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Using Critical and Transformative Theory to Describe Basic Palliative Care in the Acute Care Setting

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USING CRITICAL AND TRANSFORMATIVE THOERY TO DESCRIBE BASIC

PALLIATIVE CARE IN THE ACUTE CARE SETTING

by

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ABSTRACT

USING CRITICAL AND TRANSFORMATIVE THOERY TO DESCRIBE BASIC
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The population of chronically ill, older adults is expected to grow in the coming years as

the baby boomer generation ages. The Institute of Medicine recommends that all healthcare

providers have a basic competency in palliative care, also referred to as basic palliative care. The

definitions and descriptions to date are vague and do not provide an in-depth description of how

basic palliative care differs from the care provided by specialists. The purpose of this study was

to describe nurses' understanding and perceptions of basic palliative care in the acute care

setting. Focus group and individual interviews were utilized for data collection. The results of

this study deepen our understanding of how acute care nurses practice basic palliative care and

the challenges that exist in caring for homeless and culturally diverse patients who could benefit

from palliative care. This study offers guidance for future research, policy changes, and

integrating palliative care into practice earlier in the illness trajectory.

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Chapter 1: Basic Palliative Care

Palliative care is defined by the National Consensus Project (2013) as:

…patient and family-centered care that optimizes quality of life by anticipating,

preventing, and treating suffering. Palliative care throughout the continuum of illness

involves addressing physical, intellectual, emotional, social, and spiritual needs and to

facilitate patient autonomy, access to information, and choice (p. 9).

Palliative care has developed quickly over the past few decades; however, it is still

misunderstood. Palliative care grew from hospice care and is still frequently equated with

hospice care by health care providers (Al Qadire, 2014; Finnerty & Gregory, 2010; Gardiner,

Cobb, Gott, & Ingleton, 2011; Gott, Seymour, Ingleton, Gardiner, & Bellamy, 2011; Huijer,

Abboud, & Dimassi, 2009; Hynes et al., 2015; Mahon & McAuley, 2010; Proctor, Grealish,

Coates, & Sears, 2000; Spence et al., 2009) and the general public (McIlfatrick et al., 2013).

Both types of care have the same philosophy; however, the general difference is that palliative

care does not require the discontinuation of life-prolonging treatment and can be started earlier in

the disease trajectory (U.S. National Library of Medicine, 2016). Palliative care has been

developed differently around the world. In the United States (U.S.), the main difference between

palliative care and hospice care are the benefits and standards set through Medicare, the main

health insurance for Americans over the age of 65 (Meghani, 2004). Under the Medicare Hospice

Benefit, beneficiaries must agree to forego life-prolonging treatments (Meghani, 2004).

However, with the passage of the Affordable Care Act of 2010, Medicare eligible patients are

now able to access palliative care, through certain hospice programs under the hospice benefit,

for a trial period of 5 years (Center for Medicare and Medicaid Services, 2016). Unlike, the

hospice benefit under Medicare, palliative care does not have a universal benefit covered by

health insurance.

The definition of palliative care from The National Consensus Project (NCP) (2013) includes the coordination of care by an interdisciplinary team; patients, families, palliative and non-palliative health care providers collaborate and communicate about care needs. Palliative services are available independently or alongside life-prolonging care (NCP, 2013). Patients' and families' hopes for peace and dignity are supported throughout the course of illness, during the dying process, and after death (NCP, 2013, p. 9). The World Health Organization's (WHO) (2015) definition is also widely used in literature. The WHO (2015) definition is similar to the NCP's (2013) definition but includes that palliative care is appropriate "early in the course of the illness, in conjunction with other therapies that are intended to prolong life." This chapter will discuss the significance and prevalence of palliative care, define concepts related to palliative care, report on the status of educating healthcare professionals in basic palliative care, and provide an overview of the current study.

Significance

Palliative care was initially provided to patients with cancer (Meghani, 2004). However, as palliative care has evolved, it has been recognized to be beneficial to patients with a variety of chronic illnesses (Meghani, 2004). One important factor that makes palliative care significant is the worldwide aging population. According to the United Nations Population Fund (2011), there will be an estimated two billion people over the age of 60 by 2050. As people age, they are more likely to develop and live with chronic illness. In the U.S., 78% of adults over the age of 55 have at least one chronic condition, which increases to 85.6% for adults over the age of 65 years (Center for Disease Control and Prevention, 2009). By 2030, six in 10 adults over 65 years will have one or more chronic illness (Institute of Medicine, 2012). Diseases that constitute a chronic illness are diabetes, cardiovascular disease, chronic obstructive pulmonary disease, asthma,

cancer, and arthritis (Centers for Disease Control and Prevention, 2009). In certain parts of the world, human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS) have become chronic illnesses due to the advent of successful antiretroviral treatment (Fan, Kuo, Kao, Morisky, & Chen, 2011).

