

Challenges Home Health Nurses Experience Transitioning Chronically Ill Heart Failure  
Patients from a Curative to a Palliative Level of Care

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## Abstract

Home health nurses provide nursing care to acutely and chronically ill patients with a wide variety of diagnoses and comorbidities. Patients with heart failure present a unique challenge for home health nurses, because these patients transition from a curative to a palliative level of care and eventually to hospice care. Advanced heart failure results in an illness trajectory that often changes and may improve or deteriorate until the time of death. The purpose of this study was to describe the experiences of home health nurses assisting patients with advanced heart failure to transition to palliative or hospice care. Thirty home health nurses were recruited from four home health agencies located in the Southeastern United States. Data were collected through taped interviews and analyzed using qualitative thematic analysis research methods. Three main themes were identified: illness awareness, communication skills, and knowledge. Patterns emerged during the interviews showing factors that triggered the nurse to consider transitioning a patient to hospice or palliative care. Results indicated the nurses' communication skills with the patient, families, and physician were a key factor in the timing of the transition discussion. Finally, a need for increased knowledge was expressed by nurses regarding disease trajectories, differences between home health, hospice, and palliative care, and ways to successfully transition patients to hospice or palliative care. The major conclusions of this research were that home health nurses would benefit from knowledge of indicators about the timing of conversations with patients and families; and that home care nurses are seeking ways to handle situations related to end-of-life care, including difficult situations when patients and/or families refuse to transition to hospice.

**Dedication Page**

I dedicate my dissertation work to my husband, family members and many friends that have been a source of support throughout this journey. These individuals have offered words of encouragement and never wavered in their delivery of supportive listening skills. My husband, Michael J. Crandall, has always been my biggest source of support and inspiration. You inspire me in ways that cannot be put into words – as your never-ending logic and reasoning coupled with an ability to design and rebuild broken items while maintaining wit and courage at levels that a mortal wouldn't seem capable of...makes me want to try even harder to be an even better nurse and wife.

Friends and family members have served as a source of support and provided the spark to my passion. This includes: Dr. Cathy L. Campbell for having a shared passion for palliative and hospice care with wisdom beyond her years and a spirit that is a delight to be around. Dr. Dorothy Fontaine for her infinite wisdom and for being a role model for all nurses through her leadership skills and compassionate care initiatives that have taught me and many others that are lucky enough to know her what it is that is so special about nursing. Warren Crandall let me witness how important it was to offer comprehensive palliative support and served as source of encouragement as I embarked on this journey. I also want to share my deep gratitude to the staff where I work for helping me juggle a full-time job while pursuing this degree and to Maggie Short for seeing how important this work was and striving for the highest quality care for home health patients. Thank you all for being there for me throughout the entire doctorate program.

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## **CHAPTER 1**

### **Background**

Heart failure (HF) is a serious illness in the U.S. and U.K., affecting one to two percent of adults, and up to 15-20% of those at/over age 80 (American Heart Association, 2010; British Heart Foundation, 2010). Heart disease ranks as the second most common primary diagnosis seen in patients receiving home health with a rate of 8.8%, with 4.3% having heart failure (Park-Lee, & Decker, 2010). The diagnosis of heart failure represents a chronic, life-limiting illness that negatively impacts a patient's health-related quality of life (Moser et al., 2013). Life expectancy after the initial heart disease diagnosis has been difficult for physicians to predict. However, less than 50 percent of patients are alive five years after their initial diagnosis, and only 25 percent survive ten years with a heart failure diagnosis (HFSA, 2014). No research reports were found about the numbers of patients receiving home health care for heart failure who succumbed to the disease either during home care or within five years. However, given that people with heart failure commonly receive home care services, nurses in home health work with many people with this life-limiting illness and their caregivers, especially during the advanced stages of the illness.

Approximately ninety million people in the United States (U.S.) are living with serious and life-limiting illnesses, such as heart failure. The number of seriously ill patients is expected to more than double over the next 25 years as the baby boomer population ages (The Dartmouth Institute, 2013). Researchers have found that people living with a life-limiting illness in its advanced stages experience complex physical,

emotional, and psychosocial needs such as frequent symptom exacerbations, inadequate symptom management, and poor care coordination across settings of care (Teno et al., 2004).

### **Symptoms Clusters**

Advanced heart disease shares features with serious phases of many chronic diseases; however, the heart failure disease trajectory has some unique features that present challenges to patients, their families and caregivers, and their healthcare providers. A complex symptom cluster that is hard to manage characterizes the disease trajectory resulting in an unpredictable functional decline and complicated further by transitions across various care settings (Davidson, Dracup, Phillips, Padilla, & Daly, 2007; Metzger et al., 2013; Van Nes, 2011). The complex physical needs associated with heart failure include the symptoms of dyspnea, fatigue, edema, and depression management (Lorenz et al., 2008; Nordgren, & Sorensen, 2003) can result in frequent hospital readmissions and high mortality rates (Quinn, 2005). The physical and psychological issues that are prevalent at the end-of-life for patients with heart failure point to a need to examine challenges that impact health-related quality of life, rehospitalizations and mortality (Clark et al., 2012; Dev, Abernethy, Rogers, & O'Connor, 2012; Low, Pattenden, Candy, Beattie, & Jones, 2011). Because heart failure is a symptom-driven syndrome, the severity of the symptoms can impact not only health-related quality of life, but also rehospitalization rates, health costs, and mortality rates (Lennie et al., 2013).

**Functional Decline**

The challenge of an unpredictable functional decline among patients with heart failure adds to the complexity of symptom management. The diminished cardiac output results in fatigue and increased dyspnea, and can lead to skeletal muscle dysfunction (Hunt et al., 2001). These symptoms often lead to reduced functional activity, reducing a patient's quality of life. This typical deterioration is described in the literature as functional limitations when a patient experiences difficulty while performing activities of daily living (Fried, & Guralnik, 1997; Verbrugge, & Jette, 1994; Yamada, Shimizu, Suzuki, & Izumi, 2012.) These functional limitations in dressing, ambulating, bathing, toileting, and preparing meals greatly impact the patient's life. Adding to the difficulty of the situation is that patients often fluctuate from debility to varying levels of independence in self-care. In contrast, over the course of a cancer disease process, the functional status decline is more predictable as measured with tools such as the Karnofsky performance status measure (Jocham, Dassen, Widdershoven, Middel, & Halfens, 2009; Karnofsky, Abelmann, Craver, & Burchenal, 1948). The home health nurse caring for patients with a predictable decline while also caring for heart failure patients requires astute assessment and care coordination skills. In each situation, the nurse must exercise judgement and skill in deciding which patients have reached the point of requiring palliative or hospice care.

**Care Coordination**

Home healthcare nurses often develop and maintain relationships across the illness trajectory of their patients diagnosed with heart failure. Care for these patients

requires high level coordination skills to address psychological and social challenges, as well as assistance with symptom and functional activity limitations (Pastor, & Moore, 2013). Care coordination by the home health nurse is essential to the role of discussing clinical care goals throughout the disease trajectory with the patient, the family, and other healthcare providers. As heart failure patients reach a point of needing palliative care, the goals of home health often changes from curative treatments to a purely palliative level of care. Skillful management of such transitions requires care coordination using a patient-centered, inter-professional model of care.

### **Palliative Care Needs and Outcomes**

Palliative care requires an inter-professional model to guide end-of-life (EOL) care. The inter-professional model of care was derived from the concept of palliative care, and encompasses a broad range of care including prevention and relief of suffering. Focusing on the management of physical, psychosocial, and spiritual distress is intended to improve a patient and the families' quality of life in the face of terminal illness (World Health Organization, 2013). The services provided by palliative care personnel, supports patients with a life-limiting illness by helping the patient achieve improved comfort by offering physical, emotional and spiritual symptom management, psychosocial support and enhanced satisfaction with care (Adler, Goldfinger, Kalman, Park, & Meier, 2009; Gries, Curtis, Wall, & Engelberg, 2008; Finlay, et al., 2002; Higginson, et al., 2002). However, these services may not be utilized by patients with heart failure when needed because the patient may not have transitioned to either a palliative or hospice level of

care. Additional research is needed to identify if heart failure patients are accessing palliative or hospice care services when additional support is needed.

Home health nurses are in a prime position to assist patients with heart failure to obtain palliative care when needed. Home health nurses are skilled at providing symptom management, observing functional limitations in the home environment, offering care coordination, and serving as communication facilitators with physicians throughout the illness trajectory. At the most advanced stages of heart failure, home health providers may identify physical, emotional, and psychosocial needs of the patient and the caregivers that cannot be effectively addressed at home. The home health nurse recognizes when the knowledge and skills of a trained inter-professional palliative care team or hospice team are needed. The nurse is thus able to promote a discussion about how to make the transition from cure-oriented care to palliative care often within the same home health agency, and ultimately, to hospice care (National Association for Home Care & Hospice, 2013).

In a study conducted with five rural health nurses in Canada, researchers found four barriers to the transition from traditional home health to hospice care: (1) a lack of understanding by the home health nurse of the current definition of palliative care; (2) how palliative care is delivered in a home health patient's home; (3) poor communication; and (4) limited medical support (Arnaert, Seller, & Wainwright, 2009). In the United States, much effort has gone towards understanding the role that nurses in hospice, intensive care, oncology units and emergency rooms play in the provision of palliative care (Metzger, Norton, Quinn, & Gramling, 2013). However, little is yet known

regarding the home health nurses' challenges in providing care during the palliative transition phase or the hospice transition phase (Grainger, Hegarty, Schofield, White, & Jefford, 2010; Kirk, Kirk, Kuziemski, & Wagar, 2010). This knowledge gap is problematic for three reasons. First, the nurse is the member of the inter-professional team who is most likely to coordinate the care of a patient with heart failure during care transitions, when it is important to have interventions to guide nursing care during this critical juncture (Metzger et al., 2013; Van Nes, 2011). Second, this lack of knowledge about home health palliative nursing may be restricting access to palliative care and hospice services (Devi & Saraswathi, 2011). Third, no published research was found about palliative care length of stay prior to transitioning to hospice care. The median length of stay in hospice programs averages just less than three weeks with 30-35% of patients admitted to a hospice agency dying within seven days or less of admission (NHPCO, 2013; Campbell, Baernholdt, Yan, Hinton, & Lewis, 2013). These findings indicate that referrals to palliative care and hospice programs occur too late in the disease process. Earlier referrals would better support the emotional, psychosocial, and physical symptom management during the transitions period from curative to palliative care.

### **Gap in Knowledge**

Little empirical evidence exists to guide the transition to palliative or hospice care (Larkin, de Casterlé, & Schotsmans, 2007; Newman, Thompson, & Chandler, 2013). Making a transition is often very challenging, yet little research on best practices is available to facilitate this process (Clark et al., 2012; Dev, Abernethy, Rogers, & O'Connor, 2012; Low, et al., 2011). The purpose of this study was to build the evidence

base needed to guide patients, their caregivers, and healthcare organizations through a significant care transition, from curative care to palliative care and hospice for patients with heart disease. The specific aims of the study are consistent with goals of the National Institute of Nursing Research (NINR) and the National Hospice and Palliative Care Organization (NHPCO) to develop interventions to increase access to and utilization of palliative care and hospice services (NINR, 2014; NHPCO, 2014). As a result of these gaps in knowledge, the following specific aims of this study were chosen in an effort to address the challenges home health nurses are facing when caring for chronically ill patients, particularly those with heart failure.

### **Specific Aims**

The specific aims of the study were as follows:

Aim 1: To describe the home health nurse's experience of caring for chronically ill patients who are candidates for palliative or hospice care.

Aim 2: To describe the home health nurse's experience of transitioning patients with advanced heart failure from curative care to palliative care or to hospice.

### **Known Heart Failure Transition Challenges**

#### **Heart Failure**

##### **Disease trajectory.**

Heart failure is an example of an incurable and life-limiting disease. Many patients with heart failure develop dyspnea and unrelieved pain during the terminal stage (Martin, 2011). Although much effort is focused on managing the complex needs of patients with heart failure, palliative care can be overlooked as an option when caring for such patients

during the last year of life (Krum & Abraham, 2009). On the one hand, the use of medications and therapies such as oxygen can provide significant symptom relief, such that physical manifestations of the disease may not be evident. Dramatic changes in symptom severity make prognostication in heart failure very challenging and make it difficult for the home health nurse to initiate a conversation with the family about a transition to palliative care.

As the disease progresses, the pharmacological treatments that once provided symptom relief are not as effective, and in some patients may actually diminish quality of life. Laugaland, Aase, and Barach (2012), found the need for heart failure expertise among care providers such as home health agencies, hospice agencies, and palliative care providers. Dev, Abernethy, Rogers, and O'Connor (2012), noted the need for additional research to better understand disease trajectories and communication issues for patients with heart failure. These researchers also identified the need for care providers to provide personalized health care planning in line with the patient's care goals. The setting and the service options can greatly impact the care delivered.

Advanced heart failure and other advanced illnesses share the need for healthcare providers who can offer palliative care that addresses suffering, develops an understanding of the patient's challenges at the end-of-life, addresses educational needs, and solves inherent end-of-life system and economic issues. These topics provided the rationale for the development of this dissertation research; the literature synthesis of what was known and what would be desirable to know, point to the above four categories. These categories presented a challenge for hospitals, palliative care teams, and hospices;

yet it is unknown where home health fits in this level of end-of-life care situation.

Patients prefer to die at home, surrounded by their loved ones, yet they are not always able to do so (Tang, 2003). As home health nurses work with the growing numbers of patients with heart failure, they require high-level skills to address the complex needs of this population. Home health nurses need the ability to promote the relief of suffering, to help provide support and educational needs, to address communication issues and fragmented care challenges in the healthcare system. When home health nurses have these abilities, care they deliver can be better aligned to link patients to a palliative phase and a hospice phase when needed.

### **Home health role versus palliative care**

#### **Home health roles.**

Home health is care that is provided to patients in their place of residence. Home health is physician-ordered care that provides nursing care, therapy, home health aide, or social services to patients. The goals are to help patients remain in their home and to stabilize or return to a functional level of independence (CMS, 2011). This healthcare team addresses functional, symptom, and psychosocial needs in conjunction with the physician, who is responsible for overseeing the care. Efforts to avoid facility-based care are consistent with the latest research indicating that patients want to be cared for in their home environment during the end-of-life phase (Harst de Werkander, and Andershed, 2004; Hunt, 1992; Karlsson, Berggren, 2011; Koffman & Higginson, 2004; Teno et al., 2004). Options exist as patients progress to a level that requires additional support. Traditionally, the goal of care for the home health team has been to help patients remain at home while

returning to a functional level of independence. However, as home health patients experience a deteriorating level of function, supportive care needs change. These patients reach a point of benefiting from palliative care when what has been working no longer helps which is when palliative care services can step in to help the patient.

### **Palliative Support.**

Palliative care offers support and expertise to address pain, suffering, emotional and psychosocial support for patients and their caregivers across the disease course. In the United States and Canada, the terms hospice and palliative care have been used interchangeably, to describe end-of-life care. Yet Dr. Balfour Mount, one of the preeminent international palliative care physicians, used the two terms interchangeably as an attempt to expand the use of palliative care services throughout the trajectory of a disease by not limiting the utilization of palliative care services to only the last days and months of life (Campbell & Campbell, 2012; NHPCO, 2012). Palliative care focuses on the prevention and relief of suffering by relieving symptoms such as pain, and other physical, psychosocial, and spiritual problems, while improving quality of life when faced with a life-threatening illness (World Health Organization, 2013). There has historically been a lack of clear definitions for the terms used in palliative care to describe end-of-life care, which constitutes the use of the term “palliative” (Hui et al., 2012). A key aspect is that the focus of palliative care is to alleviate pain and suffering for patients, while concurrently pursuing life-prolonging or curative therapy.

A component of awareness is required to be able to determine when a patient is in the life-limiting or life-threatening phase of an illness. This awareness is required before

an understanding of what specific needs and services could help the patients transition from a curative to a supportive phase or from a home health to a palliative care phase. While palliative care offers support that is life-prolonging with curative therapy options that match home health support, hospice is the transition phase that occurs when the patient is in the terminal phase of life.

### **Hospice support.**

Hospice care is defined by the Center for Medicare and Medicaid Services (CMS) (2013) as the provision of care to a terminally ill patient by a program that uses a written plan of care that is managed by the patient's attending physician and the hospice agency medical director, as well as the patient's interdisciplinary group. Nurses generally provide direct care to hospice patients. Hospice care also includes options for physical therapists, occupational therapists, speech-language therapists, social workers, home health aides, homemaker services, and minister support. These services are provided in either the patient's home or in a care facility. Hospice care also offers counseling services to help address a terminally ill patient's need to adjust to an impending death. Efforts to help patients with impending death issues are a key aspect of support that is needed during the end-of-life phase of care, which are specifically provided by hospice healthcare providers. Although hospice care is generally focused on managing symptoms, providing comfort, and helping the patient and family address issues related to future planning, these aspects mimic the services provided by home health. However, the additional support of death planning and maintaining a patient's quality of life while dying (Oldenquist, Scott, & Finucane, 2001) is what differentiates these services from home

health. The variation between palliative and hospice care occurs as treatment and teaching opportunities transition from the goal of attaining a cure to living comfortably until death.

### **Care Transition**

The palliative care literature highlights the challenges of transitions that are occurring when caring for palliative patients. The three major issues identified in transitioning patients are: (1) communication challenges; (2) limited expertise of healthcare providers; and (3) issues with the referral process. If the transition process works seamlessly to move a patient from one level of care to another, quality of life challenges can be better addressed. Training is needed to perform this process. Training is necessary to confidently communicate with palliative patients and their caregivers about end-of-life care (Metzger, Norton, Quinn, & Gramling, 2013). To provide a successful transition and an enhanced quality of life, communication and adjustment skill sets help transition from the curative to the palliative phase.

Meleis' middle-range theory of transitions has been described as a method of adjustment that is used by patients, their family members, nurses, and physicians, to adjust to changes that are occurring in the disease trajectory (Meleis et al., 2000). The major concept of Meleis' theory involves developmental transition phases, situational phases, health/illness progression or resolution, and organizational changes that occur during changes in phases (Naylor, 2000). The use of transition theory can help healthcare providers identify options when attempting to transition patients from a healthcare facility to a home health agency that could subsequently transition qualifying patients to

palliative or hospice care. Naylor (2000) described these changes as the impact that happens during the period when a safe and timely transfer from one level of care moves to another level of care. If the transition phase is negatively impacted by an exacerbation of symptoms or deterioration in health status, the transition may then lead to an unsafe or untimely transition. Research findings demonstrate several factors that affect the provision of care in a home environment during the end-of-life process. Several of these factors are safety, respect, and individual dignity (Karlsson & Berggren, 2011), trust and participation (Harst de Werkander, & Andershed, 2004), and hope (Olsson et al., 2011). The goal of showing respect and preserving dignity while building trust without diminishing hope and helping home health patients participate safely in their care needs is an important aspect of a transition process. Transition challenges have also been noted as a source of anxiety for non-home health nurses who are attempting to transition patients to palliative or hospice care (Bolmsj , Nilstun, & L fmark, 2007; Marsella, 2009).

### **Heart Disease and Palliative Care**

Home health nurses are responsible for providing care for patients with a wide variety of health problems. Most health conditions that require palliative care are chronic and debilitating and require the expertise of home health nurses (Ornstein et al., 2013). Three specific issues have been identified that warrant greater examination during care transitions for heart failure patients: (1) the unpredictable nature of functional decline; (2) increasing dependence over time; and (3) inadequate delivery of information and interventions to the patient and family (Davidson et al., 2007). Transition difficulties

occur when determining which patients with heart failure might benefit from palliative care (Beckelman et al., 2009). It is currently difficult to identify if there are characteristic trajectories to guide care-givers (Murray et al., 2007). Another difficulty in transition planning is that there are no studies to document whether objective symptom-monitoring is conducted (Clark et al., 2012). To further complicate care decisions, some patients with heart failure who are transitioning from hospital to home health care may not qualify for hospice care, in spite of needing end-of-life care. These complex factors require the home health nurse to navigate the care system as well as to have specific technical and communication skills to care for these patients (Quinn, 2005).

### **Research Impact**

Results of this research are significant to nursing because it enhances knowledge about clinical care and the delivery of care for dying patients in three significant ways. First, results of this study provide information about the experience of a sample of home health nurses when they realized a patient needed palliative or hospice care. Nurses interviewed in this study were able to highlight underlying issues attributed to this experience. Home health nurses in this study were not only visiting patients in their homes, but also developed long-term relationships with the patients, family members and other caregivers, in addition to other professional team members, particularly the patients' physicians. Results of this study indicate that nurses played a pivotal role in addressing the patient's end-of-life decision-making while they attempted to meet the physical, emotional, and psychosocial needs of these complex patients. Nurses reported that they were able to respond to verbal and nonverbal cues as they learned about the

patient's choices regarding end-of-life care options. Interviews indicate that it is often the home health nurse who begins conversations about end-of-life care issues that surround symptom management, communication, and fragmentation of care. Results of this study provide insights and rich descriptions of the home health nurses' experiences of caring for these chronically ill patients, with specific attention to patients with advanced heart disease. The rich descriptions that home health nurses gave about implementing care brings increased awareness about the need for palliative care or hospice being provided as the most effective type of care needed to meet patient and family needs.

Second, results of this study provide an understanding of the care planning process used by nurses when caring during the transition to palliative care. Issues have been reported from other settings on palliative care concerns such as communication, education, timing of referrals, physical decline, psychological and emotional decline, relationship fears, and physician, nurse and team dynamic challenges, and system and organizational challenges. These same issues were reported by home health nurses in this study as being prevalent in the delivery of care for these chronically ill, dying patients. Finally, results of this study contribute to the knowledge about the multifaceted impact of transition decisions. Nurses interviewed in this study reported that specific process and outcome indicators need to be highlighted because nursing involvement in these decisions either enhanced or deterred patients from transitioning to the most appropriate level of care.

