

EiBARRIERS AMONG PRIMARY CARE PROVIDERS TO UTILIZING  
PALLIATIVE/HOSPICE CARE FOR PATIENTS WITH NON-CANCEROUS  
TERMINAL ILLNESS

by

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As members of the DNP Project Committee, we certify that we have read the DNP Project prepared by Susan Eileen Ellis entitled “Barriers Among Primary Care Providers to Utilizing Palliative/Hospice Care for Patients with Non-Cancerous Terminal Illness” and recommend that it be accepted as fulfilling the DNP Project requirement for the Degree of Doctor of Nursing Practice.

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SIGNED: Susan Eileen Ellis

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## DEDICATION

I dedicate this final project to my sister Theresa. She taught me to love life with passion, be the best you can be, never judge those for the choices they make and always listen with your heart. She would be proud of me today and the work I have done. She taught me how to embrace the dying process as she died with grace and dignity.

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## ABSTRACT

Patients with terminal illness may benefit greatly from hospice and palliative care. Studies of patients with chronic terminal illness revealed that those who did not received palliative or hospice care experienced poor quality medical care characterized by untreated symptoms, unmet spiritual and personal care needs, increased burden for the caregiver, and low patient and family satisfaction (Meier, 2011). According to the World Health Organization (2011), palliative care is offered at the time of diagnosis alongside potentially curative treatment and can be utilized during the trajectory of illness until death. Hospice is a Medicare benefit considered the model for quality, compassionate care during the last six months of life and is available to all patients regardless of age, religion, race, or illness (Medicare Hospice, 2011).

This study examined why patients with non-cancerous terminal illness were not receiving timely palliative or hospice care by interviewing primary care providers.

A systemic literature review suggested possible barriers including confusion between palliative and hospice care, lack of understanding about the scope and intent of hospice care (McAteer & Wellberry, 2013), prognostic uncertainty, timing, and no clear point to originate a referral (LeMond & Allen, 2011). Insufficient training for primary care providers, including the lack of familiarity with various prognostic tools that aid in determining eligibility for the patient with a non-cancerous, terminal diagnosis might also be a barrier to referral (McAteer & Wellberry, 2013). Lastly, primary care providers lacked confidence in communicating the need for advanced care planning in non-cancerous terminal illnesses according to a survey done by Karlekar, Collier, Paish, Olson, and Elsay (2014).

The findings of this study confirmed the available literature. Much work is needed to educate providers and incorporate palliative care and hospice guidelines in academic institutions and in practice. Regulatory issues need continuous attention as the landscape of coverage, payment, and reimbursement changes rapidly. Further research is needed so that this vulnerable population will benefit from early interventions and a better understanding and acceptance of their non-cancerous terminal illness.

## INTRODUCTION

Hospice care is a Medicare benefit and considered the model for quality, compassionate care at the end-of-life; hospice services are available to all patients regardless of age, religion, race, or illness (Medicare Hospice, 2011). Hospice care occurs when a primary care provider determines that the patient will not likely survive beyond six months and the patient rejects further curable treatment (National Quality Forum, 2012).

Current federal regulations prohibit nurse practitioners from referring to hospice care. Notwithstanding, legislation effective January 1, 1998, authorized direct reimbursement to nurse practitioners for care to patients as Part B providers, encompassing hospice care (American Academy of Nurse Practitioners [AANP], 2012). This law allowed nurse practitioners to order speech, physical, and occupational therapy, as well as bill for services within the scope of their practice and as the attending physician in a hospice care program; however, the language of the legislation did not extend to hospice program referrals made by nurse practitioners. This barrier remains in effect today.

When Medicare officially recognized hospice in 1982, cancer was the only terminal illness that had a defined and predictable disease course (LeMond & Allen, 2011). It was not until the AIDS epidemic that hospice was expanded to other terminal illnesses.

In 2011, approximately 1.1 million patients died while under some type of hospice care service. Once the largest group of hospice admissions, cancer diagnoses comprised less than 38% of 2011 hospice admissions (National Hospice & Palliative Care Organization, 2013) and 25% of the nearly 2.5 million recorded deaths in the United States (Xu, Kochanek, Murphy, & Tejada-Vera, 2010); the majority of deaths were identified as non-cancerous terminal illnesses.

From 1994 to 2004, deaths attributed to heart failure increased by 28%. In 2004, death from heart failure reached 284,365, exceeding all deaths attributed to lung cancer, breast cancer, prostate cancer, and HIV/AIDS combined (Adler, Goldfinger, Kalman, Park, & Meier, 2009). Additionally, more people have been dying with at least one chronic illness involving a predictable slow decline (Emanuel & Librach, 2007). In 2006, the health care cost for heart failure was roughly \$30 billion, the mean hospital stay was six days, and more than one-third of patients were admitted for more than five days. Nearly one-half of the hospitalizations for heart failure exceed Medicare diagnosis-related group reimbursement (Adler et al., 2009). Despite our understanding of slow, debilitating, non-cancerous terminal illness, many patients have not accessed hospice to ease their transition through the dying process.

Hospice care comprises an interdisciplinary team providing health care, emotional and spiritual support, and pain management tailored to the individual patient's needs. Support is also extended to the family; the focus is on caring rather than curing. At the center of hospice care is the belief "that each of us has the right to die pain-free and with dignity" (Medicare Hospice, 2011, para. 1). Typically, hospice services are provided in a place that the patient considers *home*.

Palliative care is similar to hospice care. The World Health Organization (WHO) defined palliative care as

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of

pain and other problems, physical, psychosocial, and spiritual (World Health Organization [WHO], 1998, p. 1).

Palliative care seeks to optimize patient choice, autonomy, and access of information throughout the terminal illness trajectory and can be provided well in advance of the final stages of illness, both within and beyond hospice programs (National Quality Forum, 2012). According to the WHO, a more appropriate concept for palliative care would be a service offered at the time of diagnosis alongside potentially curative treatment as well as being utilized during the trajectory of illness until death (Hall, Petkova, Tsouros, Costantini, & Higginson, 2011).

Meier (2011), a professor at Mount Sinai School of Medicine and Director of the Center to Advance Palliative Care (CAPC), posited that palliative care, unlike hospice, could be primary, secondary, or tertiary care. From a primary care provider perspective, patients could be cared for with symptom management and communication regarding advanced care planning. The secondary care view of palliative care included referral to the palliative care specialist for unusually complex symptoms. In the tertiary care environment, research and teaching are incorporated within the palliative care specialist expertise.