Palliative care has been shown to be effective in many ways in the care of patients with chronic illness and various cancers. Research has focused on how palliative care interventions can impact symptom management, quality of life, and cost effectiveness (Brumley et al., 2007; Temel et al., 2010). There are six frequently cited randomized control trial (RCT) studies that examine the effects of palliative care interventions (Hughes & Smith, 2014; Parikh, Kirch, Thomas, Smith, & Temel, 2013). Outcomes measured in these studies included symptoms, quality of life, mood, satisfaction, use of resources, advance care planning, survival, and costs (Hughes & Smith, 2014). Temel et al.'s (2010) landmark study was the only one of these six studies that reported a longer survival time for palliative care patients as compared to the control or standard care group. Four of the six studies also reported improvement in the outcomes of symptoms and quality of life (Hughes & Smith, 2014).

As the population ages and will need palliative care services, there are an insufficient number of specialized palliative care providers (Institute of Medicine, 2014; Quill & Abernethy, 2013). The Institute of Medicine (IOM), NCP, American Nurses Association (ANA), and the Hospice and Palliative Nurses Association (HPNA) support recommendations for all nurses to have the knowledge and skills to care for chronically ill patients with a palliative approach (American Association of Colleges of Nursing (AACN), 2016a).

Prevalence

It is well documented that the number of older adults with one or more chronic illnesses is expected to grow. Recent studies have explored the prevalence of palliative care needs in various settings including primary care (Dalkin, Lhussier, Philipson, Jones, & Cunningham, 2016; Marcucci et al., 2016), inpatient hospital settings (Ryan et al., 2013; Szekendi, Vaughn, Lai, Ouchi, & Williams, 2016), intensive care units (ICU) (Creutzfeldt, Wunsch, Curtis & Hua, 2015; Hua, Li, Blinderman, & Wunsch, 2014), and in the home (Gomez-Batiste et al., 2014; Herce et al., 2014). Most of these studies used specific criteria-based tools to determine if patients were appropriate for palliative care referrals. Two studies that collected data from the same large database associated with Project IMPACT found similar results (Creutzfeldt et al., 2015; Hua et al., 2014). Creutzfeldt et al.'s (2015) study showed that 15.8% of 1,268 neurology ICU admissions and 13.9% of 13,694 non-neurology ICU admissions met one criterion for palliative care during the years 2001-2008. Hua et al.'s (2014) study reviewed the same database of all ICU admissions and found that 13.8% met one or more criteria for palliative care consultation and 93.6% met only one criterion.

Other studies have shown that many patients admitted to hospitals qualify for palliative care but often do not receive it (Ryan et al., 2013; Szekendi et al., 2016). In Szekendi et al.'s (2016) study, 19% of patients admitted to one of 33 hospitals across 19 states in the U.S. in the University HealthSystem Consortium met the appropriate criterion for palliative care referral; however, 60.9% of those patients appropriate for palliative care did not receive a referral for these services. Ryan et al.'s (2013) study of two hospitals in England found that of 514 patients surveyed, 36.2% met the criteria for palliative care, but only 8.2% received specialist palliative care services.

There is a global misconception about which diagnoses should qualify a person for palliative care. Palliative care is appropriate for patients with any life-limiting disease. One study found that patients with non-malignant disease were 11 times less likely to be registered for palliative care services than those patients with malignant disease (Dalkin et al., 2016). Healthcare professionals disclosed the reason for fewer non-malignant referrals to palliative care was related to unpredictable illness trajectories and confusion surrounding the terminology of palliative care and end of life (Dalkin et al., 2016). Many of the professionals equated palliative and end of life programs to be appropriate only for patients with malignant disease (Dalkin et al., 2016). While it is understandable that patients with cancer diagnoses need palliative care services and cancer is also considered a chronic illness, healthcare professionals must also recognize the benefits of palliative care for non-malignant, chronically ill patients.

Underserved Populations and Palliative Care

When considering how palliative care can be effective to patients with chronic illnesses, healthcare providers need to assess how palliative care can be appropriate, accessible, and effective for all populations cared for in the healthcare system. Homeless and culturally diverse populations have scarcely been addressed in the literature related to palliative care.