The findings from this study include the identification of patterns of challenges faced by home health nurses when attempting to transition patients to hospice or

palliative care. Examples are provided of successful transition experiences and measures the nurses can implement to improve transitions. A major contribution of this study is an appreciation of the role and relationship home health nurses have with patients. Results of the interviews demonstrate the highly skilled support these nurses provide to patients in direct-care and self-care education, and also demonstrates the oversight role of guiding and directing care in a complex system, as patients and healthcare providers struggle to provide optimal end-of-life care.

**Long-term goal of the study.**

The goal of this study was to better understand the home health nurse's experiences prior to and during the transition to palliative and hospice care for patients who are chronically ill with heart failure. The long-term goals of this program of research are to improve the quality of life of home health patients by identifying interventions home health nurses can use to facilitate a successful transition to hospice care, and to address the challenges nurses experience when home health patients are unwilling to transition to a hospice care provider. In the next section of the dissertation, a review of the research literature is presented to describe the transition challenges and summarize current knowledge about palliative and hospice care transition and complexities for nurses, patients and families during this process.

## CHAPTER 2

### Literature Review

The need to study nurses experiences in home health care for patients with advanced heart failure was chosen because the aging population is experiencing more chronic illness while living longer (Lynn and Adamson, 2003). Challenges exist for home health agencies to provide care for patients with a deteriorating health status who refuse to transition to hospice care. As a director for a home health agency, this researcher noted this problem when home health nurses began to complain that their patients were refusing to transition to a hospice agency although the nurses determined it was indicated. These nurses explained that they did not know how to communicate the benefits for patients and their caregivers. The nurses therefore expressed a desire to increase their knowledge of care delivery, but also how to overcome the transition barriers in order to provide quality care at the end of these patients' lives.

Prior to conducting this research on the challenges home health nurses experience to promote a transition to palliative care, a preliminary search in the literature pointed to the need to further explore this problem. It was unknown if home health nurses knew how and/or when to transition patients to a palliative type of service or a hospice agency. These elements of care were significant to the home health nurses ability to function in the realm of palliative care, thus greater knowledge and training were needed once the process of transitioning was clearly described. The literature review revealed four areas in non-home health palliative care transition challenges. The challenges that were

identified were: (1) realization of patient suffering; (2) challenges of understanding patient care at the end-of-life; (3) educational needs of nurses; and (4) system or economic issues that are impacting the provision of quality palliative care (Meier, Isaacs, & Hughes, 2010).

### **Palliative Care and Home Health Research**

Home health nurses are in a key position to support the growing number of patients who have heart disease and need care in the home. The chronicity and complexity of the disease management process often results in a period of several years that these patients will be receiving home health services (Metzger et al., 2013; Van Nes, 2011).

### **Suffering**

Suffering may occur when patients are not offered palliative or supportive care at the end-of-life, or when healthcare providers offer care that is not effective or even harmful to the patient (Meier, Isaacs, & Hughes, 2010). This situation can result when patients experience severe pain, have poorly managed symptoms, or are offered ineffective or intrusive treatments that may prolong suffering, which is counter-intuitive to enhancing comfort during the dying process. By not offering comfort and life-ending closure options in a timely manner at the end-of-life, suffering may be the result. Reports in the literature indicate the pervasive problem of late referrals to palliative care resulting in patients not allowed to die at home (Fukui et al., 2011). Reasons for the differential use of palliative care services include the limited ability of patients or caregivers to request

services that meet differing needs of patients, and the difficulties of coping with complex care needs at home (Walshe, Todd, Caress, & Chew-Graham, 2009).

In a study of heart failure patients, Harding et al. (2008) found that patients and their caregivers had not discussed disease progression or advanced care planning. Thus, suffering occurred because of a lack of understanding of heart failure symptom management. The clinicians that specialized in heart failure described an unwillingness to disclose a poor prognosis to patients and their families. In another study by Krum and Abraham (2009), heart failure patients with advanced symptoms and poor quality of life, who were resistant to pharmacological regimens and other therapeutic strategies, relied heavily on palliative aspects of symptom control. These studies indicate a need for more research on palliative care for patients with heart failure to enhance clinician ability to recognize the need for palliative care, to thus prevent suffering and enhance symptom control.

### **Lack of Knowledge: Patient-Family**

Patient and families need information and support in order to understand symptom management, diagnostic, prognosis, and preferred care options, anticipated outcomes related to quality of life, and ultimately, how to manage the dying process, (Meier, Isaacs, & Hughes, 2010). Metzger, Norton, Quinn, and Gramling (2013) found that patients and family members were unprepared for the palliative care team; the patient's perception of their prognosis dictated the plan of care which may not have addressed the patient's needs. Results of this study demonstrated the need for palliative

care services. In addition, researchers found that patient and family members would often reject or defer palliative care options if they believed that palliative care was the same as hospice care. To patients in this study, electing hospice care was the same as declining aggressive symptom management, which is in fact the opposite case.

Patients with symptomatic heart failure experience symptom burden, depression, and challenges to spiritual well-being (Bekelman et al., 2009). The patients often have a limited understanding of these burdens and don't know when and how to seek help. Common misunderstandings exist among clinicians in knowing which patients with heart failure are appropriate to receive palliative care (Beckelman et al., 2009), what the discernible characteristic trajectories are (Murray et al., 2007), and how to prioritize the development of objective symptom monitoring (Clark et al., 2012). Possibly the most challenging aspects for patients with heart failure and their caregivers is the lack of understanding of the unpredictable course of functional decline, increasing dependence over time, and inadequate delivery of information and interventions during care transitions (Davidson et al., 2007).

### **Lack of Knowledge: Health Care Providers**

Healthcare providers need to recognize the final phase of an illness, develop an effective strategy for care, and communicate those strategies with patients and their caregivers during the advanced illness phase (Meier et al., 2010). This challenge encompasses the healthcare provider's attitude, beliefs, values, and emotions that surround care for any population of patients (Ferrell & Coyle, 2006). Nurses and

physicians have their own attitudes and beliefs about end-of-life and the resulting opportunities for palliative care. Any fear or lack of support for palliative care would need to be addressed in order for the nurse or physician to refer patients for this type of care. Training for health care providers is a necessary component to be able to communicate confidently with palliative patients and their caregivers about end-of-life care (Metzger et al., 2013). High level communication skills are needed during the palliative care or hospice phase to be able to prepare patients for end-of-life care (Grainger, Hegarty, Schofield, White, & Jefford, 2010; Kirk, Kirk, Kuziemski, & Wagar, 2010). A lack of knowledge may restrict efforts to make a timely referral to palliative care (Devi & Saraswathi, 2011). Despite advancements in end-of-life care, there is sparse empirical evidence to guide the transition to palliative or hospice care (Larkin, de Casterlé, & Schotsmans, 2007; Newman, Thompson, & Chandler, 2013).

Low et al. (2011) noted the need for an improvement in coordination of care and communication between patients, their families, and health professionals. The need is particularly great for nurses with expertise in coordinating care with palliative care team members. We currently do not know how many heart failure trained specialist nurses work in home health. This is not documented in the literature. If the home health staff members do not have expertise in care of patients with heart failure, other options might be nurses working physician's offices or clinics in which clinicians are trained to monitor and provide care for these patients. The research conducted by Low et al. (2011) indicated that heart failure patients who had a better understanding about management of their illness could improve their quality of life. The teaching role of home health nurses is

often critical to the patient's success in managing heart failure and in understanding benefits of palliative or hospice care.

The ability to provide care to the population of patients with heart failure requires training on palliative care communication methods, comfort measures, and end-of-life choices. In addition to the essential components of understanding the disease and self-management, training in symptom assessment and management skills, social functioning and behavioral needs were found to be important for the heart failure patient population (Low et al., 2011). Because of the unpredictable trajectory of heart failure, education on early and systematic approaches for referral options would benefit these patients and their family members.

### **System and Economic Obstacles**

Obstacles in the health care system and financing are prevalent in the fragmented care delivery process largely because Medicare restricts hospice care to patients who are within the last six months of life (Meier Isaacs, & Hughes, 2010). More patients could benefit from palliative services if these services were offered during the entire spectrum of an illness. When a patient is in the advanced stage of illness, home health nurses can address system and economic problems when symptoms are being poorly addressed. This becomes a system or economic issue when caregivers are grappling with ways to support the patient, and are deciding which drug or supportive needs are not met because of limited financial funds causing an economic challenge during the end-of-life period. Hospice and palliative care access is impacted by health system and financial barriers.

Health system and financial barriers impact symptom management, quality of life, and continuity of care in non-home health settings (Reb, 2003) which may also impact home health patients. It is unknown how these barriers are impacting home health patient care.

The flow of appropriate care can be restricted by organizational and system structures when providers try to refer patients with heart failure for the right level of care. Home health agencies may not want to transition patients to hospice care if such a transition would reduce revenues for the home health agency. While research supporting this premise was not available, it is evident that financial success is a standard goal of home health agencies. For example, a home health agency may be unwilling to keep a patient who is re-hospitalized if the patient is no longer undergoing treatment that is curative and the patient is progressively deteriorating. The patient may experience deterioration on a continuous basis that may negatively impact the outcomes for the home health agency that are publicly reported. The art of identifying appropriate “triggers” or indicators for referring heart failure patients to palliative care programs would help both patients and healthcare providers (Metzger et al., 2013). Healthcare systems would benefit from research that identifies specific triggers for referrals to palliative or hospice care: specifically for patients with heart failure as they reach the phase of needing palliative care (Schneider, Oster, Hager, & Klindtworth, 2011). Home health agencies are required to care for this population when they are discharged from hospitals to address suffering, provide education, enhance patient understanding, and to address organizational and economic issues. Stuart (2003) noted the need for better home-based

transition management for high-risk chronically ill patients to help transition patients appropriately to a hospice agency.

There have been no studies reported in the literature that examine the home health nurse's understanding of the term "palliative" care, necessary assessment skills, and transition issues affecting patients with heart failure in an advanced disease state.

Research studies noted that patients are often admitted to hospice within the last week of life, which may reflect a gap in the appropriate type of care being delivered (Institute of Medicine [IOM], 2014; Miller, Weitzen, & Kinzbrunner, 2003). Home health agencies are in a prime position to make referrals to both palliative care and hospice care when home health patients experience suffering, lack of understanding, and need care from trained palliative or hospice healthcare providers. Prior to this study, it was unclear why patients receiving home health care for heart failure were not transitioning to palliative and hospice care. The current study contributes to knowledge development of nursing science by offering an understanding of the challenges home health nurses' experience when caring for and attempting to transition chronically ill patients with an advanced stage of illness. To complement the existing literature regarding palliative and hospice transitions, a literature review of theories that were developed to address the process of moving patients to another level of care is presented below.

## **Transition Theory**

### **Theoretical and Operational Definitions of Transitions in the Literature**

Transition Theory was derived from the concept of transience that is a related, yet different use of the term: transition (Larkin et al., 2007). From an etymological perspective, the word transience was derived from the arts and humanities to explain the process involved in making a transition. Transience is defined as “passing away with time, temporary, passing quickly, fleeting, staying only a short time,” while the term “transition” is defined as “a passing from one condition, place, etc. to another” (Webster’s New World Dictionary, 2009). The correlation between these terms demonstrates movement and location, while the difference is the aspect of time. Transition timing can be described as a disease or a condition that is not bound by time, yet requires a finite component of the deterioration of the disease/condition that is impacted by time as the disease progresses. The use of the term transience in the field of palliative care was investigated by Larkin et al. (2007). The authors presented a conceptual evaluation of the term that encompassed an ephemeral state of being, expression of time, and spatial phenomenon used in the construct of the place called “home.” Freud (1916/2013) explained transience historically as a change from a state that had been considered as a permanent state. Because the state of being, time, and spatial aspect are elements of caring for chronically ill patients with advanced disease states, the use of a Transition theory is appropriate for this research.

**Transition Theory Model**

Transition theory has been deemed a vital concept in nursing practice (Meleis, Sawyer, Im, Hilfinger, Messias, & Schumacher, 2000). The concept of transition is helpful in identifying challenges that nurses were experiencing in patient care, which resulted in the development of a framework that became a middle-range theory. The middle-range theory of transitions was developed to encompass the nature and conditions for transitions, and the patterns of responses (Meleis et al., 2000). Schumacher and Meleis (1994) posit that multiple and complex transitions are a necessary aspect because nursing care is deeply rooted in delivering care within multiple organizational structures. Transitions are also integral to the many situational experiences, developmental needs, and illness challenges of patients in varied settings. Transition theory recognizes various types and patterns of transitions as well as various properties of the transition experience. The types of transitions described by Meleis et al. (2000) are: (1) developmental types that explain growth stages or role changes; (2) situational, health/illness progression or resolution; and (3) organizational changes. The nuances or properties that Meleis et al. (2000) viewed in the development of the middle-range theory of transitions were delineated as: awareness, engagement, change and difference, transition time span, and critical points and events. Each of these properties helps focus the nurse directing a patient's transition when triggering events occur or there is a change in the duration of the transition process.

Nurses play a key role in assisting patients through transitions, while understanding and addressing personal conditions that patients are experiencing. Personal

conditions involve the nurse understanding how patients assign meanings, addressing cultural beliefs and attitudes, and understanding the impact of socioeconomic status, while assisting with direct care and the patients' needs for information (Meleis et al., 2000). Both community and societal conditions serve as facilitators or inhibitors through the transition process. Distinct process and outcome patterns occur depending on how patients feel connected, interact with others, feel supported given their situation, and develop confidence and coping methods (Meleis et al., 2000).

Palliative nursing care may find the middle-range theory of transitions helpful to them to express their goal for helping patients make a healthy transition when moving from a well phase to a deteriorating illness phase. Patients with advanced chronic illness would benefit from the skills of the palliative care trained nurse who is able to enhance such transitions. Meleis' (2000) middle-range transition theory also has the potential to guide future research on care transitions as patients move from acute care hospitals to home health and hospice care.

### **Naylor's Nursing Transition Theory**

Naylor (2012) developed a model of transitional care in 1981 with a focus on the advanced practice nurse's role in transitioning patients from one level of care to another. This transitional care model was further developed over the years to enhance the discharge planning process and home follow-up services for older adults hospitalized with common medical and surgical conditions. The model developed by Naylor encompassed features consisting of a comprehensive assessment of a patient's goals and

preferences, physical, emotional, cognitive, and functional abilities and needs, as well as social and environmental considerations. The model also required the application of an evidence-based plan of transitional care that is initiated at hospital admission and extends through to the actual discharge home.

Naylor (2012) noted the need to gather and share information across various sites of care while keeping the patient and caregivers involved in the planning and follow-through of the plan of care. This process affirmed the need for care coordination using advanced practice nurses. Bradway et al. (2011) applied the transitional care model to hospitalized older adults with cognitive deficits and found that advanced practice nurses provided care that exceeded the type of care typically staffed and reimbursed in the U.S. health care system. The need for advanced judgment skills and nurses “doing whatever it takes to prevent negative outcomes” revealed the need for high level skills and knowledge for examining how systems impact transitions as patients move from one environment to another (Naylor & Keating, 2008).

### **Challenges in care transition.**

Specific challenges exist in the care transition process from home health to hospice as patients move from one level of care to another. Transition challenges identified in the literature were classified into one of three categories: (1) communication issues; (2) expertise of healthcare providers; and (3) the referral process. Each of these challenges fit appropriately into the previously presented transition theory.

*Communication issues.*

Communication requires choosing the right words at the right time, knowing the trajectory of the disease, and having the ability to start a conversation about options. The ability to deliver “bad news” was cited as a challenge that requires extensive skill to assist the patient and family to accept difficult information (Back et al. 2010; Ngo-Metzger, August, Srinivasan, Liao, & Meyskens, 2008).

*Expertise of healthcare providers.*

Expertise issues, specifically the clinicians’ need for education needs and skills, were identified as critical to improving care during the end-of-life phase (Edwards, Olson, Koop, & Northcott 2012; McWilliam, Ward-Griffin, Oudshoorn, & Krestick, 2008; Newman, Thompson, & Chandler 2013; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). Patients want health professionals who have the necessary expertise (Conner, Allport, Dixon, Somerville, 2008). Expertise is needed when attempting to identify patients that would be eligible for hospice care (Moyle-Wright, 1999), and to recognize the signs and symptoms of active dying and closeness of death (Gott, Small, Barnes, Payne, & Seamark, 2008; Woods, Craig, & Dereng, 2006). These complex care issues point to a critical need for home health nurses to understand patient and family needs for information and understanding related to end-of-life.

*Referral process challenges.*

Miller, Weitzen, & Kinzbrunner (2003), noted, 36% of non-nursing home patients who need hospice care are not transitioned to hospice until the final week of life because the

referral process is delayed. Patients are more often open to other methods of referral that can give them better access to specialist palliative care services (Conner, Allport, Dixon, & Somerville, 2008). It was unknown prior to this current study what specific referral challenges existed for home health nurses in palliative care situations.

### **Literature Review Summary**

Due to the paucity of studies conducted in home health care settings about palliative care and transition challenges, this current study was designed to focus on the process of delivering palliative care to those needing transition. The palliative care challenges highlighted in the literature include the physical and psychological decline that creates patient suffering, communication issues related to understanding patient needs, education concerns of healthcare providers, and system and economic obstacles. These challenges impact referral timing, healthcare team dynamics, and operational issues that may impact home health patient care. The existing research that addresses palliative care has been conducted primarily in emergency rooms, intensive or acute care units in hospitals, hospice agencies, or in specific palliative care agencies or units. These studies attempted to identify the challenges and address staff educational needs in order to better help the palliative care patient population. Transition theories and models, as developed by nurse scholars Meleis et al. (2000), and Naylor (2012), were identified as useful frameworks for examining the phase of care in which home health nurses can assist patients to move from a curative approach to palliative or hospice care. In this chapter, a review of literature related to the issues of suffering, understanding patient challenges at the end-of-life, educational needs, and system and economic issues revealed

a gap in the application of palliative care support offered by home health nurses. This review supports the research question and study design that explored whether nurses experienced similar issues in home health.

## CHAPTER 3

### **Methodology**

The design for this study was a qualitative descriptive design selected to capture descriptions by home health nurses caring for patients with advanced heart failure as they transition to palliative or hospice care. Strauss and Corbin (1998) explained that the use of a qualitative method is appropriate to examine areas of research where little is known about the topic of interest. There has been no published research on this topic, which makes it an appropriate study to use a thematic analysis qualitative research design.

### **Objective**

The primary purpose of this study is to describe home health nurses experience of caring for patients with advanced heart failure during the transition phase to palliative care or hospice care. The essence of this study is examining the contextual awareness or realization that occurs when these transitions are required. The study is guided by the following research questions:

1. How do home health nurses describe the experiences of caring for chronically ill patients who are candidates for palliative or hospice care?
2. How do home health nurses describe transitions of advanced heart failure patients from a curative plan of care to a palliative plan of care or hospice?

## **Qualitative Research**

Qualitative research offers a method of exploration while attempting to better understand the meanings that people assign to a social situation or a humanistic issue (Creswell, 2009). The methods used in this form of research incorporate questions and behaviors of human approaches used in a specific setting. Glaser & Strauss (1965) described differences in quantitative research from the qualitative research. The quantitative researcher functions as one who can only verify facts, as opposed to the qualitative researcher who conducts research while being able to generate an explanation. Qualitative research according to Glaser and Strauss (1967) “is often the best way— and often the only way— to get data on a subject” (p.260). This is a key aspect of the present study because we do not know enough about the current state of science of home health nurse transition experiences to be able to identify the elusive or hard-to-define qualities of the phenomena itself. Research is needed to identify care challenges while also appreciating the sensitive nature of this topic of death and dying. Qualitative descriptive research is the best method to gain access to the realm of a phenomenon that is currently not described in the literature.

Using qualitative research methods, when data are collected, an inductive process of building themes and interpreting the information is done while reviewing and conducting data analysis. Inductive steps require the use of reasoning to review facts or statements with an end goal of establishing a general conclusion (Websters NW Dict 2003).

Qualitative methodology is based on constructivist philosophical assumptions that are founded in advocacy and participatory knowledge needs of society (Creswell, 2009). The methods of conducting qualitative research involves using open-ended question, analyzing emerging approaches, while positioning the researcher in the role of collecting information about the study subjects. The process of collecting information requires a focus on a single concept or phenomenon, studying the context or setting of the study subjects, validating the accuracy of the findings, making interpretations of data, while creating an agenda for changes (Creswell, 2009).

### **Basic Characteristics of Qualitative Studies**

Characteristics of qualitative research include the process of conducting the study in a natural setting, using the researcher as a key instrument, using multiple sources of data, conducting an inductive approach to data analysis, respecting the study subjects meanings, and allowing an emergent design to offer a theoretical view that is interpretive while using a holistic perspective (Creswell, 2009). Natural settings allow the research to occur in the field, at the site where the study subjects function. This process is inductive because it allows the researcher a chance to find themes and make sense of the study subject's experiences related to their views.

### **Data Collection**

#### **Setting**

This study was conducted in the southeast United States, often referred to as the mid-Atlantic region. The researcher selected home health agencies in the Central,

Northern and Southern Virginia area. A review of the ethical aspects of the study was conducted by the University of Virginia Institutional Review Board. Approval was also provided by directors and administrators from each home health agency. Home health care nurses in each agency were then recruited. Four home health agencies participated in this study, which included two urban areas that also supported rural areas and two rural only service areas.

### **Study Sample and Selection**

A purposive sampling strategy was used to select home health nurses to participate in the study. The inclusion criteria were: 1) adults over 21 years of age; 2) able to speak and read the English language; 3) having worked in home health care for at least three months; and 4) willing to consent to tape-recorded interviews. The sample size was pre-determined to be either 30 participants or enrolling new participants until the information gathered did not add any new information (Seidman, 2006). Over the period of data collection, the sampling strategy was modified in an effort to identify participants of varying ages and years of experience to be able to capture and describe the variety of experiences of home health nurses caring for people with advanced heart failure who are nearing the end-of-life.

The researcher obtained permission from the agency administration to present an overview description of the study to registered nurses at each home care agency to invite nurses' participation. The description included the specific aims, a description of the sample, recruitment, and the data collection method (audiotaped interviews). The

participants were recruited through agency administrators, attendance at staff meetings and individual meetings, and through referrals from fellow nurses who participated in the study. The researcher obtained informed consent after a home health care nurse agreed to participate in the study.

