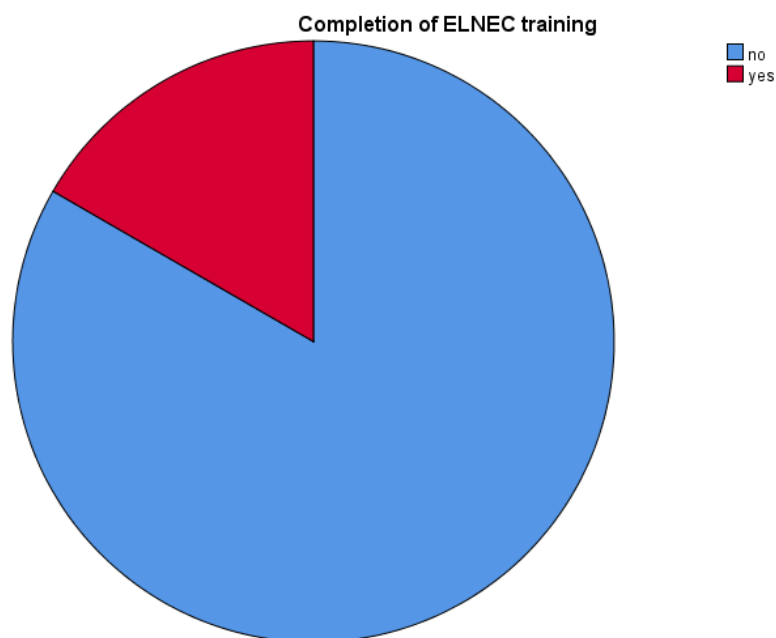


Figure 3: Participation in ELNEC

Major Findings

A 20 question Attitudes about Palliative Care (PC) questionnaire (questions 4 through 24) followed the initial demographic section of the emailed survey. Each question was independently reviewed to determine any areas indicating potential barriers to initiating PC referrals in the primary care setting. Descriptive statistics were performed on every question to determine frequencies of responses on each question. Question 20 and question 22 were omitted from data analysis due to inconclusive responses and lack of relevance to this study. On question 20, five participants answered “neither agree nor disagree”, three answered “strongly agree”, two answered “agree”, one answered “disagree”, and one answered “strongly disagree”. Both question 20 and 22 regarded physician-assisted suicide which did not translate well from the original hospice survey to one on PC. Because of the inconclusive response to question 20 and lack of relevance for both questions, these questions were not included in the results.

Question 4 stated, “I feel knowledgeable enough to discuss palliative care with patients and families.” This question was answered by all 12 respondents (n = 12). A cumulative 83% of participants answered “strongly agree” and “agree” to this question (Table 1). Two participants responded “neither agree nor disagree” for a percentage of 17% (Table 1).

Table 1

Question 4.

Question 4: I feel knowledgeable enough to discuss palliative care with patients and families.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	5	41.7	41.7	41.7
	agree	5	41.7	41.7	83.3
	neither agree or disagree	2	16.7	16.7	100.0
	Total	12	100.0	100.0	

Question 5 stated, “I am well trained to care for terminally ill patients.” All 12 participants answered this question (n = 12). A cumulative 83% of participants answered “strongly agree” and “agree” to this question (Table 2). Two participants responded “disagree” for a percentage of 17% (Table 2). Twenty-five percent of participants responded “neither agree nor disagree” (Table 2).

Table 2

Question 5.

Question 5: I am well trained to care for terminally ill patients.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	5	41.7	41.7	41.7
	agree	2	16.7	16.7	58.3
	neither agree or disagree	3	25.0	25.0	83.3
	disagree	2	16.7	16.7	100.0
	Total	12	100.0	100.0	

Question 6 stated, “I think it is essential for a dying patient to be told of his or her prognosis.” There were no omissions on this question (n = 12). A cumulative 92% of participants responded “strongly agree” and “agree” to this question (Table 3). One participant responded “neither agree nor disagree” for a percentage of 8%.

Table 3

Question 6.

Question 6: I think it is essential for a dying patient to be told of his or her prognosis.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	7	58.3	58.3	58.3
	agree	4	33.3	33.3	91.7
	neither agree or disagree	1	8.3	8.3	100.0
	Total	12	100.0	100.0	

Question 7 stated, “Talking with patients and families about death and dying is difficult for me.” All 12 participants answered this question (n = 12). Sixteen percent of participants answered “agree”, 33% answered “neither agree nor disagree”, and a cumulative 50% answered “disagree” and “strongly disagree” (Table 4).

Table 4

Question 7.

Question 7: Talking with patients and families about dying is difficult for me.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	agree	2	16.7	16.7	16.7
	neither agree or disagree	4	33.3	33.3	50.0
	disagree	3	25.0	25.0	75.0
	strongly disagree	3	25.0	25.0	100.0
	Total	12	100.0	100.0	

Question 8 stated, “I never raise palliative care as an option unless the physician has discussed it already with the patient or family and primary caregiver.” There were no omissions on this question (n = 12). One participant responded “strongly agree” for a percentage of 8% (Table 5). Twenty-five percent of participants answered “neither agree nor disagree”, and a cumulative 67% responded “disagree” and “strongly disagree” (Table 5).

Table 5

Question 8.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	1	8.3	8.3	8.3
	neither agree or disagree	3	25.0	25.0	33.3
	disagree	4	33.3	33.3	66.7
	strongly disagree	4	33.3	33.3	100.0
Total		12	100.0	100.0	

Question 9 stated, “Many patients would benefit if palliative care were initiated earlier in the course of their illness.” All 12 participants answered this question (n = 12). A cumulative 100% of participants responded “strongly agree” and “agree” to this question, with 75% responding “strongly agree” and 25% responding “agree” (Table 6).

Table 6

Question 9.