Despite the rapid growth of hospice and palliative care research over the last 20 years, deficits remain in the evidence-based literature that could ensure access to and delivery of effective palliative and hospice care for the patients with non-cancerous, life-limiting illness (Aziz, Grady, & Curtis, 2013). Additionally, studies of patients with chronic terminal illness revealed that patients who had not received palliative or hospice care experienced poor quality medical care characterized by untreated symptoms, unmet spiritual and personal care needs, increased burden for the caregiver, and low patient and family satisfaction (Meier, 2011).

### **Purpose**

This study describes how primary care providers utilize hospice and palliative care. Aims are to (a) describe the current referral practice among primary care providers, (b) describe providers' perceived barriers to hospice and palliative care referral for the non-cancerous terminally ill patient, and (c) make recommendations for improved use and referral to hospice and palliative care for chronic progressively ill patients.

### **Background and Significance**

As the Medicare population ages, it is challenged with lengthy chronic, terminal illness. Fragments of these patients comprise the majority of health care spending. "Of the \$491 billion spent by Medicare in 2009, 27% (\$132.5 billion) was spent on acute care services and a small proportion, 10% of the sickest Medicare beneficiaries accounted for about 57% of total program spending" (Meier, 2011, p. 346). Despite the high cost of care, evidence suggested that these same patients received poor quality care defined as fragmented and riddled with medical errors with subsequent poor quality of life. For most patients, their end-of-days care was delivered in a non-hospice, acute care, inpatient setting.

Most chronic conditions have specific guidelines for the delivery of care (e.g., diabetes, chronic obstructive pulmonary disease, hypertension, congestive heart failure); those guidelines incorporate palliative care or hospice, yet questions remain about how the primary care provider utilizes those guidelines within the last six months of life. What also remains elusive is the demarcation between chronic and terminal illness, thereby making the trajectory of the illness unclear (Nolan & Mock, 2004).

Once hospice/palliative services commence, treatment can focus on symptom management, optimizing quality of life, initiating advanced care planning, and providing identification of a care plan consistent with the goals, values, and preferences of the patient and family (Bakitas et al., 2013). Professional organizations, including the American College of Cardiology and the American Heart Association, have recommended palliative and hospice care for end stage disease. The evidence-based clinical guidelines, however, are lacking in the nature and timing for referral, making the clinical decision for hospice services unsubstantiated (LeMond & Allen, 2011). Family practice physicians McAteer and Wellberry (2013) explored the benefits of palliative care, barriers, and best practices for patients desiring palliative care. Patients electing palliative care experienced less depression, an increased sense of control over their illness, and were often able to avoid risks associated with their illness (e.g., increased disease-related symptoms, exacerbation). The added benefit in utilizing palliative care included a reduction in hospital stays, decreased overall cost of care, and better utilization of health care resources.

Despite the known benefits of hospice care, questions remain about patient access to those services when they are diagnosed with a non-cancerous terminal illness. According to Lo, Snyder and Sox (1999), research suggested that providers were not referring patients for hospice care, primary care physicians were unclear about patients' preference for end-of-life care, and when those conversations did take place, communication was often poor. This is in sharp contrast to the functional trajectory of patients enrolled in palliative care and hospice care (Stabenau et al., 2015).

Many patients who suffer from chronic terminal illness are seen daily in primary care. Currently, 6 million Americans over the age of 65 are diagnosed with heart failure; 50% of them will die within five years. Prior to death, these patients routinely experience multiple hospitalizations, incur great personal and economic costs, and have substantial physical and emotional suffering. A study by Baristas et al. (2013) also revealed that only 19% of Medicare-aged heart failure patients accessed palliative or hospice services while 50% of cancer patients utilized these services. In addition, 800,000 people suffer from cerebral vascular accident annually, a number that will likely double with the Baby Boom generation. Despite these advances, severe disability is a typical outcome (Holloway et al., 2014). Stroke is a non-cancerous terminal illness appropriate for hospice/palliative care services. While end-of-life care has improved in recent years, referral for the non-cancerous terminal illness remains low.

Value in health care is defined by the ratio of quality to cost (Adler et al., 2009). Robust evidence supports the effectiveness of the advanced practice nurse fulfilling this gap in primary care. Nurse practitioners have demonstrated that they provide safe and responsible care to their patients and have expert assessment skills (AANP, 2012). They also represent the largest segment of the health care workforce. Nurses are uniquely suited to collaborate with other professionals to meet the increased demand in primary care as the population of chronic patients expands. The Institute of Medicine recommended the extension of nurses' roles and responsibilities to allow them to practice fully according to their education and training (Shaw et al., 2013). Advanced practice nurses are educated to model optimal care and assume leadership roles in specialty areas such as palliative/hospice care in both practice and developing policy (Bryant-Kukosius, DeCenso, Browne, & Pinelli, 2004).

### **Problem Description**

Barriers to the referral of non-cancerous, terminally ill patients to palliative or hospice services remain low across multiple care settings. Barriers most commonly identified in the literature included confusion between palliative care and hospice and a lack of understanding about the scope and intent of hospice care (McAteer & Wellberry, 2013), prognostic uncertainty, timing, and no clear point to originate a referral (LeMond & Allen, 2011). Many barriers have prevented the referral to hospice/palliative care by the primary care provider whom, according to the literature, treated the majority of patients with terminal chronic illness in the outpatient setting (Shaw et al., 2013). Insufficient training for primary care providers, including the lack of familiarity with various prognostic tools that helped determine eligibility for the patient with a non-cancerous, terminal diagnosis might also be a barrier to referral (McAteer & Wellberry, 2013). Lastly, primary care providers lacked confidence in communicating the need for advanced care planning in non-cancerous terminal illness according to a survey done by Karlekar, Collier, Paish, Olson, and Elsay (2014).

This study describes the facilitation of hospice/palliative care services for the non-cancerous, terminally ill patient by primary care providers, and then describes barriers to referral. The framework developed by Nolan and Mock (2004) (Figure 1) examines external and internal factors affecting the integrity of the patient with terminal illness. External factors include the veracity of the health care professional, professional/patient relationship, organizational culture, and health care resources. Internal factors are culture, community, family, and the spiritual domain. This framework was used to guide and inform this study.