### **Ethics Approval & Consent Procedure**

The University of Virginia Health System Social and Behavioral Sciences Institutional Review Board (SRS-IRB) approved the study. Prior to data collection each participant received the informed consent information and was given time to ask the researcher questions about the study. The informed consent (Appendix A) was signed and a copy of the consent form was provided to the participant. The researcher kept a copy of the signed consent form in a secure location following IRB data retention requirements.

To protect participant confidentiality, a number was assigned to each participant and it was recorded in a code-book/master file located in a locked cabinet at the researcher's home office and upon completion of the data collection phase, the code was kept in the office of the chairperson of the dissertation committee to be retained for a minimum of three years. The same number was assigned to the transcript and audiofile. Assigning the number to the transcribed text was done to ensure confidentiality. The real identities of the participants were protected and will not be used in any verbal or written presentations, reports, or publications. In presentations or publications, any direct quotes or reference to exemplars was identified with a number or pseudonym.

## **Interviews**

In-depth interviews included a demographic profile review (Appendix B) and the interviews were conducted as guided by a semi-structured, interview guide (Appendix C.) In-depth interviews are conducted in qualitative research to uncover participants' beliefs and perspectives. Qualitative interviews strive to appreciate the holistic aspect of the participant's experiences while finding meaning about a phenomenon that unfolds (Wojinar & Swanson, 2007). All interviews were recorded using a digital recorder and transcribed verbatim into a Word document. Using data transcribed verbatim was an advantage because it gave the study participants a chance to directly share their perspectives and have the information captured to ensure that no critical aspects were missed. The interviews lasted anywhere from 10 to 44 minutes and took place in a quiet office, the participant's car or home, or at a conference or meeting room in the home health agency. The researcher asked each participant if the meeting place was a comfortable and confidential location where they could speak freely with the researcher and maintain privacy at all times.

Before the interview, the participants completed the demographic data form (Appendix B) that was reviewed by the researcher to determine whether the participant met inclusion criteria and had experiences of caring for patients with heart failure. Each participant was asked questions directly from the interview guide. According to Patton (2002), the wording of the interview questions functions as an important component of the data collection process. Patton (2002) identified four important methods to use in establishing interviewer behavior as:

(1) using and providing to reviewers of the study the exact instrument used in the study, (2) minimizing variation among interviews when a number of interviews will be conducted, (3) keeping the interview highly focused so that the participant's time is efficiently used, and lastly, (4) analysis can be further facilitated by making responses easy to find and compare (Patton, 2002, p. 346).

This method of interviewing participants allowed an appreciation that there was a structure to the questions that were posed, while allowing the researcher an opportunity to deviate from the sample questions when topics or issues that were not anticipated were uncovered during the interview process. Probes were used in an effort to elaborate on specific aspects of the nurses' experiences. Up to two follow-up contacts with the interviewees were allowed to address any missing data or concerns about the data analysis results. The participants were contacted by phone or interviewed in person (as determined by the participant).

The initial interviews were audio-taped and transcribed. Field notes that were recorded during the interviews, using reflective journaling as a methodology, were incorporated using these notes to validate the study findings. All study materials were kept confidential and stored in a secure place in the faculty advisor's office. The items to be maintained for three years include the transcribed interviews and signed consent forms.

### **Data Management**

A tape recorder was used as the primary means of data collection. Field notes were written to reflect document observations, thoughts, and experiences of the researcher that arose during the interview. The audio recordings were transcribed into text verbatim by a transcriptionist trained to type exactly what was heard in the recording,

or by the researcher. Transcription accuracy was assured by comparing the transcripts with the interview notes, audio recordings, and field notes. Non-verbal responses were documented in the field notes as well as any relevant information that would describe the behavior or the environment that the participant and interviewer were experiencing during the interview.

Each transcription was formatted into a Word document and stored on a computer that is backed up on the researcher's private computer drive. The recording device was kept in a locked cabinet in a secure location at the researcher's home or advisor's office when not in use. Field notes were recorded in loose-leaf notebooks. The notes were labeled with the site, coded sequentially by number, dated and timed for each encounter. Field notes from the second phone or in-person interview were managed in the same way. The field notes were set up in bullet and paragraph formats and were organized by the date of the interview. These notebooks will be destroyed at the conclusion of the study.

Meetings with the dissertation advisor occurred on a regular basis throughout data collection and data analysis to keep her informed of progress, to discuss any issues or concerns and to prepare updates for the rest of the dissertation committee as necessary. The documentation of the meetings were recorded in a journal. The journal notes were also kept in a locked cabinet in the researcher's home. The code book, field notes, and audio-tapes will be destroyed at the completion of the study.

### **Data Analysis**

In this study, a thematic analysis process and end product results followed a six-step process derived from Miles, Huberman & Saldana's (2014) examples (See Table 1.)

**Table 1: Thematic Analysis Components**

<b>Step</b>	<b>Process</b>	<b>End-product</b>
<b>1</b>	<b>Initial Transcription Review</b>	<b>Initial Code Developed</b>
<b>2</b>	<b>Coding</b>	<b>Descriptive Codes Identified</b>
<b>3</b>	<b>Development of Pattern Codes</b>	<b>Sub-themes or Themes Emerge</b>
<b>4</b>	<b>Matrix Development</b>	<b>Grid Documenting Thematic Links</b>
<b>5</b>	<b>Creation of Thematic Map</b>	<b>Visual Representation of the Connections Between the Themes</b>
<b>6</b>	<b>Final Analysis</b>	<b>Findings Section (Chapter 4)</b>

#### **Thematic Analysis Step 1: Initial Transcription Review**

A review of transcription was completed on each of the 30 interviews using analytic memoing. An analytic memo has been described as a narrative documentation of the researcher's reflection and thought process while listening to or reading the data (Miles, Huberman, & Saldana, 2014). Because this process is used to not only synthesize, but to also construct a higher level of analytic analysis, it allows the researcher to condense or draw conclusions that can be an effective method of initial data analysis when a researcher has large volumes of data. This researcher used the memoing process to define the overall impression of the narrative with a detailed commentary on the experiences nurses had when transitioning patients to palliative care or hospice. This

review also highlighted the issues and experiences the nurses were having while caring for chronically ill patients. Reflections on the topics mentioned were noted at the end of the memo. An example of a memo procedure follows:

Memo #3: Overall Impression: *The nurse conveyed limited experiences in transitioning home health patients over to hospice care as she had worked in home health for one year and had only one patient that had heart failure that was “sick enough” to go to hospice. She indicated that most of her patients were being rehospitalized frequently.*

Details of First Review of Transcription: *Success with cancer patients transitioning to hospice, physicians not willing to discuss hospice with patient, daughter of patient refusing to allow discussion of disease progression and hospice options. Patient asking nurse to explain to daughter she is tired.*

Reflections: *The nurse’s limited experience may have impacted her ability to determine “when” to bring in hospice services. She struggled to have conversations with the patient and the patient’s daughter which may be impacted by her lack of training on use of palliative care and hospice services.*

Analytic memoing was used to provide a narrative document of the researcher’s reflections and thinking process about the data as described by Saldana (2013). This was done because the present area of research is in a field of the researcher’s expertise with a potential for pre-conceived beliefs about home health care. The researcher is also aware that home health care research does not provide a description of the experience of the home health nurses assisting patients to transition to palliative or hospice care.

**Thematic Analysis Step 2: Coding**

Coding is defined by Miles and Huberman (2014) as a method used to “to retrieve and categorize similar data chunks so the researcher can quickly find, pull out, and cluster the segments relating to a particular research question, hypothesis, construct or theme.”

This process used the printed transcripts with space on the right-hand column, to note descriptive codes of interest to the researcher or a word document was used to capture the coding as interview content was reviewed. Descriptive codes that related to the research questions with specific attention to successes, challenges, or significant features were noted. Clear operational definitions of codes were delineated as the researcher identified a code; operational definitions were summarized so in the future, other researchers could identify codes during the analysis phase. An example of this coding step follows:

Memo #3:

*“I’m not that sick” um, and we’ve had people from hospice talk to us, and they say “Oh, it’s nothing like that,” but it is. You know, you don’t get hospice if unless the end...is coming. There is no nice way to say...it’s serious, and you’ve gotta, you’re looking at the end of your life, so when patient’s hear hospice, they automatically think “Oh, I’m not that sick,” “I’m not gonna die.”*

**Illness Awareness**

Example of Code Definition:

**Illness Awareness** – the moment when patients or their family members verbalize or acknowledge they are aware of the degree of illness or refuse to acknowledge the patient’s degree of illness. This includes awareness and lack of awareness.

Braun and Clarke (2006) explained the need for familiarization with the data so that it helps to organize the data into meaningful codes and separate key aspects from the original data set by being able to sort the meaningful codes into potential themes. By coding interesting features of the data systematically across the entire data set, and collating data that is relevant to each code, the researcher sets the stage for pattern identification (Auerbach, & Silverstein, 2003). Matrices using rows and columns to display qualitative data were used initially and further developed into networks in an effort to find links between complex interrelationships variables (Miles, Huberman & Saldana, 2014.)

### **Thematic Analysis Step 3: Pattern Codes—Sub-themes or Themes Developed**

Patterns are a result of common ideas or quotes that specifically identify an area that requires further exploration by the researcher (Boyatzis, 1998). Building on the descriptive codes developed in Step 2, the codes in Step 3 are refined into a smaller number of themes and sub-themes. As an example, this step took the initial Family Decision Maker (FDM) codes: into FDM sub-themes: emotional reactions, lack of knowledge of disease process, and influencers that impacted FDMs.

### Thematic Analysis Step 4: Matrix Development

The process of developing a matrix to analyze identified themes and subthemes for transitions and to identify any key aspects that correlated with the themes or offered support for the thematic analysis. The matrix contained columns and rows for considering patterns that may not have been evident in individual coding and pattern assimilation noted in Step 2 and Step 3. An example of this Matrix is:

	<b>Illness Awareness</b>	<b>Family Decision Maker</b>	<b>Home Health Nurse Challenge</b>	<b>Communication Skills</b>
<b>Timing Issues</b>	Patient keeps bouncing back then all of a sudden doesn't	Home health nurse to continue being invited into home	Nurse needs additional time to be able to provide complex Palliative care	Issues with MD calling staff back in a timely manner to address issues
<b>Disease Trajectory</b>	Refusing to acknowledge how sick patient is	Lack of knowledge of disease process and family wants to keep fighting	Healthcare team at hospital sends patient to home health vs. hospice	Patient tells nurse it is time, nurse unsure what that means

Matrices using rows and columns to display qualitative data were used initially and further developed into a thematic map as described below in an effort to show links between complex interrelationships between variables (Miles, Huberman & Saldana, 2014.)

**Thematic Analysis Step 5: Development of Thematic Map**

The thematic map is a visual representation of the data, which shows the linkage between themes and sub-themes that have been identified. This is a visual cue of the connections between the themes as they emerged from the interview and data collection process. In thematic analysis, a theme is the “outcome of coding, categorization, and analytic reflection” as noted by Saldana (2009), in which data are coded to allow the researcher an opportunity to “discern and label its content and meaning according to the needs of the inquiry.” An example is:



This step in the analysis process included recognition of Vaismoradi, Turunen, and Bondas’ (2013), requirement for analysis of meaningful latent and manifest content in data analysis. In this phase, the researcher gathers all data relevant to each potential theme and then reviews it while generating a thematic map. The themes were independently reviewed and revised after reexamining the original data for each potential theme. The process of expanding, collapsing, or discarding initial themes and generating new themes as they occurred, allowed for a redirection of the themes. Latent and manifest content that supports the defining and naming of themes leads to clear definitions and names for each theme. The final opportunity for analysis occurs when selecting vivid and compelling examples and using the extracted examples to relate to the research question and the literature review while producing a report of the analysis.

**Thematic Analysis Step 6: Final Analysis**

The interpretation of the themes is the outcome of methods; themes in and of themselves do not make sense until they are placed within a specific context such as the transition from home health to hospice or palliative care. One of the strengths of qualitative research is that the researcher can introduce the setting context and use this step in the analysis process to describe complex data. Explaining meanings by using thematic analysis supports the researcher's ability to identify themes. Because the goal of thematic analysis is to become aware of the study participant's meanings while blending the researcher's understanding of a phenomenon, the blending and delineating aspects using the matrices described above were of critical importance. Upon completing these steps, any field notes related to the interviews and data analysis and transcripts from the interviews were read and reread for outliers, and for extreme situations with the interview cases.

**Assuring Rigor****Qualitative Research Rigor**

All research studies are required to meet quality expectations by meeting rigor or trustworthiness requirements. Qualitative researchers typically use terms such as credibility, transferability, dependability and confirmability in place of the quantitative terms internal validity, external validity, reliability and objectivity to evaluate the quality of research (Lincoln & Guba, 1985). Quantitative researchers use reproducibility in an effort to demonstrate that a study can be replicated through the same or similar research

processes. This effort is not likely to happen in qualitative studies because social phenomena vary widely. However, as stated by well-known qualitative experts, “given the same theoretical perspective of the original researcher, following the same general rules for data gathering and analysis, and assuming a similar set of conditions, other researchers should be able to derive either the same or a similar theoretical explanation for the phenomenon under investigation” (Strauss and Corbin, 1998). In this study, the researcher provided details for the construction of the study process and the analysis process that could be used by other researchers.

Objectivity and confirmability in this study included the study’s methods and procedures as described above, explicitly and with great detail to ensure that a complete picture was provided in the research data collection, analysis and reporting procedures. The actual sequence of how data were collected, processed, condensed, and displayed as it related to specific conclusions was provided along with data exhibits to support decisions, following procedures recommended by Miles, Huberman & Saldana (2014). The researcher also provided self-awareness of personal assumptions throughout the data collection and analysis process. Rival conclusions have been considered along with any plausibility issues. Lastly, these data are available for reanalysis by others, as allowed by institutional review board and researcher-participant agreements.

Reliability, dependability, and auditability ensure that the research process is consistent, reasonably stable over time and across research methods, as noted by Miles, Huberman, and Saldana (2014.) This study provided clear questions with congruent features built into the research design. The researcher’s role and status within all four

research sites was explicitly described as there was no pre-established relationship between the researcher and participants, and they were informed that the researcher was a registered nurse with home health experience, studying palliative care issues impacting home health patients with heart failure. The identified findings show a meaningful parallel between and across data sources (participant, contexts, and times.) Forms of peer or colleague review were built into the design of the study.

Qualitative validity requires the researcher to check the accuracy of the findings by employing specific procedures. Trustworthiness is the equivalent of validity in a quantitative study (Jacelon & O'Dell, 2005). The level of trustworthiness used in quantitative research is scientifically inadequate in qualitative research when rigor remains strict and inflexible. In contrast, Gadamer's tenets (Gadamer, 1989) of qualitative research state that the term of integrity matches the wholeness that takes both the parts and view of the whole research to lend integrity to the research (Watson & Girard, 2004). The method this researcher used to assure trustworthiness was to review the transcribed data for accuracy by listening to the audiotapes and amending the transcripts as needed. Credibility and authenticity were clarified by Lincoln and Guba, (1985) as a conscious effort to establish confidence by providing an accurate interpretation of the meaning of the data. Confidence is accomplished when the interpretations are trustworthy and they reveal a truth that is external to the researcher's experience (Whittemore, Chase, & Mandle, 2001). By virtue of the authentic nature of qualitative research, the meanings and experiences that have been perceived by the participants can be truly authentic by interviewing the participants (Sandelowski, 1986;

Sandelowski, 2000). Criticality and integrity are a responsibility of the qualitative researcher who attempts to appreciate the differing interpretations concluded by different researchers. The ability to instill criticality and integrity to the research process requires an ability to be reflexive while conducting a critical analysis of the obtained data (Whittemore, Chase, & Mandle, 2001). Integrity and criticality were instilled in this study by providing recursive and repetitive checks of interpretations as interviews were conducted and data were analyzed. The researcher, and dissertation chairperson working with this population functioned as an interpretation analyzer, as described by Merriam (2009).

Whittemore, Chase, and Mandle (2001), identified secondary criteria used to establish validity in qualitative research of explicitness, vividness, creativity, thoroughness, congruence, and sensitivity. Auditability ensures explicitness as a method of defending interpretations. The presentation of rich data allows readers a chance to personally experience and understand the phenomenon and context of the study to meet the vividness requirement (Whittemore, Chase, & Mandle, 2001), while creativity is demonstrated by providing innovative findings that are grounded in the scientific process of inquiry (Thorne, 1997). Thoroughness of sampling data and data adequacy combined with the congruency found between the research question, the method, findings, data collection, and analysis further supports the validity of qualitative research. By the very nature of qualitative research, sensitivity occurs when respecting research participants while preserving human dignity (Lincoln & Guba, 1985). Specific techniques of demonstrating validity entailed the following in this research study: development of a

self-conscious research design, ensuring sampling adequacy, giving voice to home health nurses, articulating data collection decisions, providing verbatim transcription, articulating data analysis decisions, performing a literature review, conducting reflexive journaling, providing an audit trail, acknowledging the researcher perspective, and providing thick descriptions. Because of the need to demonstrate clear descriptions of the qualitative research analysis procedures, a documentation form as described by Miles, Huberman, and Saldana, (2014) was developed to provide a clear description of the procedural steps, decision rules, analysis operations, conclusions and comments as a means to support validity of the research methods.

### **Limitations**

This research study had three major limitations: use of purposive sampling strategy, the sensitive nature of research topic, and potential for researcher bias. Purposive sampling allowed the researcher a chance to identify participants with varying ages and years of experience to be able to capture and describe the rich experiences of the home health nurses caring for people with heart failure. The development of a human subjects' protection plan and the Institutional Review Board approval helped support the purposive sampling methodology choice. Casarett (2005) emphasized the need for addressing the need to understand the participant's decision-making capacities specifically when conducting palliative care research. Questions were proposed so as to allow the participant a chance to not have to answer the questions if uncomfortable with the interview due to the potentially sensitive nature of the research questions. This limitation was addressed from two angles. First, the researcher functioned as an insider

by being a member of the group of nurses who specialize in home health care, which enhances the support offered regarding the sensitivity of the issues being discussed. Second, to address the complexity of the interviewer-respondent interaction, the researcher interviewed using a respectful interaction (Merriam, 2009). The researcher sought and found four home health agencies that were 45 minutes to 3 hours' drive from the researcher's home and place of work to assure that the interviewer relationship could remain objective.

Appropriate ethical conduct is a required component of conducting any research but is of a particular concern when investigating the views of those caring for patients at the end-of-life. Researchers should not harm patients and should not cause undue distress when conducting research (Addington-Hall & McCarthy, 1995). Additional respect is needed when delving deeply into sensitive issues (Gray et al., 2000; Seymour & Skilbeck, 2002). Maintaining informed consent helps to address the sensitive nature of this type of research. Allowing patients (or nurses) the opportunity to change their minds and withdraw from research at any time is an imperative aspect in palliative research (Seymour & Skilbeck 2002; Woods, Beaver, & Luker, 2000). End-of-life discussions need to be handled in a sensitive and supportive way while incorporating innovative approaches to help relieve these anxieties (Harris et al., 2008). Research in to end-of life care can be challenging due to the emotionally laden nature of some of the topics. When investigating experiences of being with heart failure patients at the end-of-life, appropriate ethical conduct is of a particular concern. Respect is needed when delving deeply into sensitive issues (Gray et al., 2000; Seymour & Skilbeck, 2002).

Researcher bias can be addressed by demonstrating respect for the participant's experiences and supporting the participants by not imparting researcher beliefs or experiences on the participant. Bias issues can be addressed by using a self-reflection process and providing an honest narrative of the researcher that includes the researcher's background (Creswell, 2009) and having an awareness of researcher specific preconceptions, values, and beliefs (Jacelon & O'Dell, 2005). By spending a prolonged amount of time in the field, researchers enhance validity by having an in-depth understanding of the observations. Performing research in a home health agency allowed an opportunity for in-depth understanding and to address potential bias issues. By offering home health agency nurses a voluntary option to participate in the research helped to address any concerns regarding discussions with the researcher. Bias was also avoided by conducting the research in home health agencies where the researcher did not work, with participants not met before the interview.

The dissertation study offers valuable information that identifies how home health nurses perceive palliative patient care needs, especially during the transition from curative to palliative care. The study was designed to address the role home health nurses play in caring for the population of patients that are living with a life limiting illness who are nearing the end-of-life and needing palliative care or hospice care, which would enhance the quality of patient care.

## CHAPTER 4

### Findings

The primary purpose of this study was to understand the home health nurses' experiences of caring for home health care patients with heart failure during the transition phase to palliative care or hospice care. Describing the awareness or realization that occurs when transitions are required is the contextual essence of this study. The study is guided by the following research questions:

- 1 How do home health nurses describe the experiences of caring for chronically ill patients who are candidates for palliative or hospice care?
- 2 How do home health nurses describe transitions of patient with advanced heart disease from a curative plan of care to a palliative plan of care or hospice?

The research findings from the current study are presented in three parts. First, a description of the sample demographics and characteristics is presented. Second, major themes and subthemes are described. Finally, exemplar quotes are presented in the theme and subtheme sections. Each quote is labeled with the participant's number as assigned by the researcher prior to data collection. No other identifying information about the participant is presented.

Participant demographics were collected using the Participant Demographic Form (Appendix B). After collecting the demographic variables, the researcher began the study by interviewing home health nurses about care they had provided to chronically ill

patients and what these nurses knew about the terms “palliative” care and “hospice” care. These questions helped lead into the semi-structure interview questions (Appendix C) that included in-depth questions to help the home health nurses describe their answers to the research study questions.

### **Sample Characteristics**

Thirty-one nurses consented to participate in the interview process, and during the demographic question review with the participants, one nurse explained that she was a licensed practical nurse. Because the inclusion criteria specified registered nurses, the practical nurse did not complete the interview process. Therefore thirty registered nurses completed the interview process. Sample characteristics are presented in Table 2.