Question 9: Many patients would benefit if palliative care were initiated earlier in the course of their illness.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	9	75.0	75.0	75.0
	agree	3	25.0	25.0	100.0
	Total	12	100.0	100.0	

Question 10 stated, “In my experience, physicians usually order enough pain medication for terminally ill patients.” This question was answered by all 12 participants (n = 12). Seventeen percent of participants responded “agree”, 42% responded “neither agree nor disagree”, 8% responded “disagree”, and 33% responded “strongly disagree” (Table 7).

Table 7

Question 10.

Question 10: In my experience, physicians usually order enough pain medication for terminally ill patients.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	agree	2	16.7	16.7	16.7
	neither agree or disagree	5	41.7	41.7	58.3
	disagree	1	8.3	8.3	66.7
	strongly disagree	4	33.3	33.3	100.0
	Total	12	100.0	100.0	

Question 11 stated, “Palliative care generally meets the needs of the family better than conventional care does.” There were no omissions on this question (n = 12). A cumulative 75% of participants responded “strongly agree” and “agree” (Table 8). Twenty-five percent of respondents answered “neither agree nor disagree” to this question (Table 8).

Table 8

Question 11.

Question 11: Palliative care generally meets the needs of the family better than conventional care does.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	2	16.7	16.7	16.7
	agree	7	58.3	58.3	75.0
	neither agree or disagree	3	25.0	25.0	100.0
	Total	12	100.0	100.0	

Question 12 stated, “Most patients’ symptoms, such as pain, shortness of breath, and nausea are not controlled any better with palliative care than with conventional care.” Each of the participants responded to this question (n = 12). Eight percent of participants answered “agree”, and 8% answered “neither agree nor disagree” (Table 9). A cumulative 83% of participants responded “disagree” and “strongly disagree” on this question (Table 9).

Table 9

Question 12.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	agree	1	8.3	8.3	8.3
	neither agree or disagree	1	8.3	8.3	16.7
	disagree	7	58.3	58.3	75.0
	strongly disagree	3	25.0	25.0	100.0
	Total	12	100.0	100.0	

Question 13 stated, “Most physicians believe they do not have a role in palliative care.” All 12 participants answered this question (n = 12). A cumulative 58% of respondents answered “strongly agree” and “agree” on this question (Table 10). Twenty-five percent of participants answered “neither agree nor disagree”, and 17% answered “disagree” (Table 10).

Table 10

Question 13.

Question 13: Most physicians believe they do not have a role in palliative care.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	1	8.3	8.3	8.3
	agree	6	50.0	50.0	58.3
	neither agree or disagree	3	25.0	25.0	83.3
	disagree	2	16.7	16.7	100.0
	Total	12	100.0	100.0	

Question 14 stated, “When physicians first discuss the possibility of palliative care, patients and families often lose hope.” This question was answered by all 12 participants (n = 12). A cumulative 42% of participants responded “strongly agree” and “agree” to this question (Table 11). Thirty-three percent of participants answered “neither agree nor disagree”, and 25% responded “disagree” to this question (Table 11).

Table 11

Question 14.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	1	8.3	8.3	8.3
	agree	4	33.3	33.3	41.7
	neither agree or disagree	4	33.3	33.3	75.0
	disagree	3	25.0	25.0	100.0
Total		12	100.0	100.0	

Question 15 stated, “Talking with patients and families about dying is difficult for most physicians.” There were no omissions on this question (n = 12). A cumulative 58% of participants answered “strongly agree” and “agree” (Table 12). Thirty-three percent of participants responded “neither agree nor disagree”, and 8% answered “disagree” (Table 12).

Table 12

Question 15.

Question 15: Talking with patients and families about dying is difficult for most physicians.

	Frequency	Percent	Valid Percent	Cumulative Percent
Valid strongly agree	1	8.3	8.3	8.3
agree	6	50.0	50.0	58.3
neither agree or disagree	4	33.3	33.3	91.7
disagree	1	8.3	8.3	100.0
Total	12	100.0	100.0	

Question 16 stated, “Usually, physicians are reluctant to tell a patient directly that he or she is dying.” This question was answered by all 12 participants (n = 12). Eight participants responded “agree” for a percentage of 67% (Table 13). Twenty-five percent of participants answered “neither agree nor disagree”, and 8% responded “disagree” (Table 13).

Table 13

Question 16.

Question 16: Usually, physicians are reluctant to tell a patient directly that he or she is dying.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	agree	8	66.7	66.7	66.7
	neither agree or disagree	3	25.0	25.0	91.7
	disagree	1	8.3	8.3	100.0
	Total	12	100.0	100.0	

Question 17 stated, “Most, older patients want their doctors to determine what care is best for them.” Twelve participants responded to this question (n = 12). Four participants answered “strongly agree” and eight participants answered “agree” for a cumulative percentage of 100% (Table 14).

Table 14

Question 17.

Question 17: Most, older adult patients want their doctors to determine what care is best for them.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	4	33.3	33.3	33.3
	agree	8	66.7	66.7	100.0
	Total	12	100.0	100.0	

Question 18 stated, “Most patients know they are dying before the physician tells them.” This question was answered by all 12 participants (n = 12). Fifty-eight percent of participants answered “agree”, 16% answered “neither agree nor disagree”, and 25% answered “disagree” (Table 15).

Table 15

Question 18.

Question 18: Most patients know they are dying before the physician tells them.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	agree	7	58.3	58.3	58.3
	neither agree or disagree	2	16.7	16.7	75.0
	disagree	3	25.0	25.0	100.0
	Total	12	100.0	100.0	

Question 19 stated, “Many terminally ill patients would should receive palliative care do not receive palliative care.” There were no omissions on this question (n = 12). A cumulative 100% of participants responded “strongly agree” and “agree”, with 50% answering “strongly agree” and 50% answering “agree” (Table 16).

Table 16

Question 19.

Question 19: Many terminally ill patients who should receive palliative care do not receive palliative care.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	6	50.0	50.0	50.0
	agree	6	50.0	50.0	100.0
	Total	12	100.0	100.0	

Question 21 stated, “An interdisciplinary team approach can interfere with patient care.” All 12 participants answered this question (n = 12). A cumulative 100% of participants responded “strongly disagree” and “disagree”, with 50% answering “strongly disagree” and 50% answering “disagree” (Table 17).