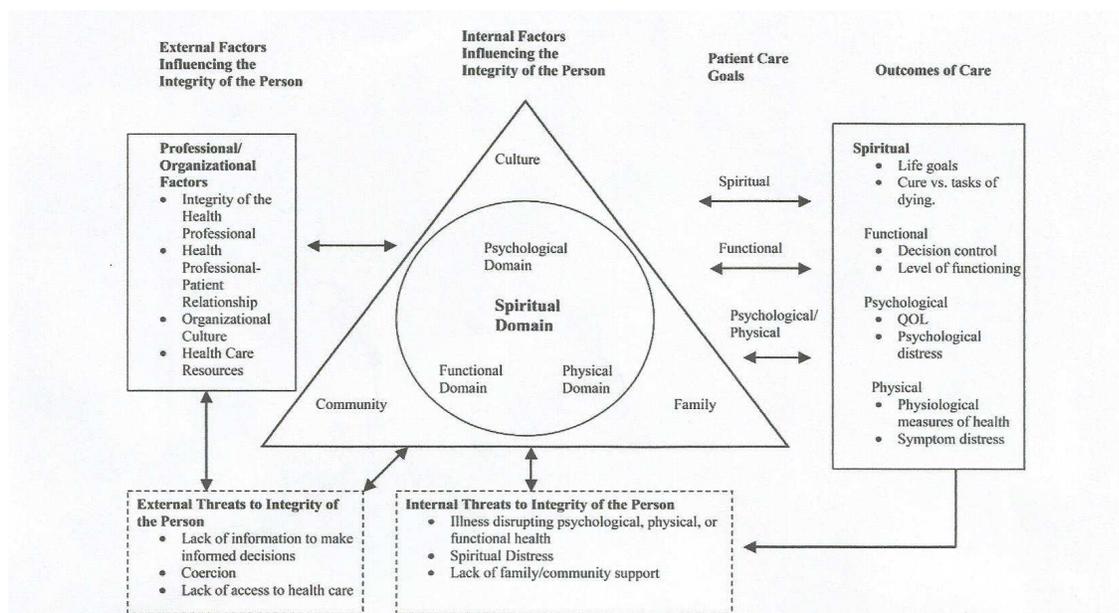


FIGURE 1. Conceptual Framework for End-of-Life.

## LITERATURE REVIEW

A discussion of the literature follows in order to gain an understanding of barriers that may prevent primary care providers from referring their patients to palliative/hospice care services. Particular attention was given to those patients with non-cancerous terminal illnesses. The review of literature explored chronic progressive illness and terminal illnesses to inform how, when, and where conversations regarding palliative and end-of-life care occurred. Also reviewed were barriers one might encounter and how that could affect the perception of the provider across various care settings.

Search terms included *palliative care*, *providers*, and *end of life discussion* in the Arizona Health Sciences Library's Evidence-Based Medicine (EBM) website. This University of Arizona resource included the Cochrane database, PubMed systemic reviews and clinical studies, scholarly publications via Pub Med and Google Scholar, and lastly, textbooks and websites.

Forty-three articles appeared in PubMed; however, after narrowing down to English publications within the last five years, there were merely 10 articles. Seven publications were selected to examine various disease processes and attitudes towards palliative care. In the EBM site, key words *palliative care*, *providers*, and *attitudes* yielded 263 articles. Limiting that search to the last five years yielded 106 articles. Six of those articles were of good quality and pertinent to this review because they were specific to the outpatient setting. Lastly, utilizing key words *referral to hospice* yielded 120 articles within the last five years, of which 18 articles were retained. The articles were largely qualitative, consisting of focus groups, systemic reviews, and semi-structured interviews.

Inclusion criteria were articles that focused on providers' perspectives across varied clinical settings. The research done by Kavalieratos et al. (2014) explored factors perceived by primary care, cardiology, and palliative care providers that impeded referral for heart failure patients and found that there were deficits in providers' knowledge and comfort in discussing palliative care for heart failure patients. Multiple misconceptions were discussed in relation to palliative/hospice care from the providers' point of view. For example, palliative care was often confused with hospice care; the majority of providers thought that palliative care was diagnosis-driven, suspending life-prolonging treatment (Kavalieratos et al., 2014). Palliative care as a specialty within itself is a multidisciplinary intervention focused on optimizing care for patients who are affected by chronic, progressive, often life-limiting illness, allowing them to live their best life. Palliative care benefited those with serious illness, life threatening, or chronic progressive disease who wanted to pursue active end-of-life treatment. Referrals for palliative/hospice care were driven by the following specialties: family practice, cardiology,

pulmonology, critical care, geriatrics, internal medicine, neurology, and adult as well as pediatric oncology.

Pediatric oncologists felt that supportive care was a better title than palliative care and suspected that the name alone was a barrier to referral. As with the adult oncologist, they often delayed referral to palliative care until symptoms were out of control or prognosis was short. In addition, they were the least likely to refer for psychological, social, or spiritual reasons (Wentlandt et al., 2014). The name, *palliative care*, for many of these providers meant end-of-life care, which was difficult to accept in the pediatric population with its robust focus on continued aggressive treatment. Another reason for late referrals was the confusion between palliative care and hospice. Hospice care, limited to patients with a life expectancy of 6 months or less, and must meet specific Medicare guidelines. Conversely, palliative care could be initiated at any point in the disease trajectory and utilized in conjunction with curative or life-prolonging treatments (Kavalieratos et al., 2013). In his study consisting of semi-structured interviews of 18 health care professionals, physicians, nurse practitioners, and physician assistants, Kavalieratos discovered that palliative care referral for heart failure patients might be suboptimal due to limited provider knowledge and misconceptions of palliative care as a service reserved for those near death. Providers were uncertain about the patient's prognosis and timeline in the progression of chronic terminal illness as well as concerned that less aggressive treatment equated to reduced survival (Doll et al., 2013). Other literature cited that the palliative care end-of-life conversation occurred a median of 33 days before death (Mack et al., 2012). The literature described a lack in the timely origin of referral, lack of personal comfort on the provider's part with palliative care discussions, and general misconceptions about the benefits

across settings and disciplines. Patients embracing palliative care often visited the ER when symptoms were out of control or because family members were distressed over symptoms at the end-of-life. Smith et al. (2009) performed a qualitative study to explore attitudes, experiences, and beliefs of ER personnel utilizing three focus groups consisting of mixed providers in the ER setting. They identified six emerging themes: (a) participants equated palliative care with end-of-life care; (b) participants disagreed with the feasibility and desirability of palliative care in the ER; (c) palliative care patients often visited the ER when symptoms were out of control; (d) communication between the patient and ER provider was rarely clear and was described by ER providers as a difficult situation, often with less-than-desirable outcomes (e.g., resuscitating a do-not-resuscitate [DNR] patient); (e) conflicts about withholding life prolonging treatment, despite written advanced directives; and, (f) inadequate training in pain management.

There was a paucity of literature that described barriers to hospice and palliative care referral. In one of the few published articles, Dubois and Reed (2014) identified factors that limited nurse practitioner referrals of patients to hospice and palliative care; scope of practice and reimbursement. In order to meet the health care demands in this expanding field with too few physician providers, nurse practitioners must be allowed to practice to the full extent of their license and receive adequate reimbursement from Medicare for the provision of these services.