The majority of the participants were Caucasian (27, 90%) and female (29, 97%). The mean age and mean years of nursing experience for participants in the study was 48 and 21 respectively. Of note, 12 (40%) of the nurses had at least 10 years of home health experience. The range of years of experience in home health varied from 3 months to 36 years. Nine of the thirty nurses had a 1.22 mean years of experience in palliative or hospice care. The nurses described their “location” of their hospice and palliative experiences, and noted that these experiences were primarily in-patient or hospital-based units. Sixteen nurses (53%) indicated that they had never received any palliative care education, whereas 14 nurses noted that they had received some education about palliative care. When asked to describe their agency characteristics, the participants noted they primarily worked in home health agencies described as not-for profit (80%), hospital-based (73%), and covered both rural and urban areas (73%).

Table 2

*Sample Characteristics (N=30)*

<b>Variable</b>	<b>N</b>	<b>%</b>
Age (mean age = 48; median age = 49; range = 26-71 years)		
Gender		
Male	1	3%
Female	29	97%
Ethnicity		
African American	3	10%
Caucasian	27	90%
Years of Nursing Experience (mean years = 21; range = 2.5-45 years)		
Years of Home Health Experience (mean years = 11; range = 3 months-36years)		
Years of Experience in Hospice or Palliative Care (mean years = 1.22 years; range = 0 months-7.5 years)		
0 months	21	70%
1-4 years	5	17%
5-7.5 years	4	13%
Received Palliative Care Education (a)		
No	16	53%
Yes	14	47%
Access to a Palliative Care Mentor (a)		
Yes	12	40%
No	18	60%
Home Health Agency (financial) Status		
For-Profit	6	20%
Not-for-Profit	24	80%
Home Health Agency Status		
Privately Owned	8	27%
Hospital Based	22	73%
Home Health Agency Setting		
Urban	2	7%
Rural	6	20%
Both Urban and Rural	22	73%

Note. a. Self-reported estimate from the nurses.

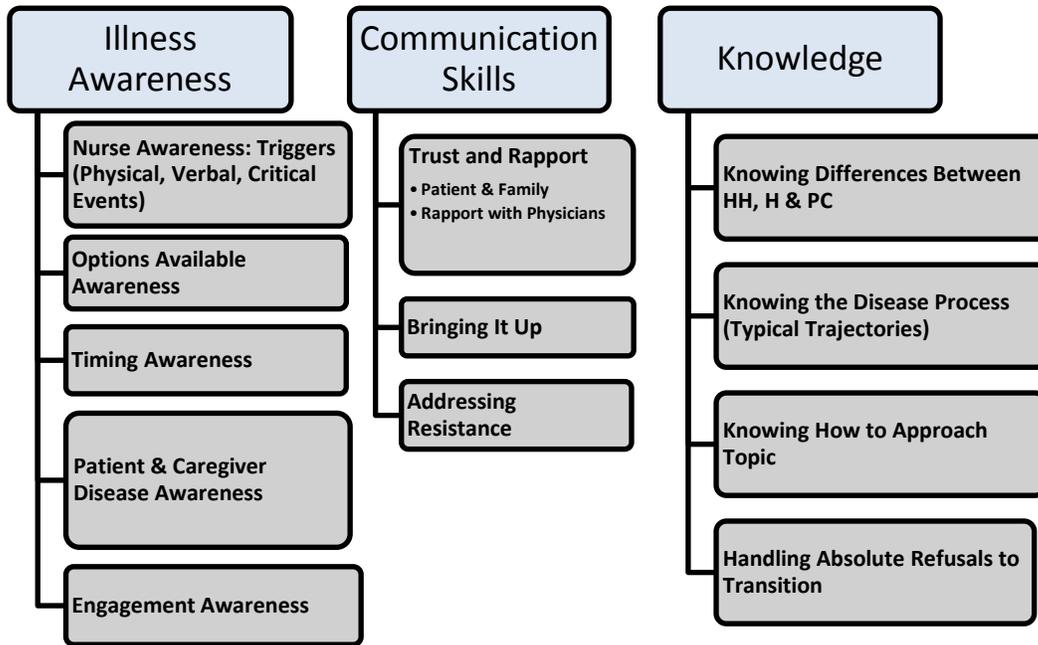
**Description of patient populations served in home health.**

The nurses were asked to identify the type of patient populations with chronic diseases that they currently saw in home health. Twenty-eight (93%) nurses mentioned patients with heart disease or specifically heart failure as a chronic illness they addressed in home health. The nurses additionally mentioned other diseases such as chronic obstructive pulmonary disease (COPD) (18, 60%), cancer (18, 60%), and diabetes, kidney disease or renal failure (23, 77%) as frequently noted diagnoses for patients enrolled in home health programs.

**Themes and Subthemes**

Three major themes emerged from the thematic analysis of transcripts from the interviews, namely: (1) illness awareness; (2) communication skills; and (3) knowledge. These themes were derived from the experiences the participants described from their attempts to help patients transition from home care to palliative, end-of-life care with hospice. Each of these themes contains carefully defined sub-themes (See Figure 1).

**Figure 1. Themes and Subthemes**



In this study the three themes required specific definitions to clearly delineate what the home health nurses were describing.

Illness awareness was defined as the moment when patients, their family members, the nurse or the physician verbalizes or acknowledges they are aware of the degree of illness, or the point where these individuals refuse or acknowledge a patient’s degree of illness.

Communication skill was defined as the nurse’s skill of giving information, exchanging information or ability to connect in order to have a meaningful relationship.

Knowledge was defined as being ready, equipped or furnished in an effort to be ready to deliver care; or having the knowledge required to deliver a specific level or type of care.

These themes developed from specific sub-themes and patterns that are described and defined within each theme. Common patterns became evident during the analysis.

Illness awareness became a dominant theme affecting not only the patient, but also the

three groups that were involved in the patient's care as the patient approached the end-of-life. Those groups included the patient's family members, nurses and the patient's physicians. While other disciplines were occasionally mentioned, the home health nurses primarily focused their comments on the three other roles. These same role opportunities prevailed when the nurses discussed themes regarding communication skills and knowledge.

Because heart failure is viewed as a chronic illness, the nurses were asked about their experiences of caring for chronically ill patients in general to ascertain the complexity of caring for this population in the home environment. The home health nurses mentioned the top two predominant issues for the chronically ill patients -- an unwillingness to change lifestyle, or described non-compliance (non-adherence) with medication regimen, diet, or treatments (n=19, 63%); and a need for patient and family education (n=16, 53%).

The nurses infrequently mentioned other challenges such as symptom management challenges; frequent readmissions to the hospital; progressive deterioration; and challenges with family or caregiver support that become evident when the illness begins to impact patient independence. These elements are broadly explained as issues in caring for chronically ill patients rather than specifically when caring for heart failure disease issues. As such, the nurses spent their time during home visits attempting to address these elements when caring for chronically ill patients.

Twenty-eight (93%) nurses gave examples of their experiences of caring for heart failure patients, and the predominant comments included noncompliance (non-adherence)

(n=11, 37%) with medication regimen, diet, heart failure fluid restrictions, daily weights, and with treatments. The home health nurses noted a need for education about the disease (n=4, 13%) and repeat hospitalization challenges (n=5, 17%). While these comments point to specific interventions home health nurses deliver as they provide care to heart failure patients, the nurses conveyed a level of frustration when caring for this population. Nurse 66 described,

*I have one right now that I, since I have been in home health myself, I've probably had him six times...is one that while we are seeing him, he tends to do well (laughing), because we're, there pushing the compliance and the weights and things like that...what he needs...is someone all the time because as soon as we leave, within about two or three months, he'll be back, back where he was again...in fluid overload and just missing medicines and not doing daily weights and sticking to fluid restrictions and things like that, but he can be the perfect patient while we're seeing him.*

The frustration with the readmissions and repeat home health admissions coupled with the deterioration they were seeing in the heart failure patient's functional abilities warranted a review of the home health nurses' understanding of what hospice and palliative care meant, because they appeared to grapple with the ability to meet the patient's needs. If palliative or hospice care would be a better option for the patient, the nurses would need to be able to identify what it was that the other service options would be able to provide for the patient. Home health nurses would need to identify first if they had the ability and skills needed to provide care to a chronically ill population of patients with heart failure who had reached the point of needing either palliative or hospice care, and second, knowing when to transition to palliative or hospice services.

**Illness Awareness Theme**

Illness awareness became a dominant theme when the awareness theme was identified in 25 (83%) of the interviews with home health nurses. The nurses offered examples of both successful transitions, and transitions that did not occur because either the patient or the patient's family members had expressed a desire to not transition to a hospice agency. Being aware of the need to transition can involve the nurse observing that it is time to transition a patient, as well as the patient, family members or caregivers, and the physician's awareness of the need to transition care to either palliative or hospice care. The theme of "illness awareness" was identified as having subthemes of nurse awareness triggers, timing, disease and options available awareness, change and difference awareness, and engagement awareness that had a distinct repeat pattern that involved challenges found when working with family decision makers.

**Nurse awareness triggers subtheme.**

In this study, the decision was made to describe awareness as involving a "trigger" which is defined as a "lever pulled to release a catch or to initiate – an action" (Webster's New World Dictionary, 2003.) These triggers occurred when the nurses gave examples of specific physical changes, verbal cues (*i.e.* mentioned certain topics), or when the nurse noticed patterns of changes that were happening to the patient that served as a trigger to initiate the need for a transition from a curative plan of care to a hospice/palliative plan of care for a person with advanced heart disease. Three types of triggers for a hospice

referral were identified as, physical triggers, verbal triggers, and critical events (sentinel events).

*Physical triggers.*

The physical changes were described as: vital signs changing – blood pressure, pulse, and respirations; oxygen levels decreasing; weight gain/loss, shortness of breath, death rattle (breathing at end-of-life), unresolvable weakness, decreased level of consciousness.

Healthcare providers notice some of these same physical symptoms are not related to the end-of-life, but may be seen at various stages throughout various diseases. It is important to note that these physical descriptors became clear and were “telling” the nurse, either in combination with knowing the disease progression, or repeated observations of patients, those who were deteriorating to the point of requiring hospice care. It was clear that a nurse would continue to provide home health care to patients until individual features or a combination of these “triggers” were displayed to give the home health nurse the confidence that it was now time to consider having a discussion about hospice with the patient, physician and the patient’s family members.

*Verbal triggers.*

The nurses mentioned that a trigger for them was sometimes when the patient or the patient’s family would begin discussing the need or desire for hospice services. When the nurse would explain to the family or get the family member’s input regarding what a patient used to do as opposed to what the patient could now do, verbal displays of depression, lack of engagement, not wanting to talk, or the patient telling the nurse they

are “ready to go home” (die), “talking to people who have passed on,” and expressing hopelessness or a desire to give up the fight or being tired of fighting, which was sometimes described as a “loss of will to live.” When these topics were brought up, the home health nurses used these topics as a starting point for conversations about hospice care.

*Critical event triggers.*

The nurses identified certain events that helped them decide that a patient was suddenly needing hospice care. The critical events included multiple hospitalizations, multiple home care admissions, the patient’s health history that demonstrated deterioration over time, or the patient becoming suddenly detached. These events were sometimes not singularly the trigger for transitioning a patient, but when they happened in concert with other features noted above, the nurse would then make the leap to starting a discussion about the changes from a curative level of care to a palliative or hospice level of care. The blanket challenge would be to know “when” specifically to have the conversation as the patient or family may be welcoming or unwelcoming of the topic of hospice care.

These trigger examples can be described as the pieces of a quilt that when observed together, represent a pattern that helps the person touching the quilt to feel the “down” or “cotton filling” and see the stitches and intricate details that combine to make a quilt as opposed to a simple bedcover. Single triggers such as a decreasing blood pressure would be similar to a solid blue bedspread that could possibly be managed by the home health nurse. A floral bedspread could likewise be described as having several

components just like a nurse observing increasing pain levels, decreasing oxygen levels, and deteriorating mobility. Although these three physical changes may not warrant a transition, it is with the additional component of a patient describing the desire to die or suddenly becoming disengaged in conversations that adds a layer to the pattern that makes this bedspread suddenly become like a quilt that requires the need for palliative or hospice services. The patterns can be realized over time, when comparing historically what has happened to the patient or they can be realized suddenly when specific instances occur.

Some nurses described how they combined their knowledge of the patient's diagnoses with the patient's vital signs changing or the patient's orientation levels changing. It became evident that nurses had witnessed the pattern when patients had previously improved with treatments and then all of a sudden realized that the patient was not improving or stabilizing. Specific to the home health role, nurses noticed when patients all of a sudden did not want to leave home to go to doctor appointments. The progression of worsening symptoms that would get to the point at which quality of life was deteriorating, or when the nurse noticed that the patient was beginning to suffer -- these represented a critical event trigger for the home health nurse.

***Changes and differences: suffering, rehospitalization, & deterioration.***

The awareness aspect could not be remedied unless the families could be more realistic; for example, if they saw a family member's health deteriorating as described by nurse 69:

*Sometimes the families are more realistic if they see their loved-one really going downhill, and uh a lot of times it's the patient that's a little more uh hesitant.*

The nurses described instances of patients suffering treatment after treatment, in and out of the emergency room, until the patient got to the point of being tired of the process. The ability of home health nurses seeing patients over time provided a clear perspective of the need to be able to observe the changes and differences as the disease progressed.

These examples point to both ends of the spectrum in which family members can support a successful transition or they can be the reason why the transition never occurs. This situation presents a challenge, because of the limited amount of time the patient has to receive hospice care until the time of death. A nurse described an option of “explain it to the patient what they were doing last week and what they are able to do this week” to help heighten awareness for patients and family members to understand the changes and differences between what the patient is doing now versus previously. By seeing the changes occurring when patients all of a sudden would stop eating or drinking was described by one nurse as the “body is preparing to make the transition.” The use of the triggers mentioned previously was deemed useful to the nurses when they began to ponder starting a conversation about hospice with the patient. By witnessing not only the lack of intake, but also the fatigue, wasting, difficulty ambulating, or changes seen in a deteriorating patient, the nurses helped intensify awareness and felt it was a good time to bring up the subject. Sometimes the nurses had a hard time “looking at a patient and saying - you are not going to get any better.” This aspect of witnessing change and differences is linked closely to the ability to engage the patient in a transition.

**Options Available Subtheme: Refusing Hospitalization and Needing****Palliative Care.**

The nurses described an awareness of options that were available when it became clear that the services that the home health nurse could offer were inadequate. One nurse explained that she could see the pattern when a patient was “just exhausted to the core – emotionally, physically, psychologically, spiritually” or when she realized that the patient was not “enjoying things, whatever it was, that they used to.” The need for change became clear to some nurses when the patient would refuse to go to the hospital any more. This would set the stage for the conversation about hospice care. The burden became the home health nurses’ issue when nurses needed to send the patient to a hospital because the nurse could no longer meet the patient’s needs or keep the patient at home with hospice services. Throughout the interviews, the limited access to palliative expertise was mentioned as nurses dealt with situations in which patients would refuse to be transitioned to hospice, yet that left the home health nurse feeling inadequate in the role as the patient’s primary professional caregiver.

The ability to identify the appropriate time to transition required the triggering events or situations, coupled with the availability of various options for the patient to choose from that required an awareness that the patient’s disease status was progressing. These three areas are deeply embedded in the timing challenges related to the physician’s prognosis, best time to transition, and patient and family readiness. The nurses pointed to instances in which hospitals were sending patients home with home health services although patients should have been sent directly to hospice care. These timing challenges

are reviewed in-depth below because they point to the need for the home health nurse to know when to transition. In addition the examples demonstrate that hospital staff and physicians, as well as patients and family members, need to know the best time to transition.

### **Timing Subtheme.**

Timing is a critical component of a transition process because it impacts the patient, family, nurse and physician at different stages. The home health nurses identified that the patient's physician should have an awareness of the patient's prognosis, which would then guide the physician's conversations regarding treatment plans. As discussed in the previous section, the nurses were asked to describe "triggers" that were indicators that it was time to send the patient to hospice. Those triggers helped the nurse decide when to start the conversation with patients and their family members. The home health nurses described the importance of being aware of the best time to have the discussion with patients or their caregivers. The home health nurses had witnessed patients being sent to home health care when the patient should have been transitioned directly to hospice.

Nurse 59 described the hospital staff missing an opportunity:

*when they've had repeated hospitalizations, and this is, we're talking years, and all, they're repeat home health patients that I've had, I've discharged, I've had, discharged, at what point then do you really say...they are more hospice eligible than they are home health?*

Another nurse claimed that the hospital gives the patient an impression they are doing better by sending the patient to home health because previously the patient has

improved, yet the patient was deteriorating and the hospital needed to better explain what was happening.

The timing challenge happened both at the hospital and while receiving home health care. Home health nurses mentioned that family members were “not ready to hear their loved one was dying.” The nurses described hand gestures showing “stop” as they attempted to start the conversation at times when family members would halt the conversation by using this hand gesture. Another timing aspect involved the home health nurse’s belief that the nurse needed to “know the family before you approach with hospice.” This could delay the start of hospice services; if the home health nurse is waiting to bring up the subject of hospice until some later point after a relationship had been established.

One nurse noted that heart failure patients were tired of going to the physician’s office and hospital and the decision to have a conversation with patients experiencing this lack of desire to continue visits or hospital stays resulted in discussions about hospice care. It was mentioned by Nurse 60 that the heart failure patients were particularly a challenge to know when the time was right to discuss care as:

*Sometimes it takes people a really long time, the...heart failure patient in general are tough folks. They’ve got great endurance. They’ve been through so much...and I think sometimes it takes longer to fatigue those tough people than it does...other people.*

This may be a key feature in patients with heart failure who refuse to transition to hospice. Or it may be that nurses and physicians are unable to identify the best time to encourage the transition. The nurses claimed that the advanced heart failure patient would

eventually “get to the point where they don’t really care” which was reflective of the time the patient had spent fighting the battle. Because of this, the nurses mentioned the need to figure out what stage the patient was in.

One nurse used the patient or family members asking about hospice or asking the nurse what the nurse knew about hospice as a trigger. Several nurses mentioned a lack of family support as a trigger when they realized the patient did not have the support to help them remain in their home. It is not surprising that patients are admitted to hospice most often in the last few days or week of life when the home health nurses wait until the patient has blood pressure changes, dropping oxygen saturation levels, or wait for patterns or changes that are only occurring in the final days or hours of life. The patient or family members, and the physician may be waiting for the nurse to broach the topic or may believe the home health nurse is able to offer them everything they need. It is important to note that the home health nurses would connect signs together to make the decision rather than rely on a single trigger similar to the way a quilt is made of patterns and cotton and backing that are bound together, that alone would be just a bedspread, but together, become a quilt.

#### **Patient and Caregivers Disease Awareness: Acceptance and Bouncing Back.**

The nurses mentioned that patients became aware that they were not getting any better or would struggle through other family members being aware of their health status as nurse 53 described:

*Although a lot of times they don't want it, they don't want anyone helping them... and they don't want to talk with their families.... I've had patients that have said "don't tell my daughter, that I'm dying."*

***Acceptance.***

This observation of the difference between those who successfully transition to hospice and those who do not may be linked to how quickly they become aware and handle the shared experiences with family members. The struggle of becoming aware was noted in the example where nurse 58 described that the patient's son was not aware of his mother's deteriorating status:

*he's not seeing how she's withered away, all he sees he's holding onto... "mom has always bounced back, every time she has gone to the hospital, she's always bounced back," and I've heard that so many times.*

***Bouncing back.***

The "bouncing back" issue is the opposite of a hospice "trigger." It adds an additional challenge of bringing a level of awareness to the patient or the patient's family members. Another example of the role of the family in the delay of transitions to hospice is the arrival of family members who lived far away. Because family members from out of town had not observed the physical and cognitive changes, they had not realized how ill the patient was when they arrived. The excerpt from the interview with nurse 61 illustrates this challenge:

*Sometimes people from out of town, have to sort of come in, and see for themselves...when you are out of town, it's hard to believe things have changed, or deteriorated.*

The home health nurse's ability to provide the required care was impacted by the ability to bring up the subject (if allowed) and dealing with families lack of awareness.

The excerpt from the interview with nurse 50 describes the nurse's frustration when the family could not see how illness was negatively impacting the life of the patient.

Additional frustration came when they dealt with family members who would keep saying to the patient they were going to get better when they were not. This situation was described by nurse 50:

*We did have one recently that was renal failure, on dialysis, had really had a rapid decline, family still, um, you know, "oh you're gonna get better..." miserable, miserable, huge pressure ulcers, and finally they did come to the realization that they needed to stop the dialysis, and let her die. She wanted to die.*

There were also instances where the nurse and the family members were trying to convince the patient to go with palliative care because both realized it was time, yet the patient kept trying to fight (to live) as described by nurse 51:

*but he finally got to the point where he couldn't do any of it for himself, but he still felt like he had to fight, and so it was like that delicate balance when you are talking about palliative care, trying to...convince him, maybe you should...and the family trying to convince him... he finally ended up accepting it....He came home, and within a week, he, he was gone. Very peacefully, and he never did have that drowning feeling again was what the family told me.*

The seriousness of the diagnosis was mentioned as a frustrating component to the ability to help family members be aware of the disease's progression. These examples point to the challenges of helping patients and their family members to become aware of their disease state and accept either hospice or palliative care.

**Family decision makers: power, financial, religion and out of town influences.**

A pattern emerged regarding the challenges the home health nurses faced when dealing with family members who had become the care “decision makers”, who were either engaged or not engaged in the transition decisions. The home health nurses cited examples of being challenged by attempting to provide what the patient wanted versus what the family wanted.

***Power Issues.***

Examples of the family members exerting power or control occurred when the home health nurses knew the patient desperately needed hospice care, but the family did not like the word “hospice.” Another situation explained that family members kept the patient on home health service when the patient “could have had an easier death.” The families were able to force their opinions in the instances when the patient had reached a point of not being able to voice an opinion because of their disease state. The home health nurses had to also deal with families who were not in agreement, had no set Power of Attorney, or when they kept searching for another doctor, or another treatment option. One nurse gave an example that a family seemed to back-away instead of coming together because they didn’t feel comfortable and didn’t want to be with the patient when the patient died. While only one nurse mentioned this, the home health challenge of becoming aware of all of the potential reasons why family members may be refusing

hospice, may relate to the fear of the patient dying in the home as opposed to a hospital.