Table 17

Question 21.

Question 21: An interdisciplinary team approach can interfere with patient care.					
		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	disagree	6	50.0	50.0	50.0
	strongly disagree	6	50.0	50.0	100.0
	Total	12	100.0	100.0	

Question 23 stated, “I would like to work more closely with the palliative care team.” This question was answered by all 12 participants (n = 12). Seventeen percent responded “strongly agree”, 58% responded “agree”, and 25% responded “neither agree nor disagree” (Table 18).

Table 18

Question 23.

Question 23: I would like to work more closely with the palliative care team.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	strongly agree	2	16.7	16.7	16.7
	agree	7	58.3	58.3	75.0
	neither agree or disagree	3	25.0	25.0	100.0
	Total	12	100.0	100.0	

Question 24 stated, “Physicians often disagree with the recommendations made by the palliative care team.” There were no omissions to this question (n = 12). One participant responded “agree” for a percentage of 8% (Table 19). Forty-two percent responded “neither agree nor disagree” (Table 19). A cumulative 50% responded “disagree” and “strongly disagree”, with 33% responding “disagree” and 16% responding “strongly disagree” (Table 19).

Table 19

Question 24.

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	agree	1	8.3	8.3	8.3
	neither agree or disagree	5	41.7	41.7	50.0
	disagree	4	33.3	33.3	83.3
	strongly disagree	2	16.7	16.7	100.0
	Total	12	100.0	100.0	

Question 25 was an open-ended question that allowed participants the option to provide additional information on barriers to PC. Question 25 stated, “What barriers do you encounter in your practice to referring patients to palliative care?” This question was answered by nine of the 12 participants (n = 9). The responses are listed below.

- “From previous referrals, it takes quite a while for palliative to get out and assess the patient and then they are quick to respond when families call them for assistance”.
- “The physician’s depth of knowledge about what the program offers and how it can assist the patient”.
- “None, the physicians that I work with are quick to make the right call”.
- “Reluctance of physicians to initiate palliative care and limited understanding of palliative care by physicians (some think that it is very close to Hospice). I also feel a physician does not want to give up that control of the patient and may feel as if initiation of palliative care would seem as if the physician did not know how to manage their patients' symptoms”.
- “Patients tend to think of palliative care and hospice as the same. They don't realize that palliative care does not mean they will die soon. It just is a way to enhance the quality of life with chronic illnesses”.
- “Physicians are afraid to lose patients, lose money due to less direct services being provided by primary care. Some are not welcoming to multi-discipline involvement with "their" patients”.
- “I feel the physician should initiate that conversation”.

- “Palliative Care in our area is limited to the types of patients they are able to take on”.
- “It seems that most patients, and a great many providers, do not really understand the difference between palliative care and hospice care. Also, many providers see palliative care as giving up the "control" of the patient's care instead of an extension of care”.

Summary

A total of 12 participants responded to the anonymous survey questionnaire. Demographic information was collected and indicated a variety in age and years of experience for the participants. A majority of the participants had not completed ELNEC or formal end-of-life educational programs (83%). The Attitudes about PC section of the survey consisted of 20 questions that were evaluated individually to identify potential barriers to initiating PC referrals in the primary care setting. The final question provided an opportunity for the participant to list any specific barriers they encounter to PC within their particular practice. Common trends emerged in both the Attitudes about PC survey and the open-ended final question.

CHAPTER V

Discussion

Palliative Care (PC) is an interdisciplinary service that is designed to maintain or improve the quality of life for patients suffering from life-limiting chronic medical conditions. PC differs from Hospice care in that services can be offered for any length of time as opposed to only during the final six months of life, and can also be offered congruently with disease-directive and curative treatments (Kelley & Morrison, 2015). Ideally, PC should be initiated at the time of diagnosis of a chronic, life-limiting illness (Keim-Malpass et al., 2015). Research suggests that PC referrals are often delayed until there is a clearly terminal event, leading to unnecessary suffering from preventable symptoms and poor quality of life (Wilson et al., 2016).

Early involvement of PC can improve the quality of the elderly patient's life through effective management of distressing symptoms and incorporating psychosocial and spiritual care, with consideration of the patient's and family's needs, values, beliefs, and culture (Morrison, 2015). Nurses working in the primary care setting have frequent interactions with elderly patients living with chronic illnesses. Approximately 75% of Medicare recipients in the United States have at least one chronic disease, making it necessary for them to visit their primary care provider as often as every three months (Auer, 2008). Primary care nurses must possess the ability to build strong and trusting nurse-patient relationships with their patients. The frequency of nurse-patient interaction in the primary care setting provides an opportunity to create an effective relationship where the patient views the nurse as a resource and counselor. Nurses in primary care must be able to appropriately identify patients that would benefit from PC and feel

comfortable discussing end-of-life planning with their patients. The purpose of this MSN thesis was to determine what barriers exist in the primary care setting to prevent identifying and/or referring patients to PC programs.

Implication of Findings

Data indicates that PC programs can improve the quality of life through effective management of symptoms for patients with life-limiting illnesses. The survey results indicated that the majority of the Registered Nurse (RN) care navigator participants felt that PC programs provided benefits to patients receiving services. Seventy-five percent of participants believed that PC generally meets the needs of the family better than conventional care does (Table 8). Eighty-three percent of respondents believed that most patients' symptoms, such as pain, shortness of breath, and nausea are better controlled by PC than with conventional care (Table 9).

Results demonstrated that participants believe PC services should be initiated earlier in the disease trajectory. One hundred percent of respondents stated that they believed many patients would benefit if palliative care were initiated earlier in the course of their illness (Table 6). All survey participants (100%) also indicated that many terminally ill patients who should receive PC do not receive the service (Table 16). These findings are consistent with research that indicates referrals to PC programs are often delayed until there is a clearly terminal event, leading to unnecessary suffering from preventable symptoms and poor quality of life (Wilson et al., 2016).