Homeless. Homeless people often have added challenges to receiving palliative care despite their tendencies to have poorer health than the general population (Cagle, 2009; Huynh, Henry, & Dosani, 2015). Homeless people also have a life expectancy almost 30 years less than the general population (National Coalition for the Homeless, 2009). Homeless people lack housing facilities and financial support. This affects their ability to receive palliative care in similar ways that housed people with insurance coverage and family support may receive palliative care. Many people with these resources may receive palliative care in their own homes.

When homeless people seek care, it is usually from emergency departments and hospitals (National Coalition for the Homeless, 2009). Therefore, it is necessary that research explore innovative ways to provide palliative care to this population within the hospital setting but also work towards community settings that offer palliative care.

Culturally diverse. There were also very few studies exploring the palliative care needs of culturally diverse populations. To provide palliative care at a basic level for all patients, nurses must have a good understanding of people of all backgrounds and communication skills to learn what type of care best meets the patients' needs. Periyakoil, Neri, and Kraemer (2016) surveyed patients from a variety of ethnic backgrounds. All participants felt that high quality end of life care was important but 72.2% reported the following barriers to quality end of life care: financial, doctor behaviors, communication between doctors and patients, family behaviors and beliefs, healthcare systems, and cultural and religious barriers (Periyakoil, Neri, & Kraemer, 2016). This study also recommended that to overcome some of these barriers, physicians become competent in basic palliative care (Periyakoil et al., 2016).

It is of high importance that nurses understand their role in basic palliative care in order to provide quality care to chronically ill patients and families from all backgrounds and situations. This importance also lies with knowing challenges that some patients experience when accessing the healthcare system and striving to work around those challenges so that all have the potential for care that meets their individual needs.

There is a great need for palliative care across health care settings. Palliative care team members recognized that there were patients with unmet needs due to the teams working at maximum capacity (Szekendi et al., 2016). Additionally, the palliative care providers recognized the need for primary health care professionals to become competent in palliative care to fill the

gap while also recognizing when complex patients required specialists (Szekendi et al., 2016).

The IOM (2014), AACN (2016a), and ANA (2017) have also suggested that general or primary

healthcare professionals ought to have a basic competency in palliative care. The ANA (2017)

has put out a call to action for nurses to lead the transformation of palliative care.

<div align="center">**Conceptual Definitions**</div>

The concepts related to generalist health care providers' basic competency in palliative

care include basic and specialist palliative care, the nurses' role in each of these areas, models in

which palliative care is delivered, and the preparation of healthcare professionals to provide

basic palliative care. While palliative care and hospice care are often confused, basic and

specialist palliative care have relatively similar definitions regardless of the site of care.

Basic Palliative Care

Basic palliative care, sometimes referred to as generalist or primary palliative care, is

palliative care provided by health care providers who do not have specialized training in

palliative care (IOM, 2014). The skills and knowledge needed to provide basic palliative care

include: basic pain and symptom management and the ability to discuss patients' goals of care,

prognosis, advanced care planning, and decisions surrounding resuscitation (ANA, 2017; Quill &

Abernethy, 2013; Wiencek & Coyne, 2014). Nurses providing basic palliative care should be

familiar with community resources and understand the trajectory of different illnesses that their

patients may experience (Wiencek & Coyne, 2014).

Basic palliative care can be provided in various settings by nurses and other health care

providers. Literature rarely included the terms basic or primary palliative care; however, some

studies referred to nurses providing palliative care as community health nurses (Burt, Shipman,

Addington-Hall & White, 2008) or homecare nurses (Marchessault, Legault, & Martinez, 2012).

These nurses could be considered basic palliative care nurses as these studies do not refer to the

nurses as specialists or palliative care nurses. Community health nurses in Burt, Shipman,

Addington-Hall and White's (2008) study and homecare nurses in Marchessault, Legault, and

Martinez's (2012) study provided palliative care to patients in their homes. Palliative patients

were among the nurses' caseload that also included patients needing routine, non-palliative care

(Burt et al., 2008; Marchessault et al., 2012). In both studies, nurses found it difficult to balance

both types of patients and often had to prioritize their time with palliative patients and "neglect"

their routine patients (Burt et al., 2008; Marchessault et al., 2012). Nurses working with

palliative patients in the home found value in their work despite negative aspects such as lack of

organizational support and feeling isolated from colleagues (Marchessault et al., 2012; Walshe &

Luker, 2010). Non-specialist palliative care nurses working in an acute care setting had similar

experiences as community nurses. Nurses working in an acute care hospital, who provided

palliative care, felt dedicated and grateful for their work with palliative patients but also felt split

between caring for palliative patients and acutely ill, non-palliative patients (Johansson &

Lindahl, 2012). Acute care nurses in Ireland felt they did not have adequate time to spend with

palliative patients (Roche-Fahy & Dowling, 2009). These nurses also felt they needed to create a

relaxing environment for patients that did not naturally exist in the acute care setting (Roche-

Fahy & Dowling, 2009).