Nurse 44 described the situation as:

*She said I don't want to be here, I was with my father when he passed and I had to have two policemen to lift me up and remove me.*

***Financial Issues.***

It was also stated that the home health nurse had experienced family decision makers who “wanted the patient’s money so they don’t want patient to die,” versus instances or the opposite situation in which they do want the patient’s money, they don’t want the patient to do well. Nurse 44 described it as:

*We come in contact with some family members that don't want their family members to do well and it's sad because they want their money and they're taking that money and while we're there we can see that they're in charge of the check. Oh yes, we see that they don't want them to do well. They want them dependent on them.*

Each of those situations point to the challenges the home health nurses observe when working with individuals in their homes such as a case where other family members may not own the home or may rely on the patient’s social security check that covers the entire family’s needs. As mentioned above, the family challenge was also impacted by the desire to have a patient be dependent on them (family members) or instances in which everybody in the family wanted to control what was happening to the patient, and transition decisions related to control of the patient and the patient’s money. Home health nurses were sometimes dealing with control issues and denial issues when families would concentrate on medical issues that were not going to help the patient, because the medical treatment options provided actions instead of doing nothing. Nurse 46 explained:

*And that's unfortunate, because they could have used hospice long before the last day of their life, and they just hold out, and they hold out...and sometime the families are the ones responsible for that, they are...they don't want to let go of their loved one.*

***Religious influence.***

The belief by family members that “God was going to miraculously heal” or that hospices were giving morphine that killed patients presented a challenge for the home health nurses. Nurse 71 dealt with this in a frustrating family dynamic situation as:

*she fought until the day she died, that God was going to miraculously heal her...and...her family was supporting that...and...I'm a Christian and I believe in miracles, but there is a point where your breast is completely gone, you have a hole in your chest, I can almost see her heart... I think you need to come to grips that this is not, this is not gonna go away.*

***Out of town influence.***

Some family members helped the home health nurse get hospice services started and found that there were instances where the family from outside the area was appreciative of the home health nurse transitioning the patient to hospice. Nurse 59 described the opportunity to involve family to get positive results as:

*but the family is the one that is adamant... but, sometimes they're the ones who help you get hospice...they're like, “no mom, hospice isn't ...kicking you in the casket... they're here to help get things arranged, make you comfortable, let you be at home, so you can transition.”*

Some home health nurses tried various tactics to help the transition by having conversations with the family members before discussing it with the patient because by describing what the nurse was seeing to the family members, that helped them discuss what they had been thinking, but wouldn't say to the nurse or healthcare team. Additional

tactics in dealing with family members included: talking to the person that was in charge, getting them to start talking and getting their feelings out while letting the patient get their feelings out, getting the family positively involved and when near death, strongly encouraging family members to think about hospice/palliative options.

The last aspect of family member involvement as decision makers occurred when the home health nurses described the patient and family members getting upset which was described by the nurses as not wanting to “rock the boat” because if that happened, the home health nurse would not be allowed back into the patient’s home. This points to a unique challenge as home health nurses are viewed as guests in patient’s homes (Truglio-Londrigan, 2013). Additionally unique to home health is the relationship the nurse forms with the family members and the link between staying in the patient’s home as a caregiver because if the patient refused to go to hospice, they would not lose contact with their home health nurses. Nurse 47 described this as:

*Spoke with the hospital representative because they were talking hospice with this patient and she wanted to know how that would affect us and I said, he has a private aide, with us...it won't affect his care at all. He'll still have the aide, um...he won't have the nurse in there and everything, but um... when I mentioned that to the girls, they said the family will never go with that. So, he's probably going to go back home with us.*

Home health nurses develop relationships with patients and their family members, which may be viewed as a positive or a negative challenge when it becomes time to transition to hospice care. This relationship is important because of the potential impact a home health nurse can have on a patient and the patient’s family members. A key aspect of this relationship and how home health nurses get to know their patients over time helps the

home health nurse to become aware and have an ability to recognize when a change or instance means something and care changes are needed.

**Engagement: Full, Partial, or Non-Engagement.**

A key component for successful transitions requires a level of engagement in the process of transitioning. Meleis et al. (2010), described engagement as the degree to which a person demonstrates involvement in the processes inherent in the transition. Nurses would look for the patient and caregivers to seek out information, and actively prepare, while proactively modifying their activities, yet that level of engagement cannot happen when there is no awareness. The examples the nurses gave about engagement followed witnessing patient denial, patients having a fear of the unknown, patients keeping the family members disengaged, and the challenge of dealing with family decision-makers. The home health nurses gave examples of patients who lacked engagement because they faced “total denial” or were “refusing to talk about it” (transition to hospice.) Nurse 49 explained it as:

*Well, I, as soon as they hear hospice, they... “I’m not that sick.” “I’m not that sick”*

It became clear that some home health patients refused to stop treatments or their families wanted the nurses “to pull out all the stops,” which indicates that they were not willing to consider the option of transitioning to hospice care. It would be difficult for the nurses when patients would make statements such as “don’t tell (my) daughter I’m dying,” and the daughter would say to the nurse “don’t tell Mom I know she’s dying.”

The patients and their caregivers or family members could not be engaged in a successful transition when they will not discuss it.

### **Communication Skills Theme: Step-by- Step**

The ability to communicate a need for a transition to either palliative care or hospice became a dominant theme in 22 (73%) of the interviews. The communication challenges noted throughout the theme of illness awareness warranted its own theme as the nurses described not only being aware of what was happening, but also conveying the distress they felt when attempting to transition patients. The first aspect of communication skills as a theme involved the need for the nurses to build a level of trust before starting the conversation. The nurse needed to have good rapport that could either make or break the ability to communicate successfully with patients and their family members.

#### **Trust and rapport.**

The nurses used a sequential process such as building trust and rapport, initiating the subject, and working through resistance. The step -by- step process included a preliminary need to build trust and rapport with the patient and family members; the ability to bring up a difficult subject and the communication skills needed when meeting any resistance from the patient, their family or the physicians when the nurse wanted to transition the patient to hospice or palliative care. Nurse 69 described trust and rapport as:

*It's when you develop a rapport with your patient, when you case manage or people you see in your own territory...you can keep your finger on their*

*emotional pulse, and.... you can talk to them, hopefully, you've built up a level of trust where you can talk to them about things like that.*

***Rapport with physicians: gracefully done.***

A key aspect of communications involved 18 (60%) of the nurses having a discussion with the patient's physicians. There were also instances where the nurse was also unable to have a conversation with the patient's physician because the physician was refusing to consider hospice. This presented as a challenge for the home health nurses who would then be forced to rely on their supervisors or friends at local hospice agencies to give them ideas regarding how to continue caring for a patient. These instances were situations where the patient was having severe uncontrolled pain, or such severe symptoms that the home health nurse could not manage, yet the patient or physician was refusing to transition to hospice or the patient was unwilling to go to a hospital. Nurse 50 explained:

*(Patient refused to transition to Hospice) We did the best we can. I did have one patient that... was a pain issue, and I called a hospice nurse to ask them, cause the doctor didn't know what medications to order, and I asked them like, okay, well, what do you use generally speaking, and... they told me about the sublingual Ativan, and the whatever else was available.*

The home health nurses communicated with anyone they could find that could help them in these situations. One home health nurse described the discomfort of bringing up the topic of hospice care with patients because she felt it was not her responsibility to bring up the topic. She believed only the patient's physician should bring up the topic of hospice care yet she had asked other home health nurses and they had informed her that it was a function that the home health nurses would need to perform. Nurse 74 described the challenge:

*I almost feel like it would be inappropriate for me right now, to come to my congestive heart failure people and say hey, are you familiar with hospice and... it seems like that first step ...should... some part of me it feels like it should come from the physician, but I've spoken with other nurses about that and they say "well it's not going to, it's going to be you."*

Nurse 51 described it as requiring "graceful" communication skills:

*we are working with(a patient), for months, the diuretics are failing, the blood pressure medicines are failing for example, in a heart failure patient, my...I think my biggest tool is to facilitate as much open communication between the patient and members of his healthcare team, as much as possible, especially, his doctor, so that when the time comes to order hospice, the doctor doesn't give us any problems, it's just a smooth transition, and, and, um, it's gracefully done. And, I mean the word gracefully done, and everything that word means both in religious terms and in logistical terms, um, that's gracefully done.... So, it starts with the communication between everybody.*

One home health nurse was adamant that it was not her place to bring up hospice while other nurses explained they would wait and let the patient or family members bring it up before they would do so. Other home health nurses would see the need and would begin to discuss the topic of hospice care. It became evident in the examples the nurses gave that they had a varied ability and desire to communicate the topic of hospice or palliative care options to patients.

### ***Bringing it up.***

The next step of building a relationship would involve asking questions in a sensitive, thoughtful way such as "what are we trying to accomplish here," which would start the conversation. Nurse 51 explained:

*I have had many occasions where in my career where I've had to ask people... "where do you...tell me what you know, what has the doctor said to you, about what is going on with you, where do they tell you where you are going with this, what are they trying to do?" Um...then I ask what are we trying to*

*accomplish here, are we trying to make sure this doesn't happen again, are we trying to make sure that we are comfortable, you know, and that's kind of how I get into the whole discussion.*

Having the skill of bringing up a difficult topic appeared to be easier for some and very difficult for other home health nurses. The nurses would give patients and/or family time to consider it, discuss planning for the patient and their future, and some would describe the conversation as starting by saying “home health may not be the best option.” The tactic of bringing up the need to transition in a repetitive fashion meant the nurses would “bring it up over and over.” When the home health nurses would “bring it up,” they would discuss: Prognosis, what to expect, advance directives, and would tell the patient that the nurse and the doctor had spoken which demonstrated collaboration between the physician and the nurse to the patient. The collaboration appeared to help the patient know that a nurse was not making this decision singlehandedly, but was sharing the patient’s status with the patient’s physician. The home health nurses would also spend time “planting the seed” that a hospice transition was appropriate. Nurse 71 described the challenge as:

*you get the non-verbal cues where they're uncomfortable, or they don't want to talk about it and I understand that, but ....we try to open the door and plant the seed so at least they know that it's there...*

The nurses described the importance of taking it slow (quiet and easy, with “no panic”), and would “let them [patient] take control.” This would lead to the nurse asking more questions, finding out where their comfort was (what the patient said they wanted at the end-of-life); and asking questions to determine if they realized when they were or would be tired of fighting.

***Resistance.***

Resistance became a sub-theme as the nurses told stories of patients who would not entertain the option of transitioning to hospice care. The nurses described how they struggled to communicate with patients or their family members when trying to overcome the adamant resistance to a transition option. The nurses felt a need to help the patient see reality by letting them weigh pros and cons of going with hospice and communicating the ups and downs and how the disease process would end for their specific chronic illness. A method of addressing the resistance unfolded in the interviews when the home health nurses would ask the patient and family member if they could bring in the “hospice experts.” When the patient or family would refuse to allow the hospice expert into their home, the nurses did a side-step as their next option to address resistance. Some of the home health nurses chose to communicate that death may be escapable if the patient is one of the few who could “graduate” from hospice to be able to no longer need hospice’s services.

Another communication challenge that leads to distress in home health nurses in the transition to hospice is trying to not mislead patients by offering the patient a level of “hope”—when convincing patients to go to hospice care. For example, the nurses would use phrases such as “there is a possibility of graduating” from hospice, as a way to entice the patient to transition to hospice, or “bridging” the world of home health and hospice to communicate to patients and their family members so the engagement process could begin. Nurse 66 described a communication challenge affecting a patient’s continued treatment in home health as:

*I don't want to completely discourage their hope, but you know, I think a lot of them feel like if you go to hospice then you have given up.*

Resistance could be handled if the nurse had the required skills and knowledge of examples that help patients transition. The nurses described instances where absolute resistance was met even though they had the required background and they still could not get the patient or family to transition. Combining the communication skills of bringing up the topic to begin with, along with the ability to address absolute resistance appeared to affect both the very experienced and limited home health experienced nurses.

### **Knowledge Theme**

The ability to communicate after becoming aware of the need to transition patients to either palliative or hospice care depended on the home health nurse's knowledge of not only the disease process or trajectory, but also the options to either treat the patient or transition the patient to a more appropriate care option such as hospice or palliative care. These knowledge issues were mentioned by 23 (77%) of the home health nurses. The knowledge themes were delineated into 4 sub-themes: (1) knowing the meaning of hospice and differences between home health, hospice and palliative care; (2) knowing where the patient was in the disease process; (3) knowing how to bring up the transition topic; and (4) knowing how to deal with absolute refusals to transition to hospice or palliative care.

**Knowing the differences between palliative care and hospice care.*****Hospice meaning and “death angels.”***

The home health nurses were asked what the term “hospice” meant to them. The common features included end-of-life service or care for 27 (90%) of the nurses who described hospice as “no more treatment, or less than six months to live.” Sixteen (53%) of nurses mentioned support (physical, emotional, spiritual), and comfort care as key aspects of hospice care. It is important to note that the home health nurses did not always mention each of the key aspects of hospice care and some made comments regarding how palliative care and hospice care are the same thing or they had difficulty separating palliative care from the term or services offered in hospice care. Being able to explain a service such as hospice or palliative care, would be important if a nurse would be attempting to transition a patient to a different level of service. When faced with a difficult transition to hospice care, the home health nurses shared their success stories and their frustrations. One such example came when the home health nurses had to address home health patients refusing to transition because patients were claiming that the term “hospice” = (equaled) death as a consistent reason why patients were refusing to transition to hospice care. The definition of hospice care includes the “end-of-life” component, but the nurses were facing a challenge of trying to transition patients to hospice care when patients or their family members expressed beliefs that hospice in and of itself hastens death and the frustration of patients waiting until the last few days of life to transition. Nurse 47 explained it as:

*I just think, I think people think hospice is a death sentence, you know, and it's really not.*

The belief that hospice caused a more imminent death due to the brief time that patients got to spend receiving hospice care, is consistent with published data related to the length of time hospice is able to spend with patients before they die. The home health nurses had heard patients calling the hospice nurses the “death squad” or “death angels” that they did not want to see because they felt they would be viewed as “giving up” as opposed to their desire to stay positive and hopeful while “fighting to live” which was perceived as not being an option when signing up to receive hospice care. Nurse 70 described the difficulty as:

*When, when you start to talk about it, they turn the conversation right off...so you know, you don't go anywhere with it, but they know it's there, everybody knows hospice exists...um, but I don't know if it's, if it has a reputation from when it first started...um, somebody referred to it as death angels to me, in a visit once.*

Because of these perceptions, the nurses were not able to influence the patient or their family member's decisions and they kept treating the patients in home health. In an effort to deal with the meaning of hospice = death, two nurses identified an option they had developed to tell patients they had known other patients that had “graduated” from hospice care as a way to help patients view hospice in a more positive light. Nurse 48 described why she used the concept of offering hope to patients to address the resistance to transition:

*I'm able to say “you know, we've had patients who have graduated from it” and...it changes their demeanor.*

Other nurses explained the discomfort they had experienced while trying to either explain hospice services or attempting to convince a patient that hospice could better

meet their needs than home health could. Some of the participants in this study had observed the challenges of getting patients to transition to hospice and had started programs that would switch out some of the home health nurses' visits with hospice nurse visits in an effort to be able to bridge the patients from home health services to hospice services. Nurse 54 described the program as being developed because:

*So we thought if we sort of get that in-between thing and have them see that these hospice nurses are not angels of death, kind of thing, and what they can offer...because people don't even know what hospice offers. They don't know anything about that.*

The home health nurses also did not consistently convey confidence in being able to respond to the reasons patients were giving them as to why they would not allow a transition to hospice or a visit by a hospice nurse. These statements demonstrate a lack of knowledge these nurses had when it became time to address these situations and explained the reasons alternative options were developed.

### ***Palliative meaning and chasing the "cure."***

The term "palliative care" was described as comfort, pain management, symptom management, with a focus on quality of life. Some of the nurses described palliative care as not being end-of-life care while other described it as only occurring at the end-of-life. Some home health nurses claim that the term "palliative care" meant that the patient was not doing aggressive treatments or we are "not trying to cure" patients while other nurses explained that palliative care was continuing treatments and was "for people that don't want to give up on somebody yet." The nurses varied from describing palliative care as being the same as hospice or described palliative care as a "stepping stone" or "the next

level down” before getting to the point of needing hospice care. Because the nurses offered a variety of answers to the meaning of hospice and palliative care, it is important to ensure a clear understanding of the differences between palliative care and hospice care if the nurse is unable to transition a patient to hospice care, yet would qualify and benefit from palliative services.

The nurses either used their knowledge to embrace their teaching role and handled the conflict that arose from the discussions or if they were unsuccessful in transitioning a patient, they dealt with the situation by bringing in hospice nurses, designing or participating in bridge programs or they kept the patient in home health and continued providing care until the patient died while receiving home health.

***Home health nurses need training on hospice and palliative options.***

As the home health nurses explained their comfort or discomfort with either providing care or bringing up the topic of hospice or palliative care, they provided confirmation that they had a fear of not being comfortable with the topic or they expressed that they were not well trained to know when to bring in hospice or palliative care or what these services could offer to patients. Nurse 62 explained:

*I don't know much about hospice care at all just to be honest with you...as far as what they do when they go out there.*

Nurse 65 explained:

*Once in a while, we'll get a referral, on a patient that is not ready to accept hospice, that they'll ask us to do palliative care. So we try to do that, but we haven't had any really training on that, you know, like as far as it would be good to have a training session in home health on palliative care.*

These examples point to the home health nurse's ability to know which service options would best be able to meet the patient's needs. Coupled with knowing the differences between these options is a need to know the disease procession status and the signs when home health would no longer be able to best meet the patient's needs.

**Knowing the disease process subtheme.**

Home health nurses caring for chronically ill patients can expect to eventually reach the point of being in a position to help these patients realize that the patient is no longer responding to treatments; the patient has reached the point of no longer wanting to continue treatments; or the patient has deteriorated to the point that would set a course towards a need for palliative or hospice services.

**Knowing how to approach the hospice topic subtheme.**

In order to be able to communicate with patients, their family members and physicians, the nurses gave examples of their need for an ability to know the differences between home health, hospice and palliative care. They also recognized the need to know how different diseases progress so they would know when to bring up the topic of transitioning to either palliative care or hospice services. This theme emerged with a link between the awareness theme and the communications theme but the limitations expressed by the nurses focused on their limited knowledge of how to tackle knowing when to bring it up, knowing the home health nurse's role in broaching the topic, knowing terms that other nurses had used with success in transitioning patients, and knowing how to grapple with their own fear of talking to patients about hospice or death.

***Knowing when: The train at the end of the road.***

Nurse 51 mentioned “I kind-of wonder where that train is headed” as a point when hospice should be considered in a patient's disease process. Having a foundation of knowledge regarding the best time to have a discussion rose up as an area of knowledge that the home health nurses sought. By being able to link the disease progression with the resulting observations, statements made by family members or patients, and the combination of specific behaviors such as repeat rehospitalizations could improve the nurses' ability to know when to begin the conversation regarding transition options.

***Knowing the home health nurses role.***

The home health nurse owns the responsibility of clarifying for patients and their family members when they have misinformation or limited information about hospice or palliative care. Additionally, the home health nurse is in a prime position to start the conversation as nurse 51 explained:

*Sometime you feel like you are going out on a limb, but, I think patients and their families don't want to bring it up, but they are willing to talk about it if somebody else does, more than two-thirds of the time.*

***Knowing success topics.***

These nurses gave examples of terms or questions they would ask that would start the discussion regarding the patient's situation that ultimately resulted in a successful transition to hospice care. Examples of how home health nurses had learned how to use these different questions and topics became clear as the nurses conveyed how successful they had been in transitioning patients without challenges. Those questions and topics

were repeatedly used by home health nurses with success such as the topic of letting the patient know what the nurse was seeing as “I’m noticing this...,” to help the patient, family members or physicians become aware of the patient’s deteriorating status or as nurse 50 explained:

*A lot of times, you have to wait. And you have to provide more of a listening ear, than anything else, because they do want to talk to you, more than half the time...I’ve (come) up with that phrase “what goals are you trying to accomplish” because then that gets them thinking, “what are we really trying to do here.”*

***Overcoming the fear of talking to patients about hospice or death.***

If a home health nurse has a fear of approaching a patient about transitioning to hospice care as noted by the nurse below, the nurse would need to learn how to overcome that fear as it is a topic that home health nurses will end up needing to discuss. The nurses also described a need to know how to approach a patient that feels like they are “giving up,” while addressing the home health nurse’s goal of not wanting to discourage “hope” for patients who still have hope. The ability to talk to patients about death or the dying process is an additional challenge for home health nurses who experience discomfort with the topic. Nurse 55 described the fear that nurses have when needing to approach the topic of hospice care or have a discussion with a patient about the end-of-life:

*some of our nurses are not comfortable talking about hospice. They don’t want to talk about death and dying. You know, home care is about...making you better. And we want to see everyone get better. Hospice is what you know about the final result is in a hospice, you know what it is. And we do, we have a lot of staff who...for either personal or other reasons don’t want to talk about end-of-life. It’s hard to do sometimes.*

A nurse described knowing how to approach a patient, as “feel a patient out” before having the full hospice conversation. This would help the nurse identify if the

timing was right and if the patient might be in a better place of acceptance. The claim that “some of our nurses are not comfortable talking about hospice or end-of-life/death/dying,” serves as a clear indication that we cannot begin to impact the volumes of patients who are arriving too late to benefit from hospice services if home health nurses are not having the conversation. Nurse 58 explained:

*Another fear we have is that a lot of nurses are not comfortable talking to the families about hospice, to raise the awareness of the physician this is what's going on, this is what I'm seeing, this is what's happening with the patient, that we need to move them over to hospice, a lot sooner, but it always end up being a lot later and at the end at the last minute.*

#### **Handling absolute refusals subtheme.**

Examples described by the home health nurses regarding patients that were refusing to transition posed a complex problem for the home health nurse. The options described were to learn ways to turn patients and their family members away from their negative views or refusal to transition, continue to keep the patient in home health even though the patient would clearly benefit more so from a transition to hospice care, or to learn how to provide the palliative care the patient needs. The patterns that arose were to overcome the barriers to hospice care options, to stay with the home health option, or to offer palliative care services to patients receiving home health care. Nurse 62 explained the outcome of an absolute refusal to transition to hospice care as:

*Well, you know, there's a lot of those, (refuse to go to hospice) there's probably more of those than I got to go, but as I said there's that fact that they are dying... (so what did you do?) We just continued to see them, until they die.*

***Overcoming hospice care barriers.***

Some of the barriers of transitioning home health patients to hospice was the lack of knowledge patients have about their disease process, what hospice does and what palliative services are available to home health patients. Nurse 46 described it as:

*all of us nurses have been in the field for so long, that we know about palliative nursing, and end-of-life issues, and um, how to steer patients in the direction of what they need...um, many times they are not willing to go to hospice yet, um, but we have to give them that opportunity and educate them, so they know what hospice is...*

During the course of the study, participants stated that there comes a time when home health is not able to offer the skills and services that hospice can provide, such as expertise in symptom management. If a home health nurse believes that s/he is not lacking the skills or ability to care for a hospice-eligible patient, the nurse may not transition a patient or may do so too slowly. Nurse 72 explained how a patient refused both palliative services and hospice care which forced the nurse to keep the patient in home health to receive services:

*No...I um, I tried really, really hard with one of my MS (multiple sclerosis) patients... they were not very receptive to it, they, the palliative care in and of itself, they, they were flat out refusing hospice, so I was trying the palliative care...as a kind of in-between...that did not pan out...she did not want that.*

***Stay with home health option.***

The nurses gave examples of patients having such severe pain or debilitating symptoms, they needed to call their hospice friends to ask them what to do because they were in the difficult spot of caring for patients who were unwilling to transition to hospice care. This matches the examples where the nurses described the need for better

education for home health nurses to be able to spot and know what they are seeing and for the physician to be able to believe what the home health nurse is describing. The nurses described that home health nurses can't do quite as much or as extensive a service as hospice nurses and claimed "we get referrals to do palliative care – yet no training." Home health nurses need to have a clear understanding of the differences between palliative care and hospice care as well as the appropriate time to provide a patient with both levels of service and additional training on ways to handle the absolute refusals.