Nursing knowledge of PC and comfort level in discussing end of life care with patients are commonly reported barriers in the literature. Research suggests that nursing textbooks contain less than 2% of information related to end of life care, resulting in

nurses feeling unprepared to discuss end of life plans with their patients (Malloy et al, 2015). Only two of the participants in this survey had completed the End of Life Nursing Education Consortium (ELNEC) program or other formal end-of-life education (Figure 3). Survey results indicated that although few participants had completed ELNEC education, a majority of participants (83%) felt knowledgeable enough to discuss PC with patients and families (Table 1). Sixty-seven percent of participants also indicated that they would raise PC as an option even if the physician had not already discussed it with the patient or family and primary caregiver (Table 5). These results demonstrate that nursing discomfort in discussing PC and initiating referrals to PC programs is not an existing barrier within the CaroMont primary care practices.

Many of the barriers identified in this study involved the primary care physicians. Fifty-eight percent of survey participants reported that most physicians believe they do not have a role in PC (Table 10). Most of the survey respondents (92%) believed that dying patients should be told of his or her prognosis (Table 3), and 100% of survey participants believed that older adults want their doctors to determine what care is best for them (Table 14). Results of the survey demonstrated that discussing end of life care is difficult for physicians, with 58% of survey participants reporting that talking with patients about dying is difficult for most physicians (Table 12), and 67% of participants stating that physicians are reluctant to tell a patient directly that he or she is dying (Table 13). These findings are consistent with the literature. Commonly reported barriers to initiating PC are insufficient education for providers, physician not ready to give up care, physician feels that PC is failure, and physician reluctance to communicate a terminal prognosis (Boyd et al., 2011).

The purpose of this MSN thesis was to identify barriers in the primary care setting to identifying and/or referring patients to PC. The survey results indicated that RN care navigators working within CaroMont primary care practices feel knowledgeable of PC and comfortable initiating PC discussions with their patients, even if the physician has not previously discussed PC services. Identified barriers in the CaroMont primary care practices were physician reluctance to communicate a terminal prognosis and physician discomfort in discussing end of life planning with their patients. These barriers are consistent with the literature. The results indicated a potential need for additional PC education and end of life care planning training for primary care providers.

Application to Theoretical/Conceptual Framework

The theoretical framework for this MSN thesis was Hildegard Peplau's nurse-patient relationship theory. Nurses spend more time with patients than any other health care profession (Malloy et al., 2014). Primary care nurses have a unique opportunity to develop a long-term relationship with their patients. The nurse-patient relationship takes time to establish, as both the nurse and the patient move through the orientation, working, and resolution phase. Building a trusting and effective nurse-patient relationship within the primary care setting allows the nurse to take on the roles of educator and resource person, particularly in advocating for PC services.

Barriers identified in this study involved the primary care physicians. Results of this study indicated that nurses believe physicians are reluctant to discuss end of life planning with their patients and communicate terminal prognoses. Data from this study also demonstrated that nurses felt comfortable discussing PC with their patients, even if physicians had not previously approached the topic. These results indicated that

establishing a trusting nurse-patient relationship is essential to facilitating PC referrals. Nurses in the primary care setting may be the first person to discuss end of life planning with the patient. It is necessary that patients view the primary care nurse as knowledgeable and caring. Only after the establishment of trust will the patient look to the primary care nurse for guidance in the plan of care. After a patient has been identified as appropriate for PC and a strong nurse-patient relationship has developed, the primary care nurse can advocate for PC and facilitate referrals to PC programs.

Limitations

Two limitations were identified for this study. One limitation was the small number of participants. There are a limited number of RNs working within the CaroMont primary care practices, as many positions previously held by RNs are now filled by Medical Assistants (MA). Each CaroMont primary care practice employs one RN care navigator to assist with disease management and care coordination for patients at that practice. A total of 18 RN care navigators are employed at CaroMont primary care practices. All 18 RNs were invited to participate in the research; 12 RNs actually participated in the research survey.

Another limitation in this study was the Attitudes about PC questionnaire. This tool was modified from the Attitudes about Hospice questionnaire originally developed by Cramer et al. (2003). All questions were modified from Hospice to PC. Although most questions accurately reflected potential barriers to PC, two questions (Question 20 and Question 22) did not translate well to reflect PC. These two questions were difficult to understand once changed to PC and received responses of “neither agree nor disagree” or were skipped. These questions were therefore eliminated from the statistical analysis.

Implications for Nursing

The results of this MSN thesis indicated that although nurses working in the primary care setting feel knowledgeable of PC and are comfortable initiating end of life care planning discussions with their patients, barriers to PC remain. Nurses in this study perceived that physicians do not feel comfortable delivering terminal prognoses or discussing end of life care with their patients. Nurses may be the ones to initiate PC discussions with their patients and must therefore be an excellent resource for the patient. A small percentage of survey participants have completed ELNEC training (17%). ELNEC programs are offered to CaroMont employees several times a year at no cost to the employee. A recommendation would be for all nurses working in the primary care setting to attend ELNEC training in order to increase knowledge of the services PC programs can offer. This will prepare nurses to serve as a more effective educator and counselor for their patients. Nurses may also use this knowledge to educate physicians on the benefits of PC and the importance of early referrals to PC programs.

Recommendations

A recommendation for future study was to investigate the availability of PC programs to meet the demand, especially if PC referrals were increased. Two survey participants indicated access to PC as barriers in the open-ended question. One participant stated that once a referral to PC is initiated, it takes an extended time for a PC representative to evaluate the patient and accept into the program. Another participant indicated that PC services in the area are restricted and only available to certain populations. The literature suggested that PC programs can offer benefits to any patient

diagnosed with a life-limiting illness. These barriers need further evaluation to ensure population needs are met.