### **Theoretical Framework**

This study employed a framework for end-of-life care known as the Integrity of the Human Person (IOTHP) by Nolan and Mock (2004). This framework was unique because it extended beyond care at the end-of-life to include the relationship of the health professional and the health care organization to the integrity of the person. Additionally, this framework relied on

the Institute of Medicine's (IOM) definition of end-of-life that included non-cancerous terminal illness, "the period of time during which an individual copes with declining health from an ultimately terminal illness – from a serious though perhaps chronic illness or from the frailties associated with advanced age even if death is not clearly imminent" (p. 353). The IOTHP framework guided this study and explored barriers in terms of the health professionals' beliefs and values that involve the patient, family, and community. According to Nolan and Mock, ongoing dialogue promoted mutually acceptable patient care goals and avoided patient coercion or miscommunication. Looking at the barriers to referral in terms of the external factors that influenced care and outcomes, internal factors influencing the integrity of the person, patient care goals, and outcomes of care should increase awareness of the challenges faced by providers and their patients in the chronic illness trajectory (Figure 1).

### **Summary**

Research exploring primary care provider's barriers and attitudes about initiating palliative care for non-cancerous terminal illness was limited. This review uncovered common themes: (a) confusion between palliative care and hospice, (b) timing of when to originate a referral, and (c) lack of education and utilization of palliative care across specialties and family practice. There was also consensus among studies that the conversation regarding palliative care should occur closer to the time of diagnosis. Most patients needed time to process their diagnosis and the potential of a limited or compromised existence (Mack et al., 2012). The conversation needed to occur early so that the patient and provider could agree on a plan of care as well as review it on a regular basis.

## **METHODS**

The design of this study was qualitative; data were collected utilizing individual interviews with open-ended questions. The sample was comprised of primary care providers (i.e., nurse practitioners, physicians, physician assistants).

### **Recruitment and Sampling**

After receiving University of Arizona Institutional Review Board (IRB) approval, I utilized the Healthgrades database to recruit practitioners from the desert area of Riverside County, the mountain communities of Big Bear Lake located in San Bernardino County, a rural access hospital (e.g., Bear Valley Community Hospital), managed care clinics, and private practices. The targeted sample size was between four and seven participants; recruitment continued until I had completed at least five interviews and until saturation had been reached (e.g., no new information or concepts appear with continued sampling). A letter describing the study was sent to potential subjects; those interested in participating were asked to contact me by phone or e-mail. Additionally, follow-up phone calls were made to answer any questions about the project, generate interest in participation, and schedule the interviews. I set up an interview time that was mutually agreeable and that allowed for face-to-face, private communication.

Inclusion criteria were English-speaking practitioners working in family practices, internal medicine practices, and community clinic settings who cared for patients meeting the criteria for hospice and/or palliative care. Exclusion criteria were providers from specialty practices and non-English speaking practitioners.

### **Data Collection**

The interview guide was developed utilizing the IOTHP framework (Nolan & Mock, 2004) and differentiated into three of their four factors. As this project examined the perspective of providers, the factor entitled *Patient Care Goals* was not incorporated into the interview guide. The interview questions focused on external and internal factors influencing the integrity of the person as well as the outcomes of care. Of the 11 questions, five concentrated on external factors, four questions followed the IOTHP framework capturing the internal factors, and two addressed the outcomes of care. These sections are identified in the interview guide in Appendix A. This guide was reviewed by two PhD professors of nursing and one doctorally-prepared researcher trained in instrument design. In addition, the interview questions were reviewed by two nurse practitioners who were not part of the interview process.

Participants were contacted and asked to identify a meeting time and location that was mutually agreeable and ensured privacy. The disclosure and explanation of study was mailed to them ahead of time for review; all subjects acknowledged that their participation was voluntary and that they could stop the interview at any time without obligation.

Six participants were interviewed at their respective work or home location. The intent of the interviews was to examine how providers perceived their role in the care of patients who were nearing the end-of-life due to chronic non cancerous illness.

Disclosures were used in lieu of consents. Participants were informed before commencing that they could cancel the interview at any time without consequence. Each interview lasted up to 30 minutes and was held in a mutually agreed upon time and private location to facilitate confidentiality. Interviews were tape recorded but I also took notes in the

event of mechanical failure and to observe body language, demeanor, and expression during interview to provide triangulation. Digital recordings were labeled by interview number (e.g., Interview 1) rather than by name or any other identifier to ensure confidentiality. Taped files were transmitted to a professional transcriber so that the entire interviews were captured verbatim. All data files were stored on a password-protected computer for analysis, then will be destroyed after the acceptance of this DNP scholarly project. Demographic information was also captured to help compare and contrast educational and work experiences.

### **Analysis**

First, all transcriptions were compared to the digital recordings to verify accuracy. Transcripts were then reviewed and responses categorized using the IOTHP framework (Nolan & Mock, 2004) as a guide. The responses were color coded, compared, and contrasted to the framework until patterns became apparent.

Each open-ended question was analyzed for similarities and distinctions in thoughts, feelings, and experiences. Responses were synthesized into the common elements of the IOTHP framework (Nolan & Mock, 2004), examining the relationships of the provider and health care organizations in the provision of care to hospice and palliative care patients and their families. Comparing provider responses to the IOTHP framework was examined to see if it supported this model in the clinical setting as well as identify potential barriers to hospice/palliative care referral for non-cancerous terminal illness as it related to the primary provider.

The trustworthiness of any inquiry between researcher and study participants was first posited by Lincoln and Guba (1985), including questions about truth, consistency, neutrality, and applicability. Shenton (2004) further refined this into four steps to ensure trustworthiness:

credibility, transferability, dependability, and confirmability. As the researcher, I tried to establish credibility recognizing that I have preconceived thoughts and emotions regarding the subject matter. I attempted to set my feelings aside and remain open-minded as I listened to the participants' responses to interview questions and reread their transcribed recordings.

Transferability was established by noting the multiple realities from participants as the subjects represented varied clinical environments within the primary care setting. Dependability came from the planned questionnaire and interview guide that was followed as written. This has the added benefit of allowing the study to be replicated in other community settings. Confirmability was the recognition of my own bias as I am both a primary care provider and have worked as a hospice advanced practice nurse. I was mindful of the need to resist the temptation to impose my own beliefs and perceptions. Finally, trustworthiness was addressed by having my project chair and research mentor review the recordings and actual transcriptions to confirm accuracy of translating the participants' communications into the written word.