To address the challenge of patients and their families refusing to transition to hospice care, some agencies have developed a "bridge" programs so the in-house hospice agency could send a hospice nurse in to do a visit once a week while the patient's home health nurse continued to see the patient once a week. This presents as a problem for agencies that do not have their own hospice in-house. Nurse 51 tried to use a bridge program that was available to her agency, yet the patient refused to even try that option, instead choosing to stay with home health.

*they have a bridge program that they do refer people to, but sometimes that doesn't always work or the family refuses,*

A common goal for home health nurses is to identify ways to alleviate pain and suffering.

This goal cannot be met when situations such as the one described by nurse 71 was occurring:

*it was just really, really horrible, because no matter what I tried, even going to the doctor, she would refuse to see the doctor...the doctors are saying there is nothing we can do... and I wanted her to have hospice...she couldn't do anything...and she had to be in just horrible pain, but she never took a pain pill or anything....She just, she just suffered all the way to the end...and...finally, finally... her son had her go to the emergency room, or had the rescue squad to*

*come and get her...and then when they discharged her, they discharged her to hospice...and then... she was with hospice one day, one day...and that was it.*

***Offer palliative care services.***

When a patient refuses hospice services or even palliative care specialist services, the only option that is subsequently available to the nurse is the option of keeping the patient on home health service. There is an option of discharging the patient, which would then leave the patient with no healthcare services if the patient is unable to get to a physician's office, clinic or other outpatient service, or the patient could go to a hospital for the required care needs. An option that was mentioned by the nurses was the option of using the palliative team at the hospital for support, finding oncologists that might help or developing a physician or nurse practitioner home visiting program that can come in to offer palliative care support to the home health patient. The nurses had asked for hospice consults as one avenue but this was not an option if the patient would not allow the hospice nurse to come into the patient's home. A final option mentioned was to train the home health nurses to offer palliative care services in instances where the patient needed but refused hospice. Nurse 46 described having knowledge because of years of nursing experience as:

*Well, we work with more than one hospice, um, we don't really have a palliative team, although, all of us nurses have been in the field for so long, that we know about palliative nursing, and end-of-life issues, and um, how to steer patients in the direction of what they need.*

This would require that all home health nurses have the knowledge and skills to manage all aspects of palliative care. If patients refuse to transition, home health nurses have resorted to calling the local hospice agency staff to learn what to do to be able to address

the patient's needs in situations that exceed the home health nurses expertise. Nurse 50 developed a "work-around" to a patient situation where the home health nurse did not have the knowledge or access to the medications that the home health patient needed by calling a hospice nurse to ask what medication to order.

The chronically ill research questions were answered through the findings noted above as the nurses gave examples of their experiences that demonstrated the additional challenges of managing care for heart failure patients. Patients with advanced heart failure suffered specifically from difficulties such as disease progression, timing challenges because of the improvement and decline fluctuations, frequent rehospitalizations, desire to "fight" versus losing "hope" issues versus "unwillingness" to change detrimental health behaviors, fear of hospices not treating them medically, the inability of home health agencies to offer emotional support the same as hospices can, and lastly, challenges because of the strong relationships the heart failure patients have developed with their home health nurses. Any patient unwillingness to change behaviors or potential situation where the home health nurse might diminish hope for this population serves as a critical juncture for advanced heart failure patients. By offering palliative options to this population as a bridge before transitioning to hospice may ease the transition as the option of continuing treatments for advanced heart failure patients is a reason the home health nurses explained as to why these patient will not accept hospice services until the very end. If physicians are not able to make home visits, or nurse practitioner or other bridge type programs are not available, the home health nurses would need to know how to offer a palliative level of care.

### Findings Summary

The three themes from the data analysis resulted in the themes of illness awareness, communication skills, and knowledge. The purpose of this study was to describe the home health nurses' experiences of caring for home health heart failure patients during the transition phase to palliative care or hospice care. The awareness or realization that occurs when these transitions are required is the contextual essence of this study. Nurses with this awareness answered questions asking how they described the experiences of caring for chronically ill patients who are candidates for palliative or hospice care. They also described transitions of patients with advanced heart disease from curative care to a palliative care or hospice. The thematic map was used to identify patterns and resulting subthemes that produced the following themes that became evident in the transition to hospice.



These themes were identified for both chronically ill patients and patients with heart failure in the examples the nurses described as they attempted to transition both heart failure patients and other chronically ill patients. Table 3 contains examples of each of the three themes with the definition of the theme and subthemes with exemplars that played a role in the choice of subtheme headings.

Table 3: Themes, Definitions, Subthemes, & Exemplars

THEMES	DEFINITION	SUBTHEMES	EXEMPLARS
Illness Awareness	The moment when patients, their family members, the nurse or the physician verbalizes or acknowledges they are aware of the degree of illness or the point where these individuals refuse or acknowledge a patient's degree of illness.	Nurse Awareness Triggers	“Frequent hospitalizations, without really getting a benefit from that hospitalization, reworking their cardiac medications, (Lasix, Bumex, and diuretics) and not having any effect from those.”
		Options Available Awareness	“there’s a palliative care team that’s in the hospital, but...home care doesn’t have access to that palliative care.”
		Timing Awareness	if you have cancer, I think you come to a ...realization...that you’re going to need some help, but...with heart failure people, I think it...takes a little longer...to get to that fatigue level.
		Patient & Caregiver Awareness	“mom has always bounced back, every time she has gone to the hospital, she’s always bounced back.”
		Engagement Awareness	“as soon as they hear hospice, they...“I’m not that sick.”“I’m not that sick.”
Communication Skills	The nurse’s skill of giving information, exchanging information or ability to connect in order to have a meaningful relationship.	Trust and Rapport	“when you develop a rapport with your patient, when you case manage...you can keep your finger on their emotional pulse, and... you can talk to them...you’ve built up a level of trust where you can talk to them about things like that.
		Bringing It Up	“you get the non-verbal cues where they’re uncomfortable, or they don’t want to talk about it and I understand that, but ...we try to open the door and plant the seed”
		Addressing	“I feel like a lot of people do

		Resistance	<p>have negative...feeling about what hospice is. I had a patient that was... end stage heart failure and he...died at home with home health care...but, I was trying to get him to go to hospice because that was what he needed, but...his family refused... because she said that hospice would kill him.</p>
Knowledge	<p>Being ready, equipped or furnished in an effort to be ready to deliver care; or having the knowledge required to deliver a specific level or type of care.</p>	<p>Knowing Differences Between Home Health, Hospice &amp; Palliative Care</p>	<p>“I’ve...still never been crystal clear on the difference between a patient who is receiving palliative care versus hospice care, unless we are strictly speaking hospice guidelines for Medicare...I, I honestly don’t know.” Or “I don’t know much about hospice care at all just to be honest with you...as far as what they do when they go out there.”</p>
		<p>Knowing the Disease Process (Typical Trajectories)</p>	<p>“Another fear we have is that a lot of nurses are not comfortable talking to the families about hospice, to raise the awareness of the physician this is what’s going on, this is what I’m seeing, this is what’s happening with the patient, that we need to move them over to hospice, a lot sooner, but it always end up being a lot later and at the end at the last minute.”</p>
		<p>Knowing How to Approach Topic</p>	<p>“I’ve always been hesitant to push too hard...when a patient resists...I make the information available...but, because there is such a bug-a-boo about the subject of palliative care and hospice care...if I have a sense that they are putting a wall up and shutting it down, I wouldn’t</p>

			push.”
		Handling Absolute Refusal to Transition	“it breaks your heart when you are trying to get a patient somewhere and they need something that you know ...somewhere that they can go and get it, and they, or their family, are still in denial, and they won’t do it, and then a week later...they are gone from here, and nothing has been resolved... so they die under home care.”

Illness awareness was defined as the moment when patients, their family members, the nurse or the physician verbalizes or acknowledges they are aware of the degree of illness or the point where these individuals refuse or acknowledge a patient’s degree of illness. This encompasses patient and family members, as well as nurses and physicians as the disease status progresses and the home health nurse was able to notice the changes and differences the patients were experiencing as they approach the end-of-life. The timing of the conversations regarding transitioning to hospice care coupled with having patients and family members fully engaged resulted in successful transitions or highlighted how these issues contributed to unsuccessful transitions. Family decision makers and patients struggled with hospice terms and beliefs as they sought out other treatments and physicians who could hopefully “cure” the patient.

Communication skills were defined as the nurse’s skill of giving information, exchanging information or the ability to connect in order to have a meaningful relationship. The nurses were skilled at developing trust and rapport with their home health patients, yet struggled to communicate with patients, their family members and

physicians when it came time to bring up the subject of transitioning to hospice care. The additional challenge of addressing the resistance to transition came to light when the home health nurses verbalized examples of transitions that occurred or were fraught with problems that ranged from patients suffering, to family members going against what a patient would have wanted if the patients had been able to speak for themselves.

Knowledge was defined as being ready, equipped or furnished in an effort to be ready to deliver care; or having the knowledge required to deliver a specific level or type of care. The nurse's lack of knowledge and its negative impact on the transition to hospice became evident throughout the study when the nurses gave examples of lack of knowledge of the disease trajectory, when to transition patients, and baseline service rules related to hospice and palliative care. While the participants provided examples of successful transitions and highlighted effective communication skills, the nurses expressed a fear of addressing the topic of dying and the need for transition conversation training, especially with patients who refused transition to hospice. In Chapter 5, the researcher will present the discussion and implications for clinical practice, research, and policy for each of the themes.

## CHAPTER 5

### Discussion

#### Transition Themes

The results of this study demonstrate the role the home health nurse plays in the care and transition process for patients at the end of life. A complex pathway became apparent through analyzing the findings. The thematic findings included (1) illness awareness for the nurse, patient, family members and physicians; (2) communication skills required by home health nurses as they attempt to transition patients; and, (3) knowledge requirements the home health nurses need to be able to enhance a patient's successful transition or keep the patient in home health.

These three themes dominated, yet specific aspects were identified before the home health nurse could move to a transition discussion with the patient, family members or physicians. Aspects of the transition process included knowing the differences between hospice, palliative, and home health care to address changes in health status and when to continue or end treatment options. Johnson and Slaninka (1999) identified knowledge deficits or inaccurate perceptions of hospice care as key barriers to getting patients into hospice care. The current study identified examples of home health nurses dealing with inaccurate perceptions of hospice care verbalized to them by patients and family members. The nurses also described their own knowledge limitations regarding the differences between home health, hospice and palliative care. The ability to address changes in patients' health status requires knowledge of typical disease trajectories. A

home health nurse cannot be expected to transition a patient to hospice if the nurse is not aware of the changes occurring that are causing the patient to be a candidate for hospice.

The three major themes were identified in this study as a result of examples given by the home health nurses about not being aware of the full or accurate definitions of palliative and hospice care, how these entities differ, and when each entity should be offered to the patient. Hospice services would also need to be available in the area where the patient lives. Then next key aspect would require the home health nurse to be unable to meet the patient's needs. The home health nurse would need to know what care and services hospice should be providing to the patient compared to care and services the home health nurse could deliver. Results of this study show the transition "reason" of moving a home health patient from a curative to a palliative or hospice phase was not viewed as a sole reason to make a transition. This is an important finding, because the home health nurses were not using the physician's prognosis, or medical treatment model of care as a deciding factor for the timing aspect of transitioning a patient to palliative or hospice care. Instead, the nurses considered a complex web of factors, involving the patient, family, services available, and system factors as part of assisting the patient and family to make a decision about transition.

The path to palliative care became a challenge for home health nurses interviewed in this study. The nurses had limited examples of being able to use palliative specialists and they described limited access to such services for patients in home health. However, McIlfatrick et al. (2014) identified that there was a preference for and an expectation that palliative care would be provided at patient's homes. This study is the first home health

study to give examples of the challenge that home health nurses faced when patients refused to transition and asked to remain in home health as they reached the end of their lives while receiving home health care.

### **Pathway to Hospice Care**

The research questions for the present study focused on two components of home health nurses care: (1) descriptions of the experiences of caring for chronically ill patients who are candidates for palliative or hospice care; and (2) approaches used by home health nurses in facilitating transitions of patients with advanced heart disease from curative care to a palliative care or hospice. Hospice transition examples were sought, because there would be a natural transition to hospice if the home health nurses were able to identify the patient's illness trajectory. A decision to focus on patients with advanced heart failure was made because those patients experience significant and often dramatic fluctuations in health status over short and long periods of time. Some exacerbations can be managed with treatment, yet patients ultimately reach a point at which the treatments no longer reduce symptoms or manage the disease. Results of this study were summarized in the following themes that capture the essence of the experiences of nurses describing the challenges of assisting patients to transition to palliative or hospice care: illness awareness, communication, and knowledge.

Results of this study show that these three themes required a level of awareness, as well as the knowledge and ability to communicate transition needs, before the patient could transition to either hospice or palliative services. Illness awareness was described

by the nurses as being aware of “triggers” that used the home health nurses’ observation skills, statements made by patients, changes and differences, as well as being aware of the time when the conversation should occur. The key aspect here appears to be the trajectory of the chronic disease that links awareness with knowledge and communications skills so there can be a smooth transition. Awareness was a prominent theme that linked to the communication theme and knowledge theme as nurses attempted to transition patients to hospice care.

### **Chronic Disease Management in Home Health**

Because the health care system in the U.S., and thus home health care have typically focused on the provision of care with a curative focus, it was apparent to these nurses that the chronically ill population continued to seek treatment until they reached the point at which the treatments were no longer working. The IOM (2014) report identified that the top ten causes of death were linked in some way to chronic health problems. Additionally, heart disease was the most common cause of death (Heron, 2013) for the entire population of individuals that had died. Because home health nurses are caring for patients with the most common chronic diagnoses -- heart disease, COPD, cancer, and diabetes, kidney disease or renal failure as well as many other chronic illnesses -- the added complexity of caring for this population in the home environment presents its own challenges. The challenges the home health nurses described in this study were patients’ unwillingness to implement lifestyle changes such as medication regimen, diet, or treatments, coupled with the need for education about disease management. The unwillingness to make changes in lifestyle was deemed frustrating for

the nurses, and they gave examples of shortened life-spans because of this problem. These nurses exhibited an awareness of a disease trajectory and based observation skills of similar patients with the same diagnoses, and thus recognized that patients would deteriorate.

Because of the fluctuations of health status characteristic of heart failure, the home health nurses described the potential shortened life-span along with the additional challenge of rehospitalizations. The home health nurses gave examples in which patients were better able to follow medical therapies because of assistance of the home health care nurse. In such a situation, the nurses would need to be able to identify the best service options for the patient. Hospice can only be involved as an end-of-life service when no more curative treatments are available and the patient has less than six months to live. This is a major reason why home health nurses may not be considering hospice until the last few days or weeks prior to death.

The home health nurses interviewed in this study described the support (physical, emotional, spiritual), and comfort care that would be offered by hospice nurses, yet the home health nurses conveyed their ability to provide the same level of support. From analysis of the interviews, it appears that home health nurses believe they are often able to meet the patient's needs at the end of life. Home health nurses appear to realize that the point when hospice could better meet the patient's needs is a critical juncture; specifically, when the patient has reached a non-curative, non-treatment phase. An essential skill for the home health nurse is the ability to realize the need for hospice symptom management, or comfort care that the home health nurse could no longer

support. At this point, the nurse must do future care planning that includes death planning with the patient, family and caregivers. Results of this study show that home health nurses were able to give examples of additional services that hospice can offer patients that home health agencies do not offer. Examples of hospice service options range from practical care components such as supplies (i.e. chux pads for incontinent patients, household equipment), to essential complex services, such as a ready “medication box” for uncontrolled symptoms, and spiritual support.

Results of this study provides examples of home health nurses who were unable to identify the differences between home health services and hospice services; thus pointing to a need for better awareness by nurses of the timing of services needed by the patient. This awareness was reflected as an important theme encompassing timing, triggers, options, differences, and engagement subthemes that pointed to nurse, patient, family member, and physician awareness needs.

### **Illness Awareness Theme**

Illness awareness became the initial theme that developed through repeat patterns as the nurses explained how they became aware of the need to transition patients and as they described specific examples of patient transitions. The nurses also described the patient’s awareness of the dying process as a challenge as patients became aware or refused to discuss their impending death. The analysis of the concept of the dying process has been an area of research for nurses since Jeanne Quint Benoliel examined the care of dying patients in the late 1960s in her seminal program of research. Her study examined how nursing students coped with the issues found when caring for dying patients (Quint,

1967). Around this same time period, Glaser and Strauss (1965) studied the dying trajectory of hospitalized patients and noted the specific differences in the dying process that could be used to make decisions about patient care options.

The goal as identified by Glaser and Strauss (1965), was to do everything possible to make the patient comfortable, address concerns, and focus on recovery until that phase is no longer possible. The role of the home health nurse is to help the patient and caregivers become aware of the changes that are happening to enhance comfort care. Nurses also alert the patient's physician when curative attempts are reducing comfort for the patient and caregivers to the point that transition awareness by the health care team is needed towards palliative or hospice care.

Glaser and Strauss (1965) described the dying phase for hospitalized patients, yet the home health nurses in this study identified differences in their awareness that is unique to home health. A unique example was the repeat rehospitalizations that occurred and patient refusals to go to the hospital because the patient was debilitated and unable to get out of the recliner at the patient's home. Not all of the physical symptoms described by the home health nurses are strictly seen in the final days or weeks of life, but may be seen throughout the years of caring for patients with advanced heart failure who are responding to treatment. The nurses interviewed for this study were able to identify specific physical features and most notably the patterns of functional deterioration that point to their awareness of end of life. The home health nurse would continue to provide care to patients until the point at which these physical triggers were displayed or when a combination of "triggers" heightened the nurses' awareness. These triggers mentioned by

the home health nurses are consistent with the Institute of Medicine (IOM) 2014, *Dying in America* report:

“pain; diminished appetite and wasting; weakness and fatigue; shortness of breath (dyspnea) and cough; nausea and vomiting; difficulty swallowing; bowel problems; mouth problems; skin problems; tissue swelling; accumulation of liquid in the abdomen; confusion; dementia; anxiety; and depression and other problems that were not necessarily disease related: incontinence, falls and mobility problems, delirium, and abuse and neglect.”

Although the home health nurses did not describe abuse and neglect as a trigger for hospice services, the home health nurses did give examples of abuse and neglect they had witnessed in the population of patients that were receiving home health care during the end of life.

It became clear that some nurses only identified patients in the final hours of life as needing hospice services because they mentioned examples such as the “death rattle,” “looking like they are on their death bed,” or having a decreased level of consciousness. As a result of these statements, the question that should be asked in future research studies is “how far in advance of the final days of life, should hospice services be started?” The delay in transitioning patients contributes to the shortness of hospice length of stay where the median is 18 days, and 30 percent of hospice beneficiaries are enrolled in hospice for less than 1 week (IOM, 2014) before dying. Experts in hospice care have emphasized the need to have weeks or months to help the patient and family plan for the end-of-life (Kelley et al., 2012). The results of this study correlate with the findings from Wotton, Borbasi and Redden (2005), who found that nursing care and patient advocacy were negatively influenced by a lack of awareness among patients with terminal heart

failure and their family members' in realizing the inevitability of death until the last few days or hours before death.

The nurses mentioned that a trigger for them was the patient or the patient's family beginning to discuss the need or desire for hospice services. Such a discussion often began when the nurse explained to the family or asked family members about things a patient used to do as opposed to what the patient could now do. For example, nurses noted behaviors such as verbal displays of depression, lack of engagement, not wanting to talk, or the patient telling the nurse they are "ready to go home" (die), "talking to people who have passed on," and expressing hopelessness or a desire to give up the fight or being tired of fighting, that nurses interpreted as a "loss of will to live." When these topics were brought up, the home health nurses used these topics as a starting point for hospice transition conversations. The decision to bring in hospice sometimes revolved around the statements patients made about being "ready to give up," that they or their family members were seeing the changes and deterioration, or noting that patients were not responding to treatments and were experiencing repeated rehospitalizations.