Conclusion

Results of this MSN thesis study determined that the RN care navigator participants believe that PC programs offer benefits of increased quality of life and should be initiated earlier in the disease trajectory. The majority of respondents believed that most patients' symptoms, such as pain, shortness of breath, and nausea are better controlled by PC than with conventional care; and all of survey participants stated that they believed many patients would benefit if palliative care were initiated earlier in the course of their illness. The survey results also indicated that the RN care navigators feel knowledgeable enough to discuss PC with patients and are comfortable initiating PC discussions, even if the physician has not previously discussed this service. Barriers to initiating PC identified in this MSN thesis research were that physicians are reluctant to communicate terminal prognoses and do not feel comfortable discussing end of life care with their patients. These barriers must be addressed in order to increase the number of PC referrals in the primary care setting. Early referrals to PC in the primary care setting will help healthcare organizations achieve the Institute of Healthcare Improvement's Triple Aim of improving patient quality and satisfaction, improving the health of populations, and reducing the per capita cost of health care (IHI, 2017).

References

- Auer, P. (2008). Primary care end-of-life planning for older adults with chronic illness. *The Journal for Nurse Practitioners*, 185-191.
- Beyea, A., Fischer, J., Schenck, A., & Hanson, L. C. (2013). Integrating palliative care information and hospice referral in Medicaid primary care. *Journal of Palliative Medicine*, 16(4), 376-382. doi: 10.1089/jpm.2012.0483
- Boyd, D., Merkh, K., Rutledge, D. N., & Randall, V. (2011). Nurses' perceptions and experiences with end-of-life communication and care. *Oncology Nursing Forum*, 38(3), 229-239.
- Bradley, E. H., Cherlin, E., McCorkle, R., Fried, T. R., Stanislay, V. K., ..., Horwitz, S. M. (2001). Nurses' use of palliative care practices in the acute care setting. *The Professional Journal of Nursing*, 17(1), 14-22. doi: <http://dx.doi.org/10.1053/jpnu.2001.20255>
- Center to Advance Palliative Care (CAPC). (n.d.). *How we work: Trends and insights in hospital palliative care*. Retrieved from: www.capc.org
- Christakis, N. A. & Iwashyna, T. J. (1998). Attitude and self-reported practice regarding prognostication in a national sample of internists. *Archives of Internal Medicine*, 158(21), 2389-2395.
- Cramer, L. D., McCorkle, R., Cherlin, E., Johnson-Hurzeler, R., & Bradley, E. H. (2003). Nurses' attitudes and practice related to hospice care. *Journal of Nursing Scholarship*, 35(3), 249-255.
- Crosby, J. & Yelamanchi, R. (2013). Early palliative care in the office. *Journal of the New York State Academy of Family Physicians*, 2(1), 12-14.

- Hagerty, B. M. & Patusky, K. L. (2003). Reconceptualizing the nurse-patient relationship. *Journal of Nursing Scholarship*, 35(2), 145-150.
- Hughes, M. T. & Smith, T. J. (2014). The growth of palliative care in the United States. *Annual Review of Public Health*, 35, 459-475. doi: 10.1146/annurev-publhealth-032013-182406
- Institute of Healthcare Improvement (IHI). (2017). *The IHI triple aim*. Retrieved from: www.ihi.org
- Institute of Medicine (IOM). (2014). *Dying in America: Improving quality and honoring individual preferences near the end of life*. Retrieved from: www.iom.edu
- Keim-Malpass, J., Mitchell, E. M., Blackhall, L., & DeGuzman, P. B. (2015). Evaluating stakeholder-identified barriers in accessing palliative care at an NCI-designated cancer center with a rural catchment area. *Journal of Palliative Medicine*, 18(7), 634-637.
- Kelley, A. S. & Morrison, R. S. (2015). Palliative care for the seriously ill. *The New England Journal of Medicine*, 373(8), 747-755.
- Kim, S. L. & Tarn, D. M. (2016). Effect of primary care involvement on end-of-life care outcomes: A systematic review. *Journal of American Geriatric Society*, 64(10), 1968-1974. doi: 10.1111/jgs.14315
- Malloy, P., Paice, J., Coyle, N., Coyne, P., Smith, T., & Ferrell, B. (2014). Promoting palliative care worldwide through international nursing education. *Journal of Transcultural Nursing*, 25(4), 410-417.

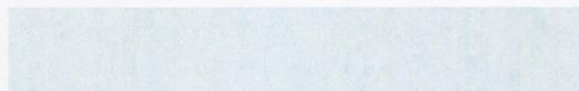
- Marchese, K. (2006). Using Peplau's theory of interpersonal relations to guide the education of patients undergoing urinary diversion. *Urologic Nursing, 26*(5), 363-370.
- McCormick, E., Chai, E., & Meier, D. E. (2012). Integrating palliative care into primary care. *Mount Sinai Journal of Medicine, 79*, 579-585. doi: 10.1002/msj.21338
- Morrison, R. S. (2015). *Models of palliative care delivery in the United States*. Retrieved from: www.ncbi.nlm.nih.gov
- Owens, D., Eby, K., Burson, S., Green, M., McGoodwin, W., & Isaac, M. (2012). Primary palliative care clinic project demonstrates benefits of a nurse practitioner-directed clinic providing primary and palliative care. *Journal of the American Academy of Nurse Practitioners, 24*, 52-58.
- Sheldon, L. K. (2015). Do I have hope? Framing end-of-life care discussions. *Clinical Journal of Oncology Nursing, 19*(6), 645-646. doi: 10.1188/15.CJON.645-646
- Smith, M. C. & Parker, M. E. (2015). *Nursing theories and nursing practice (4th ed.)*. Philadelphia, PA: F. A. Davis Company.
- Smith, S., Brick, A., & Normand, C. (2014). Evidence on the cost and cost-effectiveness of palliative care: A literature review. *Palliative Medicine, 28*(2), 130-150. doi: 10.1177/0269216313403466
- Snyder, S., Hazelett, S., Allen, K., & Radwany, S. (2012). Physician knowledge, attitude, and experience with advance care planning, palliative care, and hospice: Results of a primary care survey. *American Journal of Hospice and Palliative Medicine, 30*(5), 419-424. doi: 10.1177/1049909112452467