## **RESULTS**

### **Participant Demographics**

The six participants came from varied races/ethnicities, ages, and experience. The physician was a Persian female MD practicing for 16 years in the primary care setting. A physician's assistant (PA) was from Denmark, male, with a history as a flight paramedic. He was recently licensed as a PA and had been working for the past two years in both the primary care and urgent care settings. One FNP was a Pilipino male that had been practicing for 12 years as an NP in internal medicine, most recently in urgent care. Prior to that, he was an RN in the ICU. The DNP, PMHNP was a Black male who had been practicing for 1 year in family practice and

psychiatry. Another FNP was a White female in practice for 30 years, largely in the urgent care setting. Lastly, one of the FNPs was a Latino male who had been practicing for the past 5 years in a family practice setting. All six met inclusion and exclusion criteria, which consisted of all family practice practitioners (i.e., MD, DO, NP, PA) and excluded those practicing in specialty offices.

### **Findings**

As the interview questions were based on the IOTHP framework (Nolan & Mock, 2004), participant responses were compared to the external and internal factors as well as the outcomes of care according to the model. Multiple barriers impeding referral to hospice and palliative care for the non-cancerous illness were identified in the literature review. Similar barriers materialized during the analysis of the interviews as well, which will be discussed further in this paper.

#### **External Factors and Barriers for Referral**

Participants were asked to describe their view of external factors that influenced the integrity of each person at the end-of-life. These external factors, according to the IOTHP framework (Nolan & Mock, 2004), were integrity of the health professional, health professional-patient relationship, organizational culture, and health care resources.

#### **Organizational Culture**

Inquiry regarding education and training for hospice or palliative care revealed that none of the participants received any formal training. Specifically, any instruction was brief and did not cover who might be eligible for hospice or palliative care other than patients with terminal cancer. Some participants were perplexed by the question; most thought long and took time to

answer. Their responses reflected an apparent lack of knowledge regarding hospice and palliative care for any patient other than hospice for cancer patients. All participants shared the same sentiment and acknowledged lack of training in any tools or guidelines for hospice and palliative care for the non-cancerous terminally ill patient. As an example, one participant remarked that it was,

*“Very little training from what I can remember. Mostly it was cancerous terminal illness that we were exposed to at the VA for hospice and palliative care.”*

On the topic of organizational culture, all of the participants described a lack of workplace support for accessing hospice in order to help patients and families with the dying process. Participants also felt that there was a shortage of time available to spend with their chronic terminally ill patients. Finally, participants voiced the lack of understanding about the utilization of palliative care and hospice for the non-cancerous terminally ill patient. Examples included, “by palliative care, do you mean pain management or is that something different?” and “We refer mostly, as I know, people who are terminally ill with cancer.”

### **Health Care Resources**

The common response about time was the difficulty in exploring sensitive and emotionally charged topics in a mere 15-minute appointment. There was a clear lack of understanding about how to utilize hospice and palliative care for the non-cancerous terminally ill patient. All participants expressed that they would like more education regarding these services.

### **Health Professional-Patient Relationship**

All six participants asserted that they felt comfortable having an end-of-life conversation with their patients and families. The participants expressed that as practitioners, communication was not an issue. They also felt that their relationship with their patients was very good. As one participant summed it up: “I would say I am pretty comfortable.”

Although the participants voiced their confidence with difficult conversations regarding end-of-life, care planning, or discussing the trajectory of their chronic non-cancerous diagnosis, they all appeared to be caught off guard when we discussed the use of both palliative and hospice care throughout the illness trajectory. The common theme was one of surprise and new awareness of how palliative care or hospice could actually benefit this population. They did mention alternative barriers for not conducting a referral or end-of-life discussions, including not having the time for that particular conversation or that the presence of family members made a difference for them or to the patient.

When asked when they would likely consider making a referral for a patient with a non-cancerous diagnosis, one-half of the participants said they did not make referrals to either hospice or palliative care. The other participants admitted to using only hospice. Participants explained that a specialist would do the referring (e.g., oncologist); only three of the participants knew of a hospice company by name. One participant said she did not refer, and another described a lack of hospice care by saying, “I refer to palliative care a lot less than hospice because palliative care . . . is not really here in the valley.”

As we discussed any qualifiers for hospice care (e.g., end stage CHF, COPD, Parkinson’s), none of the providers who were interviewed were aware of specific qualifications

or eligibility for hospice. For example, beyond the Medicare guideline for oxygen use, one provider did not know that a patient with stage IV heart disease would qualify for hospice care per New York Heart guidelines for end stage heart disease. One premise was that the providers experienced a sense of non-reality that their patient was actually dying. When asked about using guidelines, one participant explained,

*“No. I have not used guidelines to determine if they would qualify. I mean, I use guidelines to treat them, and many would probably qualify, if I think about it now.”*

### **Internal Factors and Barriers for Referral**

The internal factors that influence the integrity of the person center around culture, community, and family. The interview process appeared to generate interest in the topic as observed from participants’ body language; they would lean in towards me, stop, and ponder their responses. When asked if the participants knew the difference between palliative and hospice care, only two of them could actually articulate the distinction between these services. Although these two participants seemed to have a fair grasp on the differences, they did not know how service would be billed, how much it would cost the patient, or how services would be reimbursed for either palliative or hospice care. As one participant reported,

*“I don’t know that there is a distinction necessarily, I think the old idea of hospice care as it being truly end-of-life whereas palliative care would be sort of managing symptoms that sort of bring you to end-of-life.”*

### **Spiritual Domain**

When asked about how one’s own personal or spiritual beliefs might be a barrier, none of the participants felt that his or her personal or spiritual beliefs affected a referral to hospice care.

There was strong consensus that they were aware of their own beliefs but careful not to impose them, instead supporting the beliefs of the patient. One participant acknowledged this struggle,

*“It’s difficult not to project your own beliefs on other people, but I try and be conscious of that and as aware as I can. Sort of frame things in their own context. You know, if the patient is willing to share their own beliefs, then I am willing to mirror those in an answer to them without shading it with my own beliefs. Because I really have no answers for them.”*

Another participant did not see any obstacle between his faith or spiritual beliefs and how that might affect his referring a patient to palliative or hospice care,

*“I don’t think it does, you have to identify your opinions and spiritual belief and your cultural background and try to use that as a strength, of course, but you also have to identify where that barrier is and how the patient may not identify with that same belief. So I don’t think it plays a role. I think the number one factor is what the patient is telling me.”*

### **Community Resources**

One of the common practices of hospice companies is to make their presence known in the primary care/family practice setting by doing in-services, bringing food, and informing providers about their services. Many of these companies offer palliative care too, particularly as we move away from the current fee-for-service model. Interestingly, four of the six participants stated that they did not know what services were available; therefore, they do not know what services were offered. One participant who knew of patients being referred to hospice offered,

*“If he [the physician] refers to hospice, there is a hospice center that gets on board right away. If I refer to palliative care . . . there is none, and if there is one, I don’t know about it.”*

One participant who was connected to the community hospital reported that she was not privy to the in-services offered by hospice companies. However, she was aware that the hospital had a palliative care team and she felt that hospice was for those estimated to die within a 6-month period. She gave the impression that, even though she knew what was available, often the referral did not happen.