The Center for Medicare and Medicaid Services (CMS), (CMS, 2013; CMS Home Care, 2015) categorizes care options for home health and hospice services with specific guidelines for patient admission requirements. The requirements fall into the homebound category for home health and into the less than six months to live or no further curative treatment options for hospice care. As patients reach a point of being "ready to give up", the option should be clear that hospice would be the best option for the patient. Patients who are unwilling to transition to hospice, who have reached this

point of deterioration, no longer belong in the home health service option. CMS (CMS Rehospitalization, 2015) has incentivized hospitals to reduce rehospitalizations for the same diagnoses for which that patient was previously discharged, and has focused primarily on the most common re-hospitalization diagnoses, which includes heart failure (Teno et al., 2013; Lipsitz, 2013). Physicians and nurses are aware of the goal to keep patients from returning to the hospital. Providers realize that home health is a viable option for healthcare services for any patients who have difficulty getting to a physician's office or clinic for care while still desiring and having the ability to remain in their home. Home health agencies have publicly reported re-hospitalization rates noted on CMS's Home Health Compare (CMS, 2013). This provides an incentive for the home health nurses to also ensure that home health patients stay at home rather than experience a re-hospitalization. Offering hospice care serves as a way to reduce re-hospitalization for patients who are consistently returning to the hospital and whose treatments are no longer working. A theme identified from interviews for this study was illness awareness, with the important elements of timing, change and differences, and engagement were noted as subthemes. The subthemes developed as nurses explained the challenges of dealing with patient rehospitalizations, deterioration, and refusal to transition to hospice care.

### **Timing**

Knowing when to bring in hospice was described by the nurses as correlating with the physical or verbal triggers, and with the progressive and deteriorating changes that were happening to the patient. Timing also involved the point where the home health nurse could no longer meet the patient's needs, or when the patient refused to go back to

the hospital for needed care. The instances where home health nurses would wait for the patient or the patient's family to bring up the topic of hospice were a "timing" issue and they touched on the nurses' level of engagement in the transition process or the fear of bringing up the topic. If patients, their family members, or physicians waited for the nurse to approach the hospice topic, and the nurse was not aware of the phase at which the patient would benefit the most from hospice, then the patient may suffer when hospice services would best meet the patient's needs.

Three findings in the current study were consistent with Marsella's (2009) findings regarding the timing of the transition, and the lack of information surrounding a transition, as "one of the most under-studied transitions in health care is the one from curative care to palliative care." The timing of the transition involved the patient, family members or caregivers, and the physician's awareness of the need to transition care over to either palliative care or hospice. The home health nurses could not rely on the physician to decide on the appropriate time to bring in hospice, because the patient may not be able to make it to the physician's office and the physician relies on the home health nurse to convey the improvements as well as deteriorations. Waldrop and Rinfrette (2009) identified a need for additional physician education regarding how and when to address these end-of-life issues that supports training sessions for "hospice" professionals about family dynamics and different approaches to working with patients and their family systems. This research acknowledged the same challenges the home health nurses are experiencing when identifying when to transition a patient.

The home health nurses explained in this study that physicians owned the term “prognosis,” as a measure that only the physician could determine. These nurses explained that they could not use prognosis as an indicator for transition. The nurses had their own triggers that helped them decide when to start the conversation with patients and their family members. The home health nurses realized that timing meant that the physician should be involved, but also that timing should be carefully chosen to ensure a successful transition. Concerns by the nurses that the hospital had chosen to send a patient home to home health when they should have sent the patient to hospice was a dynamic that needs to be addressed in future studies. The home health nurses were disturbed by examples of patients who were not aware that they were dying or when there were situations in which the nurse was the first person to bring up the topic to them.

Physicians may want to be the healthcare provider that discloses to patients that they are approaching the need for hospice, but the home health nurses described situations where physicians were not able or willing to discuss the option of hospice. There is a need for physicians to be aware of the patterns that point to the need to bring up hospice rather than relying on the topic of prognosis alone. The physician’s role in the transition process is influenced by the nature of the home health nurses role in a coordination model that relies on the nurse reporting back to the physician while ensuring everyone is engaged in the awareness of the need to transition. Home health nurses spend the most time with the home health patients and therefore have key information to notice when it is time to discuss palliative or hospice care.

Timing challenges were identified as a key feature that became a subtheme in this category as families played a pivotal role in the decision-making that happened regarding hospice transitions. The issue of timing was seen at home where family members were “not ready to hear their loved one was dying.” Richards, Ingleton, Gardiner, and Gott (2013), found that patients and their family members displayed a reluctance to hear information about the imminence of death. Although awareness of dying can lead to better death experiences, clinicians need to be aware of the barriers related to both timing of the conversations and the delivery of the information (Richards, Ingleton, Gardiner, & Gott, 2013). A key factor that has an impact on this study is a prior study conducted by Meeker & Jezewski (2008) -- a metasynthesis of family members functioning as decision-makers during the end of life. Results indicated that delays in decision making were impacted by patients having previous crises and recovering, making it more difficult so that recovery would be unlikely. Results of the current study were similar in that examples described by the nurses caring for patients with heart failure who had repeated recoveries led to the difficulty for the nurses in identifying timing of the transition discussion.

The identification of the best time to bring up the subject of transition depended upon an awareness of the time when the patient or family would be most receptive to the topic. Descriptions given by the home health nurses contrasted patients who successfully transitioned to hospice and those who do not, based on how quickly the patients became aware and handled the shared experiences with their family members. The challenge with timing is an important component in transition theory. Results of the current study are

consistent with Meleis et al. (2000) who developed transition theory to describe events in the transition process as “time span,” and “critical points and events” that impact the ability to transition. The present study therefore contributes to Schumacher and Meleis’ (2000) confirmation that transition functions as a process, rather than a change that occurs during a moment in time.

Being able to witness changes and deterioration of the patient were noted as necessary aspects of approaching the topic of transitioning. Families needed to be grounded in reality; a role the home health nurse plays by ensuring that the patient would not suffer because of family members’ lack of ability to come to terms with the patient’s deteriorating status. The findings from the present study correlate with Meier, Isaacs, and Hughes (2010) finding that suffering occurs when patients are not offered palliative care at the end of life. Issues of severe pain and poorly managed symptoms present a challenge for home health nurses when available options are not resolving the problems the patient is experiencing. The intrusive treatments that other locations provided, were not mentioned by nurses in this study as an issue, except when patients had dialysis treatments and a nurse mentioned the patient was clearly suffering but family members refused to notice the changes and deteriorating status of the patient until the patient refused dialysis. Aside from the dialysis example, it is important to note that the nurses did not mention the demise of patients with implanted cardioverter defibrillators (ICDs), left ventricular assistive devices (LVAD) or milrinone infusions as would be expected in the home health population of patients that are awaiting heart transplant. Research is needed to explicate the changes and differences transition theory proposes as key

components of the transition process in such circumstances (Meleis et al. 2000). Patients with ICDs, LVADs or Milrinone infusions may have experienced improvement with treatment and may have slowed the progressive decline in their disease process (Dev, Abernethy, Rogers, & O'Connor, 2012) to the point that the change and difference needed to make a transition to hospice care may not be noticed by the patients or the nurses. Recovery from medical treatments may contrast with the triggers the home health nurses mentioned as the change and difference may not be easily recognized by the home health nurse. Based on interviews in this study, triggers mentioned previously were deemed useful by the nurses when they began to consider starting a conversation about hospice with the patient. By witnessing clear signs of deterioration, nurses realized it was time to bring up the subject of hospice services.

### **Engagement**

A key component for successful transitions requires a level of engagement in the process of transitioning (Meleis et al. 2000.) Transition theory posits engagement as the degree to which a person would demonstrate involvement in the process. Engagement is limited when patient, family members or physicians were in a state of denial. Likewise, results of this study indicate that home health nurses recognized issues of engagement that occurred when patients had a “fear of the unknown” (disease progression, or transitioning to a new group of nurses in a hospice agency). Denial has been described in the literature as “a psychological defense mechanism where the person does not take in reality and suppresses it” (Benkel, Wijk, & Molander, 2014).” For the home health nurses, denial was described as patient or family member fear of discussing disease

progression, or being fearful of a change in staff from the home health team to the hospice team. This level of denial has been described in the literature as dying patients wavering between acceptance and denial. Janze and Henriksson, (2014) studied palliative home care by examining family caregiver's awareness of dying. Results showed that denial and acceptance of dying operated as interdependent and fluctuating strategies the families used to prepare for the dying and death of their partners. The phases were described by the researchers as willing and unwilling moments. Home health nurses must deal with limited engagement in order to obtain the best level of care when patients function in a state of denial or suffer from a fear of the unknown (Janze & Henriksson, 2014). The home health nurses may be able to enhance engagement by being able to offer patients and family members time to ponder what is happening. The difference that the current research offers is indicators that these home health nurses wanted to "plant the seed" to get the patient to a level of transition engagement. Home health nurses who address denial and fear of the unknown have a better chance of helping the patient arrive at the point where transitioning to hospice can occur.

The nurses interviewed in this study had a desire to avoid revealing to patients they were "giving up hope," which could lead to situations where the patients would not transition to hospice care. Hope has been identified as a necessary aspect of the healing process and has been linked to the quality of care provided to patients (Janze & Henriksson, 2014). Davidson et al., (2007) summarized five key ways for nurses to help patients and their families to transition to palliative care: (1) acknowledge the change in life circumstances; (2) restructure reality; (3) help patient deal with vulnerable situations;

(4) offer information and support; and (5) help the patient achieve normalization and address uncertainty. Implicitly, Janze and Henriksson, (2014) identified a need for nurses to offer compassionate and culturally sensitive care as patients reach out to the healthcare team for direction and support. Results of the present study demonstrated instances in which the patient or family members would reach out to the home health nurses or their physicians, resulting in a positive transition experience. Situations, in which the nurses explained they were fearful of causing the patient to give up hope, may be instances where the patients and family members were not reaching out for direction or support, which may be a delineating factor. A key area of nursing research for home health nurses was to explore the circumstances surrounding the nurses' beliefs that could cause the patient and family members to give up hope. Nurses may thus fear precipitating an earlier death for the patient by identifying the reasons why patients may not be seeking direction or support. In a study of patients with cancer, Olsson et al., (2011) explained that the single core aspect of hope was always present no matter the circumstances for the patient. Results of a study conducted in England by Hunt (1992), found the fear of not being able to preserve "hope" may affect the patient's "will to live." Therefore, the findings from this study concurs that guidance by nurses during the transition phase could benefit patients and their family members as patients attempt to live up to the expectations the nurses set for them.

The home health nurses interviewed in this study gave examples of struggling to provide what the patient wanted versus what the family wanted. This sub-theme emerged when families refused to allow hospice in and would not discuss the option with the

nurse, forcing the patient to stay with home health rather than transition to hospice. Van Nes (2011), identified that patients with heart failure often suffered from the stress of managing complex medication regimens, decreasing function, and social burdens placed on caregivers. Such stressful circumstances may make patients less involved in decision-making. The inability to engage in decision-making was an additional burden on the family members and caregivers who must make decisions at the end of the patient's life. In the present study, the point of decision-making by families was described by nurses as situations in which the patient could no longer make decisions for themselves. When hospice was discussed, some nurses had experienced instances in which different family members were fighting with each other over the best care options for the patient. They dealt with families who believed there were other potential treatments to be pursued or that they could change physicians to address the patient's deteriorating status. Realizing that family members may not want to be with the patient or have the patient at home at the time of death was a clear indicator of the reason for a lack of engagement in a transition process. The challenge for home health nurses of becoming aware of all of the potential reasons why family members may be refusing hospice is a necessary part of future research that is needed for this population of patients.

Home health nurses interviewed for this study also experienced family decision-makers who were dependent on the patient's home or money, which they believed impacted care decisions that could thwart a transition to hospice. This is a feature that is unique to home health care providers who must engage family members who rely on the social security or other retirement or financial means to be able to live in the patient's

home. Some home health nurses were facing family “control” issues and situations in which families would concentrate on medical issues rather than the goal of helping the patient transition to hospice care when it was needed. Faith-based challenges were also noted by some nurses when patients and family members would not engage in the transition process because they believed that God would heal them. Other patients or families expressed a belief that hospice was taking on the role of God by giving the patient morphine that would cause the patient’s death.

Some home health nurses reported that they tried discussing the changes and need for hospice with the family members before discussing it with the patient as a way to gauge engagement and validate awareness. These nurses would talk to the person who was deemed as ‘being in charge,’ to encourage talking about their feelings as well as learning the feelings of the patient. The overall goal was to get the family positively involved so that when death was nearer, the nurses could skillfully encourage family members to think about hospice/palliative options.

The theme of engagement is a special challenge for home health nurses who must rely on patients and family members allowing them in their house. In home health, upset family members or patients can keep the home health nurse from visiting. This delicate position needs to be recognized because of the important role these nurses play in discussing the difficult but necessary topic of hospice care that the patient, family or physician avoids but needs to consider as the end of life nears. Another unique factor impacting transition is the unique relationship the home health nurse forms with the patients and their family members. This relationship may present as a barrier because no

engagement in the transition process can occur because of patients not wanting different caregivers to come into the home to receive palliative or hospice care. In summary, the ability to fully engage a patient, family member or physician in the transition process requires high level communication skills to capture proper timing, clear awareness of the situation, and to promote patients' and family member's desire to be engaged in a transition. While these components may be evident, communication skills were described by nurses in this study as clearly required for the transition to hospice to occur.

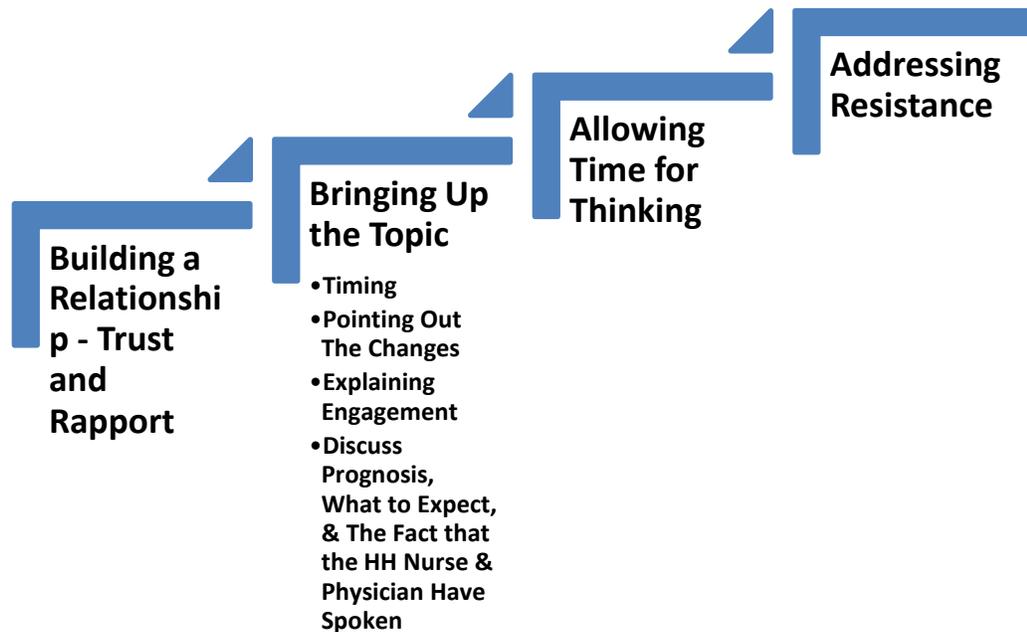
### **Communication Skills**

The ability to communicate a need for a transition to either palliative care or hospice became a dominant theme as the home health nurses in this study explained how they either could or could not facilitate transition when they used certain communication approaches. In a study by Richards, Ingleton, Gardiner, and Gott (2013) researchers found that patients were only partially aware and some were wholly unaware that they were in the end-of-life phase – a result that highlights the role nurses play in communicating in an honest, forthright manner with patients. A variety of steps the nurses used in this study were discussed. The process included a preliminary need to build a relationship with the patient and family members. The findings of this study indicate that each of these steps play a critical role in the ability of the home health nurses to facilitate transition of patients to palliative care. The subthemes of building trust and rapport, initiating the subject and addressing any resistance played a prominent role in the home health nurse ability to transition effectively. The unpredictable aspect of functional decline, increased dependence and poor delivery of information noted by Davidson et al.

(2007), are present in communication challenges, which is a finding that is consistent with results of the present study because the home health nurses verbalized these same issues. The aspect of poor delivery of information by nurses that was found by Davidson et al. (2007) and Low et al. (2011) matched the results of this present study that also confirmed the difficulty of delivering “bad news” (Back et al., 2010; Ngo-Metzger et al., 2008). The difference described in the literature is the prevalence of trust and rapport as the home health nurses described the potential challenge of not being invited back into the home if they did anything that would upset as the patient or the patient’s family members. Such a description highlights the need for very careful attention to the details when bringing up the subject of hospice or palliative care.

Trust and rapport were deemed as critical initial aspects for the home health nurses in the present study to begin the discussion. This finding is confirmed by Truglio-Londrigan’s (2013) research on home health nurses facing challenges when helping patients make healthcare decisions. Having established trust and rapport, the next phase involves choosing the right timing to have the conversation and the right statements in order to identify where the patient and family members may be in realizing the need for hospice. The skill of bringing up a difficult topic appeared to be easier for some and very difficult for other home health nurses interviewed in this study. The nurses would either meet resistance or not, but realized the need to give patients and families time to consider their situation, which would help them to start on the path towards hospice care. Figure 2 demonstrates the step-by-step skill of enabling the conversation towards a hospice option.

Figure 2: Steps in Communicating the Need for a Transition



Yang, Staps, & Hijmans (2010), identified the need to give patients time to think at the pace where they are comfortable, as they face their predicament and find answers. A single attempt at discussing hospice was not deemed as a success tactic, whereas repeatedly mentioning it often helped. Telling the patient that the nurse and the doctor had spoken was deemed as an effective communication technique as well as the nurse spending time “planting the seed” helped the transition process along.

Resistance emerged as a subtheme in the present study as nurses described some patients who would not entertain the option of transitioning to hospice care. The home health nurses struggled to communicate in these situations. Because of the inability to communicate when the pathway to hospice was blocked, the nurses would ask if they

could bring in the hospice experts. Van Nes (2011) explained how healthcare providers can become paralyzed by their inability to do anything other than proceed with the usual treatments directed at heart failure. A similar paralyzing feature was noted in the present study when the nurses either met complete resistance to transition, or when the nurses would attempt different strategies to resistance. If the nurse could not talk the patient into letting the hospice nurses come and explain their services, the home health nurse would attempt to tell the patient the hospice rules and would clarify what hospice could do that home health could not do.

Jackson et al. (2013) provided examples of communication strategies used in ambulatory care settings to help patients and their family members with awareness of the disease challenges experienced during the end of life. These strategies are examples the home health nurses could use to find out why the patient is being resistant to transition even though the study focuses more so on prognostic awareness. Being aware of the nurses' own vibes, negative word choices or personal attitude about hospice care could impact the ability to communicate. The home health nurses interviewed in the present study conveyed that they had a varied ability and desire to communicate the topic of hospice or palliative care options to patients. Resistance was addressed by conveying hope in two ways: (1) that the patient would not die in hospice if they were lucky enough to be able to "graduate" from hospice care and return to home health; or (2) by using a "bridge" program to get patients to transition over to a hospice program by allowing the patients a chance to meet and receive care from hospice nurses while continuing to receive their usual home health care.

Results of the current study offer unique contributions to the literature because home health nurses conveyed a discomfort with their skill level of talking to patients about hospice. This situation was present when negative word choices or attitudes about hospice impacted the nurses' ability to discuss the options available to patients that would best meet the patient's needs. The nurses gave examples why bridge programs were being used and how telling patients 'they might graduate from hospice' facilitated transition. While these approaches may accomplish the job, it may also be deceptive. As described by Richards, Ingleton, Gardiner, and Gott (2007), there is a need for an "open awareness" and regard for humane care of patients. This open awareness has resulted in successful training programs designed to help physicians and nurses communicate with patients by practicing specific phrases and communication techniques (Back et al., 2010; Goelz, et al., 2011; Grainger, Hegarty, Schofield, White, & Jefford, 2010; Wittenberg, Goldsmith, & Ragan, 2011). It is important to note that the practice of bridging patients would not be an option for a home health agency that did not have access to a mutually owned hospice agency or a relationship with a local hospice agency (Nakamura, Kuzuya, Matsui, & Ishiguro, 2010). These studies by Back et al. (2010) and Wittenberg et al. (2011) contribute by offering a step-by step method of bridging the communication gaps.

### **Knowledge**

Results of the present study indicate that the ability to communicate after becoming aware of the need to transition patients to either palliative or hospice care depended on the home health nurse's knowledge of several factors: (1) what hospice offered; (2) the patient's place in the disease process or trajectory; and (3) the options to

either treat the patient or transition the patient to a more appropriate care option such as hospice or palliative care. These factors were delineated into four subthemes related to knowing the differences between home health, hospice and palliative care, where the patient was in the disease process, how to bring up the transition topic, and how to deal with absolute refusals to transition to hospice or palliative care. The nurses either embraced their teaching role, handled the conflict that arose from the discussions, or they were faced with the challenge of keeping the patient in home health through the end of life. Differences between home health, hospice and palliative care were discussed previously, but the need for this knowledge might reduce the fear that the home health nurses have as knowledge serves to light the path. Clark et al., (2012) confirmed the challenges patients with heart failure experience when they seek help but realize that their healthcare provider is not able to help them as symptoms increase. Home health nurses need training to be able to identify who should be receiving hospice care, when the discussion should begin, sharing the best ways to start the transition conversation to hospice care, methods to handle resistance to transfer. Such knowledge by the nurse would enhance care for home health patients reaching the end of life. The findings in the present study are unique contributions to research because it demonstrates that training programs have fallen short on identifying the best time to have the conversation about hospice care. According to the home health nurses interviewed for this study, the best time is when patients experience deterioration or other triggers emerge. Hui et al., (2015) noted indicators of impending death in cancer patients as including nonreactive pupils, decreased response from verbal stimuli, an inability to close eyelids, drooping of the

nasolabial fold, hyperextension of the neck, grunting of vocal chords, and upper gastrointestinal bleeding. These symptoms presented as common patterns at the very end of life, which some of the home health nurses interviewed for this study described as features they would see or hear (pupils, verbal stimuli, and grunting sounds) before transitioning the patient to hospice care. This result therefore points to the need for nurses to have the knowledge about looking for these typical symptoms well before the last three days of life. If home health nurses are aware of symptoms and triggers, they may be more comfortable starting the needed conversation. Results of this study highlight the distress that nurses experience when witnessing suffering, which in turn may be causing moral distress in patients, families, and/or nurses. An effort to address moral distress could focus on ways to help home health nurses and the physicians who work with home health agencies, because physicians may be experiencing the same levels of distress.