- Van der Plas, A. G. M., Onwuteaka-Philipsen, B. D., Francke, A. L., Jansen, J. J.,
Vissers, K. C., & Deliens, L. (2015). Palliative care case managers in primary
care: A descriptive study of referrals in relation to treatment aims. *Journal of
Palliative Medicine, 18*(4), 324-331. doi: 10.1089/jpm.2014.0269
- Wharton, T., Manu, E., & Vitale, C. A. (2015). Enhancing provider knowledge and
patient screening for palliative care needs in chronic multimorbid patients
receiving home-based primary care. *American Journal of Hospice and Palliative
Medicine, 32*(1), 78-83. doi: 10.1177/1049909113514475
- Wilson, O., Avalos, G., & Dowling, M. (2016). Knowledge of palliative care and
attitudes towards nursing the dying patient. *British Journal of Nursing, 25*(11),
600-605.
- Zhou, G., Stoltzfus, J. C., Houldin, A. D., Parks, S. M., & Swan, B. A. (2010).
Knowledge, attitudes, and practice behaviors of oncology advanced practice
nurses regarding advanced care planning for patients with cancer. *Oncology
Nursing Forum, 37*(6), 400-410.

Appendix A Palliative Care Screening Tool

Palliative Care Screening Tool		
<i>Scoring= 1 point for each item</i>		
	Yes	No
EF Less than 20%		
Severe limitations (Symptoms at rest)		
Frequency of ED visits (≥ 3 in a year dx related or ≥3 any dx)		
Frequency of Hospital Adm. (≥ 3 per year or more than 1 hospital adm. For same dx in last 60 days.		
End stage COPD		
Stage 4 or 5 CKD		
Three or more of the following: CAD, DM, HTN, OSA (COPD & CKD :Not end stage)		
Weight increases and fails to respond increased doses of diuretics		
BUN > 30		
Systolic BP<120		
Inoperable CAD		
Inoperable Valve Disease		

If score is ≥ 3 in the yes column, consider palliative care referral.		
--	--	--



Appendix B

Attitudes about Hospice Care Questionnaire (Cramer et al., 2003)

Table 5. Attitudes About Hospice Care From Current Study Sample Compared With Attitudes From Medical-Surgical Nurses

Variable	N	\bar{X}	SD	Current Sample Agree (%)	Medical-Surgical Agree (%)
Self-Rated Knowledge					
I feel knowledgeable enough to discuss hospice care with patients and families.	31	2.3	1.3	62	30
I am well trained to care for terminally ill patients.	31	2.5	1.3	61	32
Comfort With Initiating Hospice Discussion					
I think it is essential for a dying patient to be told of his or her prognosis.	30	1.4	0.6	90	81
Talking with patients and families about dying is difficult for me.	30	3.5	1.2	23	44
I never raise hospice as an option unless the physician has discussed it already with the patient or family and primary caregiver.	30	3.2	1.4	26	28
Added Benefit of Hospice					
Many patients would benefit if hospice care were initiated earlier in the course of their illness.	31	1.6	0.8	90	72
In my experience, physicians usually order enough pain medication for terminally ill patients.	31	3	1.3	38	26
Hospice care generally meets the needs of the family better than conventional care does.	31	2	1.2	71	81
Most patients' symptoms, such as pain, shortness of breath, and nausea are not controlled any better with hospice care than with conventional care.	31	4.5	0.8	3	12
Perceived Physician Comfort and Responsibility					
Most physicians believe they do not have a role in hospice care.	31	3	0.9	26	32
When physicians first discuss the possibility of hospice, patients and families often lose hope.	31	2.9	1	29	53
Talking with patients and families about dying is difficult for most physicians.	30	2	1.1	74	70
Usually, physicians are reluctant to tell a patient directly that he or she is dying.	30	2	0.9	71	-
Patient Perceptions of Care and Prognosis					
Most older adult patients want their doctors to determine what care is best for them.	30	2	1.1	69	-
Most patients know they are dying before the physician tells them.	30	2.6	1.2	52	-
Results of Palliative or Hospice Care					
Many terminally ill patients who should receive hospice care <i>do not</i> receive hospice care.	30	2	1	71	-
More widespread use of hospice would lessen support for physician-assisted suicide.	30	2.2	1.1	60	-
An interdisciplinary team approach can interfere with patient care.	31	4.5	0.8	3	-
Hospice supports physician-assisted suicide.	31	4.9	0.3	-	-
Facilitation of End-of-Life Care for Nurses					
I would like to work more closely with the palliative care team.	31	1.7	0.8	81	-
Physician and Nurse Turf Issues					
Physicians often disagree with the recommendations made by home hospice nurses.	31	3.9	0.9	7	-

Appendix C
End of Life Nursing Education Consortium Flyer



Tuesday & Wednesday
 June 6 & 7, 2017

Tues.—8am-5pm
 Wed.—8am-12:30pm

Pine Room

Sign up for class in NetLearning

ELNEC

(End of Life Nursing Education Consortium)

Learning Outcome: The RN will gain information on end of life/palliative nursing care and resources necessary to integrate skills directly into their practice.

This continuing nursing education activity provides **11.0 contact hours** upon successful completion.

To receive nursing contact hours for this continuing nursing education activity, participants must:

- attend 100% of the offering;
- sign the attendance roster; and
- provide a valid email address.