Specialist Palliative Care

Specialist palliative care is provided by health care professionals who have attained

special palliative care training and are certified in palliative care (Institute of Medicine, 2014).

Specialist palliative care providers have a suggested skill set that includes managing refractory

pain or symptoms associated with advanced illness, managing more complex depression, grief,

and existential distress, assisting with futile cases, and facilitating care when conflict with patients, families or other staff was present (Quill & Abernethy, 2013; Wiencek & Coyne, 2014). Specialist palliative care is most common in hospital settings in the form of consultant services (Institute of Medicine, 2014). However, specialists also provide services in outpatient settings, nursing homes, and long-term care settings (Institute of Medicine, 2014).

Palliative care certifications have expanded to include various healthcare professionals and hospitals. In medicine, palliative care was recognized as a specialty in 2006 (National Hospice and Palliative Care Organization, 2016). According to the Institute of Medicine (2014), there are over 6,000 physicians certified in hospice and palliative medicine. The Hospice and Palliative Credentialing Center (HPCC) has been certifying nurses in the specialty of hospice and palliative nursing since 1994 (Hospice and Palliative Credentialing Center, 2016). There are certifications for all levels of nursing and over 18,000 nurses are certified in hospice and palliative care (IOM, 2014). The Joint Commission started recognizing hospital palliative care programs through certification in 2011 (The Joint Commission, 2015).

In studies reviewed for a synthesis of literature, health care providers that referred patients to specialist palliative care highly respected the specialists' skillset (Firn, Preston, & Walshe, 2016). These authors also found that the perceptions that generalist practitioners had about specialist palliative care influenced their willingness to refer patients to the service (Firn et al., 2016). Many studies in this review noted that there was at times a disconnect between generalist and specialist care providers when specialists did not keep generalists up to date on the plan of care (Firn et al., 2016). However, generalists were more likely to refer to specialists when issues arose in areas they felt they lacked knowledge or skill (Firn et al., 2016). Key factors that generalists felt would facilitate collaboration with specialist palliative care providers were

visibility in the hospital, timely and responsive requests for referral, clear communication through accessibility to specialists, participation in daily rounds, and continuity of care as the patient transitioned to different units (Firn et al., 2016; Gardiner, Gott, & Ingleton, 2012). Firn et al. (2016) also identified role confusion when there was a generalist and specialist provider of the same discipline caring for a single patient. Some of the role confusion came from a lack of understanding regarding the specialist's role (Firn et al., 2016). Ewing, Farquhar, and Booth's (2009) study found that a lack of understanding of the specialists' role resulted in inappropriate referrals. Specialists found this to be a teaching opportunity about their role on the patient care team (Ewing, Farquhar, & Booth, 2009).

Mulvill, Harrington, and Robertson (2010) reviewed literature on the role of the specialist palliative care nurse in the community setting. Similar to Firn et al.'s (2016) review of literature, the themes that emerged were communication and collaboration, clarification of role, and purpose of referral (Mulvill, Harrington, & Robertson, 2010). Mulvill et al.'s (2010) review described the benefits of good communication as job satisfaction and decision-making. Good communication impacted the continuity of care when patients transitioned between services (Mulvill et al., 2010).

Models of Care

Firn et al. (2016) identified two models of how palliative care specialists and generalists provided care to their patients. The first model was an integrated model. Integrated models, in which the generalists and specialists provided care together, had a higher use of specialist palliative care services, implemented services throughout the disease process, and utilized palliative care with patients other than those with a cancer diagnosis (Firn et al., 2016). Providers

that worked within an integrated model described this type of care as addressing patients' needs while remaining involved in the patients' care (Firn et al., 2016).

The second model in Firn et al.'s (2016) study was linear. A linear care model created endpoints of care; when one type of care began, the other ended (Firn et al., 2016). For example, when it was deemed necessary to include palliative care specialists in the plan of care, generalist care providers stopped providing any care to the patient. The generalist care providers that preferred the linear model worked in cardiology, neurology, general and vascular surgery, and oncology (Firn et al., 2016). After these providers offered all the interventions they had access to, specialist palliative care providers took over the care of the patient (Firn et al., 2016).