Additionally, overcoming a fear of talking to patients about the dying process or hospice transition remains a critical skill that these home health nurses need, and that has been widely described in the literature (Bolmsjö, Nilstun, & Löfmark, 2007; Goelz et al. 2011; Grainger et al. 2010; Löfmark, Nilstun, & Bolmsjö, 2005; Schim & Raspa, 2007). The home health nurses interviewed for this study described the complex challenge regarding patients who were refusing to transition. Results of this research identified that some of the home health nurses had been successful by learning how to turn patients and their family members away from their negative views or resistance to transition. Otherwise, these nurses would continue to keep the patient in home health even though the patient would benefit from a transition to hospice care. Penz, (2008) addressed the

complexity home health nurses faced. These challenges included professional identity challenges, forming partnerships and connections with palliative patients and their family members, and complex issues surrounding interdisciplinary collaboration and support. Results of the current study confirm the complex role the nurses play in the quest to transition patients in the multifaceted environment of home health service delivery.

### **Limitations of the study**

These study findings are subject to some limitations. Given that this is a qualitative descriptive design, the number of home health nurses studied provided a richness and depth to the description of their experiences. The participants were motivated to talk about their experiences and expressed their frustrations and feelings regarding the care of patients requiring care at the end of life. The researcher's background with many years of home health experience required the researcher to view participant's experiences with a beginner's viewpoint. This occurred as the researcher avoided any premature interpretation of the experiences described by the participants. As such, the researcher sought thorough descriptions and conveyed an openness during the interview process and subsequently in an effort to identify the various dimensions of care challenges the nurses had experienced and displayed an open acceptance of the success strategies the nurses had employed. An additional limitation is the consideration that the home health nurses who agreed to participate in a research study might be those nurses who feel that they are better prepared to manage the care of patients who are at the end of life. In addition, findings might be influenced by the fact that these four agencies provide home health versus home care which is often viewed as a different level of care as the

care is more of a continuous care option rather than the intermittent function of home health agencies. Lastly, two of the nurses that participated in the interviews had previously functioned as home health nurses who had transitioned to the hospice side of the agency. Their perspectives enhanced the study as perceived by the researcher because the nurses described their experiences of witnessing and understanding how and why the home health nurses were transitioning patients the way they were which leads to a need to continue this research focusing on the hospice nurse perspectives of home health transitions.

### **Implications**

Home health agencies can serve as a referral source for hospice agencies as chronically ill home health patients reach the end of their lives. It was unknown prior to this research if home health nurses were facing the same education and communication challenges their counterparts in acute care or intensive care hospitals, emergency rooms, and oncology units experienced. These home health nurses held close relationships with their patients and they focused their care coordination skills to help their patients with care planning, psychological and social challenges, as well as symptom and functional activity management that had been identified as critical aspects by Pastor & Moore, (2013).

### **Implications for Clinical Practice Based on the Findings from this Study**

This study illuminates not only the similarities, but also the additional challenges the home health nurses were facing as chronically ill patients with heart failure reached the end of life. Although the aim of this study was to understand the home health nurse

experiences of caring for chronically ill patients, specifically patients with advanced heart failure prior to and during the palliative and hospice phase, the home health nurses discussed their options and lack of options as well as the reasons some transitions were successful and other transitions failed. Primarily, this study identified key “awareness” differences for patients with heart failure as the nurses struggled to identify exactly when to bring in palliative care because of the illness trajectory. However, the examples the nurses gave highlighted the deteriorating functional abilities coupled with repeated hospitalizations with no improvement with treatment changes as key factors that can be used by nurses and physicians as a starting point for conversations about hospice care. Chaudhry et al. (2011) described how decreasing functional ability identified at the onset of a heart failure diagnosis linked impaired gait speed with depression and cognition issues that cause disability in this population resulting in recurrent episodes of clinical decompensation and rehospitalization. Results of the current study provide confirmation of the functional debility aspect, but also points to the need for awareness and adept communication skills of nurses as critical components to successfully transitioning heart failure patients to palliative or hospice care.

The review of transition theory as a concept that encompasses the challenges the home health nurses described resulted in a deeper appreciation of the obstacles that the nurses were encountering. The realization that home health nurses are being forced to keep dying patients in home care points to the need to ensure that the transition theory components described as “transition conditions” and “patterns of response” are built into any future research or training programs. The long-term goal of this research is to

improve the quality of life of home health patients by identifying interventions home health nurses can use to facilitate a successful transition to hospice care, and to address the challenges nurses experience when home health patients are unwilling to transition to a hospice care provider. There have been no studies documenting the progression of these patients to either palliative services or hospice care. Additionally, because the use of palliative care services continues to increase in hospitals, additional support could be offered to home health agencies as evidence from this study highlighting the limited access these home health nurses had to palliative trained professionals. Home health nurses would benefit from an additional level of support whether the patient or family refused to allow palliative care into the home, or the nurse lacked access to the support to be able to provide care to the dying population of patients refusing to transition.

The results of this study indicate that the home health nurses have three options when faced with a need to transition a patient that has reached the point of needing palliative or hospice care. Option one is to transition the patient to a hospice level of care (inpatient or home-based.) Option two is to keep the patient in home care and bring in palliative care experts to help the patient stay at home if the patient refuses hospice care. Option three is to keep the patient at home and manage care without the support of palliative specialists if the patient or the patient's physician refuses to allow the palliative specialist to help manage care needs. Two additional options to these three are not being considered in this research analysis because they do not address the bottom-line goal of receiving end-of-life care in a patient's own home. Those two options are to discharge the home health patient, which would potentially leave the patient with no clinical care, or

the option to send the patient to a hospital or facility which removes the patient from their home environment.

Results of this study offered reasons why a patient or family member would want to transition to a hospital, yet the challenge that this study highlighted was the “triggers” that point to the moment when a transition is needed. Metzger et al, 2013 recognized the need for research such as this that identifies appropriate “triggers” or indications for referring heart failure patients to palliative care programs. The AHA (2015) has identified “triggers” for consulting palliative care as uncontrolled symptoms, distress related to disease process, assistance with withdrawal of life sustaining care, assistance with care of actively dying patients, assistance with transition planning including assessment for hospice eligibility, concerns for medical decision making, and determination of goals for care. The AHA (2015) also identified that hospice care triggers for heart patients included uncontrolled symptoms, chest pain at rest, history of cardiac arrest and/or resuscitation, history of unexplained fainting due to loss of blood to the brain (syncope), and irregular heart rhythms that are resistant to therapy (arrhythmias). These appear to be unlike the examples the home health nurse provided as triggers in this study that provided the home health nurses with the preliminary aspects that needed to be met before transitioning a patient. Syncope, arrhythmias, or chest pain at-rest are examples an acute care facility may use, rather than what home health nurses were seeing. Illness awareness as a theme was identified as these home health nurses attempted to transition patients that were suffering from a life limiting illness as the patient began to deteriorate.

The themes identify the clinical practice challenges home health nurses experience as the nurses are forced to not bring in palliative specialists due to the lack of access to specialists who are willing to work with the home health population of patients. This demonstrates a need for home health leadership to institute palliative care training programs in home health agencies so nurses can learn from programs such as the End of Life Nursing Education Consortium (Barrere & Durkincitation, 2014; ELNEC 2013). The option of providing home health nurses with an opportunity to ride-along with a hospice nurse may also support the education and communication skills training needed by home health nurses.

Hospice programs are seeing more non-cancer diagnoses while home health programs are seeing increasing numbers of chronically ill patients. As such, the changes that are impacting the variety of clinical care options change with this as hospice care adjusts to the dimensions of heart failure care challenges and home health nurses witness patients using technology such as ICDs, LVADs or Milrinone infusions that lengthen patient's lives (Dev, Abernethy, Rogers, & O'Connor, 2012). This transition requires nurses to adapt clinical skills as well as communication skills regarding goals of care and the identification of when nurses will transition a patient to hospice care. Bringing together home health and hospice nurses to address these challenges is a key role that the National Association of Home Health & Hospice Care provides, yet additional support for these clinical care opportunities is necessary.

Clinically, the home health nurse needs a level of awareness reflected by results of this study. Home health nurses are in a prime position to enhance patient, family

member, and physician awareness of disease progression. Although previous research identified the importance of timing end-of-life conversations, results of this study support the need for home health nurses to time the transition to hospice to coincide with the point of deterioration rather than wait until the last minute, day, or week to transition a patient to hospice care. This timing requires an important feature of transitioning patients using a step by step process so as to allow the patient and family time to recognize the deterioration and understand their role in being engaged in a transition process. The challenge of dealing with family members provides a rich perspective of the complex dynamic of relationships, responsibilities, and burdens family members assert on their dying loved ones. Home health nurses can as a result of this research, take time to identify the main point of angst that is hindering the transition to hospice care. The identification that family decision makers and patients use claims of “death angels” and “hospice kills you” to hamper the transition which provides a nurse with an educational opportunity to address these concerns. Having an awareness of end-of-life disease trajectories and the dying process can enhance clinical care as home health nurses learn how to care for this increasing population of patients seen in home health agencies.

Nursing clinical practice can be enhanced when home health nurses no longer fear having a discussion with patients, their family members or physicians when it is time to bring up the subject of transitioning to hospice care. Additionally, home health nurses can speak up in situations that are unacceptable when witnessing examples of patients suffering or family members are keeping patients who are unable to speak for themselves from receiving the care the patient needs. Doorenbos et al., (2013) identified five most

important nursing interventions to promote dignified dying, as: (a) maintain dignity and privacy, (b) establish trust, (c) manage pain, (d) establish rapport, and (e) manage dyspnea. These home health nurses struggled with providing dignified care at the end of life and pain management for patients when family members wanted to resist the nurse's desire to transition the patient to hospice care. The nurses had examples of trust, rapport and dyspnea management, but struggled with dignity and pain management issues. Finally, home health nurses require skills in handling absolute refusals to transition to hospice when all of the training and resources have been used and patients, family members and even physicians refuse to transition a patient to hospice care. This study demonstrated that 70% of the home health nurses had not received palliative care training. The most critical aspect found in this study is the ability of the home health nurse to provide the required care needed by patients going through the dying process.

### **Implications for Research Based on the Findings**

The findings from this study highlight additional areas for research that are needed to address the issues identified by the home health nurses. The research needs are identified as:

- (1) How far in advance of the final days of life should hospice services be started for home health patients?
- (2) What are the broad spectrums of reasons family members are refusing to transition their loved ones to hospice care?
- (3) Are there specific deterioration levels that home health nurses can use to categorize when a home health patient should be transitioned?

- (4) Examples of suffering as nurses identify situations where family members are keeping patients who are unable to speak for themselves from receiving the care the patient needs because home health is more secluded setting as opposed to a healthcare institutions.

These research questions delve deeper into the issues highlighted from this research and indicate that there is a tremendous amount of work that is needed to better understand the obstacles that are emerging as new entities such as palliative specialist programs increase in healthcare institutions.

#### **Implications for Policy Based on the Findings from this Study**

Efforts to impact health policy can use the findings from this study to support illness awareness research, communication requirements, and educational activities to enhance the provision of palliative care afforded to patients that need palliative care or need to transition to hospice care. The Institute of Medicine (2014) recommendations highlight the need for access to an interdisciplinary palliative care team that includes board-certified hospice and palliative medicine physicians, nurses, social workers, and chaplains, that work together to help patients that would benefit from this level of expertise. A key aspect of the IOM (2014) recommendation is the need to have these resources available on a local level whether it be on-site or through virtual consultation. This feature demonstrates where health policies need to be developed to demonstrate support for these services. Additionally, end-of-life cost and quality measures require public policy attention as this field suffers from being viewed as a topic that individuals and communities would rather not discuss, but because of the aging population that is

living longer, requires full transparency and full disclosure of what works and doesn't work for hospices and home health agencies as well as healthcare facilities that are attempting to transition patients to their home environment.

Because of the extensive need for education as highlighted in this study, the institution of the IOM (2014) requirement that "all clinicians across disciplines and specialties who care for people with advanced illness should be competent in basic palliative care, including communication skills, inter-professional collaboration, and symptom management" points to the public policy needs of accrediting organizations to monitor compliance with these efforts that doesn't just require "death and dying" as an educational topic once a year, but rather require an analysis of each entity of the end-of-life care being provided in each accredited location.

Federal, State and private insurance programs support the delivery of quality healthcare programs and as such, the care of patients in a palliative state or nearing the end-of-life can administer funds that fully support nurses and physicians by affording the fiscal resources needed to give healthcare providers the time that is needed to fully engage patients in the discussions regarding care needs and options.

## **Conclusions**

This study offers a unique contribution to research by providing a clear example of the challenges home health nurses are experiencing when caring for this population at the end of life. This information can be used to advance research in this field and to enhance clinical practice by providing leaders with an awareness of the issues nurses experience in home health. The unique contribution of this research is highlighted above

in the “implication” sections yet the damaging perspective of hospice as an entity that “kills patients” with “death angels” serves as a warning to hospice agencies. These perspectives are hurting the efforts that could be embraced by all patients as hospice nurses and physicians attempt to help patients through the challenging and complex realm of care options experienced by individuals at the end of life. Lastly, this research offers a unique awareness of the timing challenges home health nurses experience as well as awareness opportunities that are possibly unique to home health, but perhaps it is by taking a non-medical model of prognostication to help us realize that all along, home health nurses are “seeing” and “hearing” when and how it is time to transition patients to hospice care. We have an opportunity to improve not only the lives of nurses and physicians, but also to impact the quality of life of patients as we offer both a palliative skill set required of all home health nurses and a smooth transition process to experts caring for patients at the end of life.

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**Appendix A - Informed Consent Form**

**Project Title:** Home Health Nurse Experiences of Transitioning Heart Failure Patients from a Curative to a Palliative Level of Care

**Informed Consent Agreement**

Please read this consent agreement carefully before you decide to participate in the study.

**Purpose of the research study:** The purpose of this study is to explore the meanings home health nurses assign to the process of caring for heart failure patients when the patient reaches the point of needing palliative or hospice care. You are being asked to be in this research study because you are a home health nurse with at least 3 months of home health experience who has cared for chronically ill patients. You will be asked questions related to your experience of caring for chronically ill patients who are deteriorating to the point where the patient would need palliative care or hospice care.

**What you will do in the study:** If you agree to take part in this study, you will be asked to participate in one 20-60 minute audio-taped interview at a time and place that is convenient to you either in a private office at the home health agency, or in a place that is convenient to you. A 5-10 minute follow-up phone call or private meeting at a later date may be conducted to ask follow-up questions.

**Time required:** One 20-60 minutes session followed by a possible 5-10 minute follow-up call or meeting.

**Risks:** Specific efforts will be made to protect any potential loss of confidentiality. The researcher will take steps to protect the identity of participants by assigning each participant a number that will be used to track the participant's statements rather than use the participant's name. All interviews will be conducted in a private location selected by the participant. Because of the location of the interviews, you may be seen by others as you enter the room and therefore others may know that you have participated in the study. There is also the possibility of bringing up feelings of discomfort and anxiety, which could be caused by the questions asked. If you experience these feelings, you can immediately stop participating in the research. The study may include other risks that are unknown at this time.

**Benefits:** There will be no known benefits to the participant other than the contribution to home health nursing research efforts.

**Study Withdrawal:** Taking part in this study is voluntary. You have the right to choose not to answer any questions or take part in this study. If you choose to participate, you have the right to stop at any time. If there are any new findings during the study that may affect whether you want to continue to take part, you will be told about them.

**Confidentiality:** We will try to keep your research records confidential, but it cannot be guaranteed. The information that you give in the study will be handled confidentially. Your information will be assigned a code number. The list connecting your name to this code will be kept in a locked file. When the study is completed and the data have been analyzed, this list will be destroyed. Your name will not be used in

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IRB-SBS Office Use Only	
Protocol #	2014-0156-00
Approved SBS Staff	from: 5/19/14 to: 5/18/15 2014

**Project Title: Home Health Nurse Experiences of Transitioning Heart Failure Patients from a Curative to a Palliative Level of Care**

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any reports. The results of this research may be presented in meetings or in published articles. However, your name will be kept confidential.

**Voluntary participation:** Your participation in the study is completely voluntary.

**Right to withdraw from the study:** You have the right to withdraw from the study at any time without penalty. If you want to withdraw from the study, tell the interviewer to stop the interview. If you withdraw from the study, the researcher will use the data that was collected until you withdrew from study, but no new information will be collected.

**Payment:** You will receive no payment for participating in the study.

**If you have questions about the study, contact:**

Mary Crandall, PhD student at the University of Virginia School of Nursing, Box 800780 - Charlottesville, VA 22903. 434-277-9014 mbc8n@virginia.edu

Faculty Advisor: Dr. Cathy L. Campbell - University of Virginia School of Nursing, Box 800780 Charlottesville, VA 22903. Dr. Campbell can be reached at 434-243-6789. Email: clc5t@virginia.edu

**If you have questions about your rights in the study, contact:**

Tonya R. Moon, Ph.D. Chair, Institutional Review Board for the Social and Behavioral Sciences

One Morton Dr Suite 500 University of Virginia, P.O. Box 800392 Charlottesville, VA 22908-0392

Telephone: (434) 924-5999 Email: irbsbshelp@virginia.edu

Website: www.virginia.edu/vpr/irb/sbs

**Agreement:**

I agree to participate in the research study described above.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

You will receive a copy of this form for your records.

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**Appendix B - Demographic Sheet**

Demographic Sheet

Please take time to fill in each of the blanks on this form, which will be used to provide demographic information:

Date:

Age:

Gender (Circle) Male or Female Ethnicity: \_\_\_\_\_

Years of Nursing Experience \_\_\_\_\_

Years of Home Health Experience \_\_\_\_\_

Years of Experience in Hospice or Palliative Care \_\_\_\_\_

Number of Terminal Heart Failure Patients Care For \_\_\_\_\_

Number of Terminal Heart Failure Patients Care for in the Last Year \_\_\_\_\_

Please Circle if you have received any Palliative Care Education:

Never Undergraduate Graduate Palliative Seminars

Have you ever had a palliative care mentor – someone to talk to about palliative patient issues?

(Circle) Yes No

Please circle one of the items provided for each question that applies to your situation:

You work at what type of home health agency?

For-Profit Not-for-Profit

You work for what type of home health agency?

Privately Owned Hospital Based

You work in what type of home health setting?

Urban Rural Both Urban and Rural

## **Appendix C – Interview Guide**

### Interview Guide

#### Nursing experience

1. I am interested in hearing about the kinds of chronically ill patients that you care for. Tell me about your experiences with these patients and the diagnoses that you care for...
2. Tell me about an (Describe an) experience working with a patient with advanced heart failure...
3. Tell me about or describe the experience of transitioning a patient to palliative care or hospice...

Possible Prompts—what were your thoughts? What were your feelings/emotions?  
What does care transition mean to you? What does this transition look like?

#### Meaning

4. What does hospice mean to you? What does palliative care mean to you?
5. Tell me about a patient with heart failure that you worked/cared for who made a successful transition to palliative care or hospice? What does success mean to you?
6. Tell me about patient with heart failure that you worked with/cared for who did not transition to palliative care or hospice?

Prompts—what did you do? What did you say?

## Appendix D – Definition Guide

### IOM (2014) Definitions:

**Palliative care:** Care that provides relief from pain and other symptoms, supports quality of life, and is focused on patients with serious advanced illness and their families.

Palliative care may begin early in the course of treatment for a serious illness and may be delivered in a number of ways across the continuum of health care settings, including in the home, nursing homes, long-term acute care facilities, acute care hospitals, and outpatient clinics. Palliative care encompasses hospice and specialty palliative care, as well as basic palliative care (see below).

**Hospice:** “A service delivery system that provides palliative care for patients who have a limited life expectancy and require comprehensive biomedical, psychosocial, and spiritual support as they enter the terminal stage of an illness or condition. It also supports family members coping with the complex consequences of illness, disability, and aging as death nears” (NQF, 2006, p. 3).

**Specialty palliative care:** Palliative care that is delivered by health care professionals who are palliative care specialists, such as physicians who are board certified in this specialty; palliative-certified nurses; and palliative care-certified social workers, pharmacists, and chaplains.

**Basic palliative care:** Palliative care that is delivered by health care professionals who are not palliative care specialists, such as primary care clinicians; physicians who are disease-oriented specialists (such as oncologists and cardiologists); and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care.

**End-of-life care:** Refers generally to the processes of addressing the medical, social, emotional, and spiritual needs of people who are nearing the end-of-life. It may include a range of medical and social services, including disease specific interventions as well as palliative and hospice care for those with advanced serious conditions who are near the end-of-life.

### CMS Definition of Home Health (CMS, 2013)

**Home Health** is care that is provided to patients in their place of residence that follows physician ordered care by providing nursing care, therapy, home health aide, or social services to patients with a goal of helping patients remain in their home to avoid facility based care and to stabilize or return to a functional level of independence (CMS, 2013). While hospice care is generally focused on managing symptoms, providing comfort, and

helping the patient and family address issues related to future planning, these aspects mimic the services provided by home health, yet the additional support of “death planning” and maintaining a patient’s quality of life “while dying” (Oldenquist, Scott, & Finucane, 2001) is what differentiates hospice from home health services.