CaroMont Health, Nursing Professional Development is an approved provider of continuing nursing education by the North Carolina Nurses Association, an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

Appendix D

Attitudes about Palliative Care Questionnaire

Demographic Information

1. What is your age?

- | | |
|--------------------------------|-----------------------------------|
| <input type="radio"/> 18 to 24 | <input type="radio"/> 55 to 64 |
| <input type="radio"/> 25 to 34 | <input type="radio"/> 65 to 74 |
| <input type="radio"/> 35 to 44 | <input type="radio"/> 75 or older |
| <input type="radio"/> 45 to 54 | |

2. How long have you been working as a nurse?

- | | |
|---|--|
| <input type="radio"/> Less than 1 year | <input type="radio"/> 10 years to less than 20 years |
| <input type="radio"/> 1 year to less than 5 years | <input type="radio"/> 20 years to less than 30 years |
| <input type="radio"/> 5 years to less than 10 years | <input type="radio"/> 30 years or more |

3. Have you participated in the ELNEC program or other formal end-of-life education?

- Yes
- No

Attitudes about Palliative Care Survey

This survey has been adapted with the author's permission from the Attitudes about Hospice survey (Cramer et al., 2003).

4. I feel knowledgeable enough to discuss palliative care with patients and families.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

5. I am well trained to care for terminally ill patients.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

6. I think it is essential for a dying patient to be told of his or her prognosis.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

7. Talking with patients and families about dying is difficult for me.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

8. I never raise palliative care as an option unless the physician has discussed it already with the patient or family and primary caregiver.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

9. Many patients would benefit if palliative care were initiated earlier in the course of their illness.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

10. In my experience, physicians usually order enough pain medication for terminally ill patients.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

11. Palliative care generally meets the needs of the family better than conventional care does.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

12. Most patients' symptoms, such as pain, shortness of breath, and nausea are not controlled any better with palliative care than with conventional care.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

13. Most physicians believe they do not have a role in palliative care.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

14. When physicians first discuss the possibility of palliative care, patients and families often lose hope.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

15. Talking with patients and families about dying is difficult for most physicians.

- Strongly Agree Disagree
 Agree Strongly Disagree
 Neither agree nor disagree

16. Usually, physicians are reluctant to tell a patient directly that he or she is dying.

- Strongly Agree Disagree
 Agree Strongly Disagree
 Neither agree nor disagree

17. Most older adult patients want their doctors to determine what care is best for them.

- Strongly Agree Disagree
 Agree Strongly Disagree
 Neither agree nor disagree

18. Most patients know they are dying before the physician tells them.

- Strongly Agree Disagree
 Agree Strongly Disagree
 Neither agree nor disagree

19. Many terminally ill patients who should receive palliative care *do not* receive palliative care.

- Strongly Agree Disagree
 Agree Strongly Disagree
 Neither agree nor disagree

20. More widespread use of palliative care would lessen support for physician-assisted suicide.

- Strongly Agree Disagree
 Agree Strongly Disagree
 Neither agree nor disagree

21. An interdisciplinary team approach can interfere with patient care.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

22. Palliative care supports physician-assisted suicide.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

23. I would like to work more closely with the palliative care team.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

24. Physicians often disagree with the recommendations made by the palliative care team.

- | | |
|--|---|
| <input type="radio"/> Strongly Agree | <input type="radio"/> Disagree |
| <input type="radio"/> Agree | <input type="radio"/> Strongly Disagree |
| <input type="radio"/> Neither agree nor disagree | |

Open Comments

25. What barriers do you encounter in your practice to referring patients to palliative care?

Appendix E

Invitation to Participate in Research Email

Dear Nurse Care Navigator,

You are receiving this invitation to participate in a research survey because you are a care navigator working in a primary care practice. This research is intended to gain a better understanding of the nursing knowledge of palliative care and any barriers to facilitating palliative care referrals in the primary care setting. I obtained your email address from the care navigator supervisor Suzanne Howell. She has approved your participation in the survey and that completion of the survey may occur during work hours. This research has been approved for use by the CaroMont and Gardner-Webb University Institutional Review Boards. There are no risks involved with participation. The estimated time to complete the survey is 10-20 minutes. All responses will be kept anonymous and only aggregate data will be reported. Please click on the link below to complete the survey. The survey link will be open until November 2, 2017. Clicking on the survey link implies your consent to participate in the survey. Participation in the survey is voluntary and there will be no consequences for refusal to participate. To express appreciation to those who choose to participate, there will be a drawing for a \$25 Visa gift card. All care navigators who complete the survey will be entered in the drawing. A separate survey page within Survey Monkey is available to enter your email address as to keep survey responses anonymous. The gift card drawing will take place on November 10, 2017. Feel free to contact me with any questions or concerns. Thank you in advance for your time.

<https://www.surveymonkey.com/r/YDW98RM>

Thank you,

Angela Rutherford, RN

angela.rutherford@caromonthealth.org

MSN Student

Gardner-Webb University

Appendix F
Follow Up Invitation to Participate in Research Email

Dear Nurse Care Navigator,

One week ago you are received an invitation to participate in a research survey because you are a care navigator working in a primary care practice. This research is intended to gain a better understanding of the nursing knowledge of palliative care and any barriers to facilitating palliative care referrals in the primary care setting. I am unable to know who has completed the survey due to the anonymity of the responses. If you have not yet completed the survey, it will remain open for one additional week, closing on November 2, 2017. The estimated time to complete the survey is 10-15 minutes. All responses will be kept anonymous and only aggregate data will be reported. Please click on the link below to complete the survey. Clicking on the survey link implies your consent to participate in the survey.

As a reminder, participation is completely voluntary and there are no consequences for refusing to participate. To express appreciation to those who choose to participate, there will be a drawing for a \$25 Visa gift card. All care navigators who complete the survey will be entered in the drawing. A separate survey page within Survey Monkey is available to enter your email address as to keep survey responses anonymous. The gift card drawing will take place on November 10, 2017. Feel free to contact me with any questions or concerns. Thank you in advance for your time.

<https://www.surveymonkey.com/r/YDW98RM>

Thank you,

Angela Rutherford, RN

angela.rutherford@caromonthealth.org

MSN Student

Gardner-Webb University

Appendix G

Survey/Questionnaire Permission Email

Re: Survey/Questionnaire Permission Request - Angela Rutherford 8/2/17, 11:29 AM

Re: Survey/Questionnaire Permission Request

Elizabeth Bradley <eb Bradley@vassar.edu>

Sat 7/8/2017 2:13 PM

To: Angela Featherston <aadams13@gardner-webb.edu>;

Cc: Jill Parker <jparker11@Gardner-Webb.edu>;

Sure. Just cite it. Thanks.