*“The issues are the primary care physicians; we are told to send them back. I’m in the area of medicine called ‘treat and street.’ These patients are to be seen within in an hour. If they are very ill, they are admitted to the hospital. If they are obviously terminal, hospice, well palliative care, can be called to the bedside, but that is not done very often.”*

## **Family**

One of the concerns that participants did have strong feelings about was family. Several participants even voiced that family opinions, beliefs, and perceptions might pose a barrier to referral. As one participant reported:

*“It’s trying to understand that they have their own wants and needs as individuals too, and that may not, that may run counter to the patients, so it’s to realize that and sometimes its verbalizing. It’s to say, ‘OK. I understand that you’re concerned as a family member, but my primary concern is for the patient, and yours would come secondary.”*

All participants gave examples of how difficult it can be incorporating the family and the patient in the decision-making process. A few participants even proposed that working with family is the most difficult part of caring for dying patients. At least one participant took this further by stating:

*“Families are always the difficult part. It’s not just palliative and hospice care, but in everything.”*

In several interviews, the concept of culture arose. Specifically, several participants mentioned the patient’s culture as affecting referral for hospice or palliative care. Furthermore, at least one participant described the patient’s culture as perhaps even creating a barrier to referral:

*“We make referrals based on their insurance or lack thereof. The Latino community which we serve primarily in Cathedral City, a lot of them have no insurance and it is up to the kids to keep them at home. They kind of incorporate them at home, so it’s all one. It is their responsibility, otherwise they think they have failed . . . Usually it’s the eldest daughter, she is the one to take care of it. Why? Don’t know, but it is the trend, the eldest daughter . . . the males back off and provide some money, pitch in, but it’s the eldest daughter, the unspoken rule. With the Anglos, its more, who’s got the insurance and who doesn’t.”*

### **Outcomes of Care and Referral**

Outcomes of care encompass three aspects. The spiritual aspect includes life goals, cure versus tasks of dying, functional aspects, functional decline, decisions control, and level of functioning. The psychological factors comprise quality of life and psychological distress.

Lastly, the physical components incorporate physiological measures of health and symptom distress.

### **Quality of Life**

When discussing care for patients with a chronic non-cancerous terminal diagnosis, the providers were asked about how they might approach their care of these patients; with symptom management or from a quality of life perspective. All of the providers expressed that symptom management was the same as quality of life. Many approached the patient with a terminal non-cancerous diagnosis in terms of activities of daily living; they all wanted the patients to be comfortable, but also wanted to know about their functional levels. One participant gave an example,

*“I ask them; can you cook? Who cooks for you? I look at the big picture, they can be walking around with a sat of 80-87 and be able to do some things. I ask, what are your pills? What are your inhalers? Are you taking them, do you run out? When I know they are confused or in a fog, I know we are in trouble.”*

Quality of life was discussed frequently and was seen as important for both patients and participants. However, when asked how often they discuss quality of life factors, such as advanced directives and life goals, they all paused and realized that it was not discussed as often as it should be. The participants volunteered barriers to having these difficult discussions; frequently the barriers consisted of lack of time or lack of comfort with the topic. Expressing his frustration, one participant offered the following statement:

*“Because sometimes I think they are pushed, you know we can easily treat pain, but I don’t think we always get to some of the root cause issues that really need to be solved*

*and its difficult . . . that requires a lot of care coordination, and I think sometimes it's just not there."*

### **Quality of Relationship with Health Care Provider**

All of the participants working in the family practice setting felt that they had a good relationship with their patients. Those in urgent care felt that they did not have the opportunity to develop that relationship. Subsequently, all participants were asked, if a referral was made, did they think would it affect their provider/patient relationship? The impression amongst the participants was that they did not see the referral as negatively affecting their relationship and might even improve their relationship. However, one participant, an urgent care provider, was left wondering what happened after referral, as there was never a report from the outside agency with any progress acknowledging that the patient was receiving care.

## **DISCUSSION**

This study set out to describe barriers that affected primary care providers referring to hospice/palliative care for patients with chronic non-cancerous terminal illness. Interviews supported both the literature and the modicum of research directed at this patient population. According to Aziz, Grady and Curtis (2013), there has been a rapid growth of hospice and palliative care research over the last 20 years; however, deficits remain in the evidence-based literature ensuring access to and delivery of effective palliative and hospice care for the patients with non-cancerous, life-limiting illness. Additionally, studies of patients with chronic terminal illnesses revealed that those who did not received palliative or hospice care experienced poor quality medical care characterized by untreated symptoms, unmet spiritual and personal care needs, increased burden for the caregiver, and low patient and family satisfaction (Meier, 2011).

One of the most significant barriers to hospice and palliative care referral may be lack of knowledge. Kavalieratos et al., 2014 described the barrier to referral to hospice palliative care as it related to deficits in provider knowledge. Lack of education and training for hospice or palliative care was noted among the participants in this study; none had ever received any formal training. Specifically, any instruction they had was brief and did not cover who might be eligible for hospice or palliative care other than patients with terminal cancer.

Frequently the terms hospice and palliative care are used interchangeably. Unfortunately, and as demonstrated in the literature, this creates confusion. Authors Wendlandt et al. (2014) identified that lack of understanding may stem from the interchangeable use of terminology. Confusion about terminology was echoed in this study, as most participants were unable to distinguish hospice from palliative care; in fact, only two participants could offer a clear distinction between the two terms. Furthermore, only one participant was able to offer the benefits of initiating palliative care early in the process of a terminal non-cancerous disease. Many participants in this study could not distinguish between palliative and hospice care and admitted they really do not refer for patients with chronic, non-cancerous diagnosis.

Health care providers may feel uncertain about when to initiate hospice or palliative care. For example, authors Doll et al. (2013) found that providers were frequently uncertain about how a non-cancerous terminal illness might progress, which created a barrier to timely referral. The concern about timing of referral was mirrored by the participants in this study, especially in terms of prognostic knowledge for end-stage heart disease.

Some primary care providers may not understand the financial aspect of a palliative care/hospice referral, including eligibility and reimbursement, or they may not understand how

the legislative regulations impact that reimbursement. In this study, only one participant was able to discuss the legislative barriers for nurse practitioners in regards to referring patients for hospice. Only one participant knew that there was a restriction on nurse practitioners or physician assistants to ordering hospice care in California; specifically, he felt the restrictions did not apply to him since he works in a collaborative practice. All participants were confused about reimbursement for hospice and palliative care services in the primary care setting. Furthermore, none of the participants knew who would pay for hospice and palliative care. These findings mirror Dubois and Reed's (2014) description that there is lack of knowledge among practitioners regarding legislative regulations and insurance reimbursement.