On Sat, Jul 8, 2017 at 2:09 PM Angela Featherston <aadams13@gardner-webb.edu> wrote:

Angela F. Rutherford
 Gardner-Webb University
 Masters of Science in Nursing Administration
 110 South Main St.
 Boiling Springs, NC, 28017

Dear Dr. Bradley:

I am a masters student from Gardner-Webb University writing my thesis titled *Primary Care Nursing Barriers to Identifying and Referring Patients to Palliative Care*, under the direction of my thesis advisor Professor Jill Parker, MSN, APRN, FNP-C, who can be reached at 704-406-4384 or jparker11@gardner-webb.edu. The Gardner-Webb University IRB Institutional Administrator can be contacted at 704-406-4724 or by email at jrogers3@gardner-webb.edu.

I would like your permission to use the *Nurses' Attitudes and Practice related to Hospice Care* survey/questionnaire instrument in my research study. With your permission I would like to modify the survey tool to study attitudes regarding Palliative Care instead of Hospice care. I would like to use and print your survey under the following conditions:

- I will use the surveys only for my research study and will not sell or use it with any compensated or curriculum development activities.
- I will include the copyright statement on all copies of the instrument.
- I will send a copy of my completed research study to your attention upon completion of the study.

If these are acceptable terms and conditions, please indicate so by replying to me through e-mail: aadams13@gardner-webb.edu

Sincerely,

<https://outlook.office.com/owa/?viewmodel=ReadMessageItem&ItemID=Zxqcw7hzNaIAAMUMDmaAAA%3D&isPrintView=1&wid=63&ispopout=1&path=> Page 1 of 2

Angela Rutherford

Elizabeth H. Bradley, [President](#)
[VASSAR COLLEGE](#)
[Poughkeepsie, NY 12604](#)
[@EHBVassar](#)

Re: Survey/Questionnaire Permission Request

Elizabeth Bradley <ebradley@vassar.edu>

Sat 7/29/17 2:13 PM

to: Angela Rutherford <arutherford@gardner-webb.edu>

cc: Jill Parker <jlparker@gardner-webb.edu>

Sure, just give it. Thanks.

On Sat, Jul 8, 2017 at 5:09 PM Angela Rutherford <arutherford@gardner-webb.edu> wrote:

Angela F. Rutherford
Gardner-Webb University
Masters of Science in Nursing Administration
110 South Main St
Boiling Springs, NC, 28017

Dear Dr. Bradley:

I am a masters student from Gardner-Webb University writing my thesis titled Primary Care Nursing Barriers to Identifying and Referring Patients to Palliative Care, under the direction of my thesis advisor Professor Jill Parker, MSN, APRN, FNP-C, who can be reached at 704-406-4384 or jlparker1@gardner-webb.edu. The Gardner-Webb University IRB Institutional Administrator can be contacted at 704-406-4724 or by email at rogersj@gardner-webb.edu.

I would like your permission to use the Nurse's Attitudes and Practices related to Hospice Care survey/questionnaire instrument in my research study. With your permission I would like to modify the survey tool to study attitudes regarding Palliative Care instead of Hospice care. I would like to use and print your survey under the following conditions:

- I will use the survey only for my research study and will not sell or use it with any compensated or curriculum development activities.
- I will include the copyright statement on all copies of the instrument.
- I will send a copy of my completed research study to your attention upon completion of the study.

If these are acceptable terms and conditions, please indicate so by replying to me through e-mail: arutherford@gardner-webb.edu

Sincerely,

Appendix H
Gardner-Webb University IRB Approval

Ms. Rutherford,

Your IRB Application for the Expedited research project titled “Primary Care Nursing Barriers to Identifying and Referring Patients to Palliative Care” has been approved, effective October 18, 2017. It has been assigned an expiration date of October 17, 2018, and an IRB file number of 17101301X.

Please be aware that if you need to continue your study beyond the Expiration Date, you must submit a Request for Continuance (<http://www.gardnerwebb.edu/Assets/gardnerwebb/academics/review-board/irb-request-research-continuance1.pdf>) prior to that date.

Best wishes for a productive investigation!

Kathi Simpson

Office Manager

Secretary to the IRB

Gayle Bolt Price School of Graduate Studies

P (704) 406-3020 | F (704) 406-3859

Appendix I CaroMont IRB Approval



CaroMont Health Institutional Review Board
2525 Court Drive, Gastonia, NC 28054
FWA0005497
IRB00003619

9/5/2017

Angela Rutherford, RN BSN
CaroMont Regional Medical Center
2525 Court Dr.
Gastonia, NC 28054

IRB# 2017-09-002

Study title: Primary Care Nursing Barriers to Identifying and Referring Patients to Palliative Care

Dear Ms. Rutherford,

The Vice Chair of the CaroMont Health Institutional Review Board and a Nursing IRB Member determined that this project be designated as exempt research (category # 2). This action will be reported to the IRB at the 9/28/2017 IRB meeting.

Items Reviewed:

Exempt application, dated 8/24/2017
Cover memo to Nurse Care Navigators
Attitudes about Palliative Care survey
List of Research Practice Sites

Designates as EXEMPT RESEARCH on: 9/5/2017

It is the Principal Investigator's responsibility to notify the CaroMont Health IRB if this project should change in anyway. The CaroMont Health IRB shall review such changes to assess whether the changes alter the exempt status and requires further IRB review and approval.

If you have any questions or concerns, please call Michelle Cook, Director, Human Research Ethics at 704-834-3891 or email at cookml@caromonthhealth.org.

Sincerely,

A handwritten signature in black ink, appearing to read "DL", with a long horizontal flourish extending to the right.

Dustin Letts, MD
Vice Chair, Institutional Review Board