In reference to the IOTHP framework (Nolan & Mock, 2004), external factors and deficits of knowledge, lack of training, and discomfort in discussing end-of-life can be considered a threat to the integrity of the person:

Many of the external factors that impact caregiving and patient decision-making are influenced by the health care professional serving as primary care giver to the patient.

The type of health professional-patient relationship that exists can influence the type and amount of health care information provided to the patient and family (Nolan & Mock, 2004, p. 353).

The interviews reflected a lack of information on the providers' behalf as well as a lack of identified resources for delivering palliative and hospice care. While caring for the patient with a chronic terminal illness, having an understanding of the resources available can impact the outcomes. For example, delaying the introduction of palliative or hospice care for the terminally ill patient can translate into multiple exacerbations, hence increasing distress for the patient.

Caring for patients who are chronically terminally ill resembles care that has an ebb and flow as the patient continues on the trajectory of the illness. Therefore, the primary care providers' influence has a great impact on the outcome of care given the lack of defined timing for information dissemination and discussion when anticipating needs for care in the months and years preceding the end-of-life. The IOTHP framework (Nolan & Mock, 2004) furnished a fluid canvas exhibiting the different factors to the integrity of the human person that change depending on the impact of these external factors.

Some of the barriers uncovered in the interview were ones routinely managed in daily practice. Having a hospice background tends to make one presume that others have similar knowledge about end stage non-cancerous terminal illness and an understanding of specific eligibility criteria. It was deeply moving to realize that this knowledge deficit was quite large considering the relatively small sample. One of the unexpected barriers that emerged in the interview process was that the family may create a barrier as well. In hospice practice, family members are routinely supportive of the patient's wishes; they may be consulted or included early in the process in order to work out the intimate details of the family dynamic proactively. There may also be deep-rooted cultural traditions when a family member becomes terminally ill. This barrier was particularly evident in the large concentration of Hispanics in the geographical areas in which these interviews were conducted. These families had specific beliefs when dealing with the end-of-life.

As health care moves to an exclusively managed care environment, responsibility rests with the providers to ensure they are addressing insurance criteria for payment of services. Most providers were not aware of any regulatory barriers because they were in collaborative practices

or currently not utilizing palliative and hospice care for their patients with non-cancerous terminal illness; yet these barriers are significant. For the nurse practitioner, this knowledge deficit could be the result of a slow moving legislature in the quest for full practice authority in California. In one of the few published articles, Dubois and Reed (2014) identified several factors that limited nurse practitioner referrals of patients to hospice and palliative care: scope of practice and reimbursement. External factors that were exposed in the interview process were also outlined as gaps in the literature. The framework helped to illuminate the complexity of these potential threats to the healthcare provider-patient relationship, and therefore to the overall outcomes of care.

### **Study Strengths and Limitations**

The project design was open-ended, interview questions comprising elements of the IOTHP framework (Nolan & Mock, 2004) and the study sample was relatively small. Despite the small sample size, many of the findings that arose in this study were similar to evidence in the literature. Limitations of this study included a small sample from within large areas of practice in primary care. The participants were from diverse settings, but had a large Hispanic population limiting the scope of cultural influences. The findings from this small study cannot be generalized to a larger population of health care providers.

### **Implications for Practice**

Professional organizations, including the American College of Cardiology and the American Heart Association, have recommended palliative and hospice care for end stage disease. The evidence-based clinical guidelines, however, are lacking in the nature and timing for referral, making the clinical decision for hospice services unsubstantiated (LeMond & Allen,

2011). The lack of formal training and the uncertainty of decline with chronic non-cancerous terminal illness creates a challenge for providers to make timely and appropriate referrals. The lack of prognostic tools available to primary care providers also creates a barrier to timely referral (McAteer & Wellberry, 2013). This gap in education-to-practice may threaten the integrity of the patient. Specifically, patients and providers may be lacking the education necessary for an informed consent process; this needed knowledge could help patients cope with a chronic terminal illness. Such knowledge might also help the provider and patient to develop a plan of care that allows the patient to be an active participant in decision-making as the disease progresses, even at the point of death. Hospice and palliative care is designed to support the patient; physically, psychologically and spiritually.

The lack of education evident amongst providers provides a platform to suggest improvements. Instead of identifying clear transition points for referral, as is easily done with cancer status post terminal diagnosis, I feel it is necessary to link milestones in the illness trajectory with opportunities to review possible transition times. In introducing that concept, it is important to acknowledge very specific guidelines to hospice eligibility for those patients who suffer from chronic non-cancerous terminal illness. Local hospice agencies are willing to present educational materials at the provider's clinic or meeting locations and provide detailed instruction about their services for chronically ill, terminal patients.

In order to illuminate the potential thought process a primary care provider may have in considering a palliative/hospice referral, the following examples may help to paint the clinical picture. Also included are some ideas for the improvement of referrals that could be implemented in the primary care setting.

In primary care, chronic obstructive pulmonary disease (COPD) patients are all too familiar. As an exemplar, a 74-year-old male smoker who was admitted to the ICU with an exacerbation severe enough to require intubation presents at your office status post discharge for a follow up. This was his second hospitalization in six months. He tells you today he does not want to ever “*be on that machine again.*” Here is an opportunity to create the care plan and begin the discussion for palliative/hospice care. Medicare eligibility guidelines for a COPD patient includes dyspnea at rest, hypoxia on room air, and signs of disease progression including hospitalization. An inquiry can be made to ask providers how many of their primary care patients fit in this description. Additionally, these patients often have co-morbidities (e.g., cardiac arterial disease [CAD], diabetes), yet experience tells us that patients with COPD tend to believe that this is an illness they must *live with*; few realize this is often the illness they will *die with*, largely because the story of COPD has an unclear beginning (e.g., I was a smoker . . .). Conversely, cancer diagnoses are often associated with hospice and palliative care and readily accepted as soon as all chemo and surgical interventions have been exhausted; when the illness is categorized as *terminal*, Medicare readily accepts these diagnoses with little documentation.

As for patients with dementia, we could ask how many times the provider has heard a spouse cry out, “*The medication is not working anymore, I cannot take it anymore. He was up all night, he has no control of his bladder, and is now having more bowel accidents.*” Or, “*He pulls his clothes off. I would hire help but I just can’t afford it.*” Dementia is another chronic, non-cancerous terminal diagnosis frequently seen in primary care. Medicare guidelines for hospice in the dementia patient state that a patient suffering from dementia needs to be a 6 – 7 on the Functional Assessment Staging (FAST) scale. The FAST scale is used to assess advanced

dementia when the Mini-mental State Examination (MMSE) can no longer evaluate the patient in a meaningful clinical way. FAST staging is a scale from 1 – 7, where 1 is a functional adult and 7 is advanced dementia patient (Reisberg, 1984). Stage 6 is moderately severe dementia; at this stage, the patient may begin to forget the names of family members or friends and requires more assistance with activities of daily living (e.g., bathing, toileting, eating). Patients in this stage may develop delusions, hallucinations, or obsessions. They show increased anxiety and may become violent. These patients can begin to sleep during the day and stay awake at night. Stage 7 is severe dementia; at this stage, all speech is lost. Patients lose urinary and bowel control as well as the ability to walk. Most become bedridden and typically die from pneumonia or sepsis.

Cases of COPD and dementia are fairly common in primary care practice. While hospice may only be available when these cases are clearly end stage, the practitioner can begin the palliative/hospice care conversation and assessments early in the disease trajectory.

Considerations include: (a) Who are the stakeholders; (b) Is the patient the primary decision maker, or does the provider know who possesses the durable power of attorney; (c) Do they have an advanced directive and is it in the chart; (d) Does the patient understand the disease and its progression; and (e) helping the family/patient or decision maker know all options available and support them in making whatever decision is right for them. These considerations need to be revisited at every visit. Once a referral is considered, the local hospice company will perform a palliative/hospice care evaluation free of charge. Particularly important to the nurse practitioner practice is that such referrals require a prescription that must be generated by an MD or DO.

### **Scholarship and Future Research**

I envision publishing a manuscript discussing the lack of hospice utilization along with the cost effectiveness and increased patient satisfaction associated with the utilization of palliative and hospice care for the patients with a non-cancerous terminal diagnosis.

Additionally, I will be more active in my own clinical setting as well as my professional organization (i.e., Hospice & Palliative Nurses Association [NPNA]) and help influence policy to overcome the state regulatory barriers for NP referral to hospice and palliative care.

Findings from this study illustrate the need for future research. There are several areas of interest worth pursuing.

1. The expense of long-term care frequently arises as a burden for the patient and/or their families. An investigation of the financial difference between hospice/palliative care versus the cost of frequent exacerbations necessitating hospitalization might strengthen the support of these services.
2. Health Maintenance Organization (HMO) as a cultural barrier, specifically to inquire how hospice and palliative care referral affects the provider's income under the new capitated health care model.
3. Developing an educational tool that would guide providers in order to improve the identification of patients with a non-cancerous terminal illness who might benefit from hospice or palliative care.
4. Finally, since several participants in this study verbalized not knowing about hospice or palliative care resources within their practice community, developing a resource list of palliative/hospice care services specific to a geographical region.

## Conclusions

This study is unique in that it explored barriers to hospice and palliative care referral from the perspective of providers from multiple specialties. Findings from this study may add to the body of knowledge regarding barriers to early hospice and palliative care referral for patients seen in primary care settings. The IOTHP framework (Nolan & Mock, 2004) guided the project and demonstrated external factors, internal factors, and outcomes of care that were multidirectional, illuminating how external factors could impact internal factors and ultimately affect the outcomes of care. The most common barrier identified in this study was how lack of knowledge negatively impacts early and meaningful referral to hospice and palliative care for patients with a non-cancerous terminal illness.

The availability of hospice care has grown tremendously in this country; however, the referral rate remains low in the sector of primary care across multiple settings and for those patients with a non-cancerous terminal illness. These numbers are expected to increase as the population continues to age. It is important to address this knowledge deficit in primary care to allow for quality of care in the continuum of the non-cancerous terminal illness.

Legislative barriers need to be overcome allowing nurse practitioners to practice to the full extent of their license, including referrals to hospice and palliative care. As this paradigm shifts in health care today, it will become critical to embrace the benefits and cost savings of hospice and palliative care in order to give the best available, evidence-based care to those who suffer long-term non-cancerous illness.

APPENDIX A:  
INTERVIEW GUIDE

## Interview Guide

External factors influencing the integrity of the person:

1. What kind of preparation have you had to address the needs of the patient who has a chronic non-cancerous terminal illness?
2. How does the culture of your organization support palliative/hospice care?
3. How comfortable are you in having end-of-life discussions with your patients?
4. When do you refer a patient for palliative/hospice care?
5. How do you distinguish between referring a patient to palliative care or hospice care?

Internal factors:

1. As a practitioner, how might your personal/spiritual beliefs affect a referral to hospice?
2. What access do you have in your community for services in palliative/hospice care?
3. What is your perception of services offered?
4. How does the patient's family's opinion affect your approach to palliative/hospice care?

Outcomes of Care:

1. How do you discuss the progression of the non-cancerous illness? In terms of symptom management? In terms of quality of life?

How often do you discuss life goals and advanced directives with your patients?

APPENDIX B:  
IRB SUBMISSION AND APPROVAL



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**Date:** February 29, 2016

**Principal Investigator:** Susan E Ellis

**Protocol Number:** 1602408812

**Protocol Title:** Barriers Among Primary Care Providers to Utilizing Palliative/  
 Hospice Care for Patients with Non-Cancerous Terminally Ill Patients

**Level of Review:** Exempt

**Determination:** Approved

**Documents Reviewed Concurrently:**

**Data Collection Tools:** *Interview guide.docx*  
**HSPP Forms/Correspondence:** *appendix F.doc*  
**HSPP Forms/Correspondence:** *Appendix F signature page.pdf*  
**HSPP Forms/Correspondence:** *Ellis F200.doc*  
**HSPP Forms/Correspondence:** *F107.doc*  
**HSPP Forms/Correspondence:** *Signature page.pdf*  
**Informed Consent/PHI Forms:** *Disclosure.docx*  
**Informed Consent/PHI Forms:** *Disclosure Ellis 20160223.pdf*  
**Recruitment Material:** *Recruitment letter.docx*

This submission meets the criteria for exemption under 45 CFR 46.101(b). This project has been reviewed and approved by an IRB Chair or designee.

- The University of Arizona maintains a Federal wide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted in full accordance with all applicable sections of the Investigator Manual.
- Exempt projects do not have a continuing review requirement.
- This project should be conducted in full accordance with all applicable sections of the IRB Investigators Manual and you should notify the IRB immediately of any proposed changes that affect the protocol.

- Amendments to exempt projects that change the nature of the project should be submitted to the Human Subjects Protection Program (HSPP) for a new determination. See the Investigator Manual, 'Appendix C Exemptions,' for more information on changes that affect the determination of exemption. Please contact the HSPP to consult on whether the proposed changes need further review.
- You should report any unanticipated problems involving risks to the participants or others to the IRB.
- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office. If subjects will be consented, the approved consent(s) are attached to the approval notification from the HSPP Office.

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