Literature related to specialist and generalist palliative care also addressed deskilling and skill-building (Firn et al., 2016; Gaertner et al., 2010). Deskilling was described by Firn et al. (2016) as "the fear that the integration of specialist palliative care could prevent ward staff from learning skills to provide comprehensive end of life care or that skills once acquired could be lost from lack of regular practice" (p. 251). Experienced staff held most of these fears (Firn et al., 2016). Studies reviewed by Firn et al. (2016) showed that specialist palliative care integration diminished deskilling from occurring. Despite the fear of deskilling, participants in these studies had more ability to provide basic, generalist palliative care because of the involvement of specialist palliative care. Skill-building was a positive result of an integrated model of care by enhancing the education of generalist palliative care providers through observation of specialists (Firn et al., 2016). Education of generalist palliative care providers resulted in understanding the role of the specialist palliative care team, referring more appropriately, and increasing the generalists' capacity to provide basic palliative care services (Firn et al., 2016).

An integrated approach to palliative care services seemed to address the challenges described by specialist and generalist palliative care providers (Firn et al., 2016; Gardiner et al., 2012; Mulvill et al., 2010). Roles were better understood, and referrals were more appropriate when generalists and specialists worked together rather than separately. Knowledge and skills were also improved among generalist providers when they were able to communicate and observe the work of the specialist provider (Firn et al., 2016).

Palliative Care Education in Healthcare Professionals

Research about nurses' understanding of palliative care identified a lack of knowledge and a confusion over the difference between palliative care and hospice care, (Al Qadire, 2014; Finnerty & Gregory, 2010; Gardiner et al., 2011; Gott et al., 2011; Huijer et al., 2009; Hynes et al., 2015; Mahon & McAuley, 2010; Proctor et al., 2000; Spence et al., 2009) and which patients were appropriate to receive palliative care (Finnerty & Gregory, 2010; Mahon & McAuley, 2010). One study evaluated patients' palliative care needs using the Gold Standards Framework (GSF) and patients' hospital notes, then compared the results to nurse and physician assessment of palliative care needs (Gardiner et al., 2012). The GSF is used in primary care to improve quality of life for patients and their caregivers in the last year of life (Walshe, Caress, Chew-Graham, & Todd, 2008). Nurses identified that 17.8% of the 473 patients had palliative care needs; however, according to the GSF, 36.8% had palliative care needs (Gardiner et al., 2012). There was a similar discrepancy between physicians' identification of patients with palliative care needs and the GSF (Gardiner et al., 2012). The researchers then evaluated palliative needs using the GSF and patients' self-report of symptoms; 82.2% of patients met the GSF criteria for needing palliative care (Gardiner et al., 2012). Similarly, another study found physicians and nurses agreed to a high degree whether it would be a surprise if a patient died within a year;

however, very few of the patients were identified by the physicians and nurses as being appropriate for palliative care (Gomez-Batiste et al., 2014).

The lack of knowledge in palliative and end of life care was not surprising considering the amount of education health care professionals receive in their initial training programs. Dickinson (2007) evaluated the amount of end of life and palliative care education that was provided in medical and nursing schools. Most of nursing schools (88%) did offer some type of education in palliative care (Dickinson, 2007). Only 11% of nursing schools offered an entire course on palliative care, while others provided only a lecture on palliative care within another course (Dickinson, 2007). More recently, Ferrell, Malloy, Mazanec, and Virani (2016) reviewed nursing textbooks to find an increase in palliative care and end of life content but much of it was deemed "inaccurate and outdated." Nursing faculty included some palliative care concepts in their programs; however, all components of palliative care as described by NCP and End of Life Nursing Education Consortium (ELNEC) were not consistently addressed in curriculum (Ferrell et al., 2016). The American Association of Colleges of Nursing (2016a) has recently revised their competencies for undergraduate nursing students regarding care for seriously ill patients and their families. The revised competencies include guidelines for integrating palliative care into existing nursing curricula. While this is an important aspect for educating future nurses, there remains 2.6 million working nurses in the U.S. (American Association of Colleges of Nursing, 2011) who may lack the knowledge, skills, and confidence to incorporate basic palliative care into their practice.

The ELNEC program provides train-the-trainer education in palliative and end of life care for nurses from all levels and areas of practice (American Association of Colleges of Nursing, 2016b). ELNEC started educating nurses in end of life and palliative care in 2000 and

have educated over 20,000 nursing professionals in all states in the U.S. and 88 countries (American Association of Colleges of Nursing, 2016b). Organizations should be providing end of life and palliative care education to their employees or provide funding for them to utilize training courses such as ELNEC.

The current study was aimed at engaging acute care nurses in dialogue about the experiences that have shaped their knowledge and skills related to basic palliative care, identifying knowledge and skills that would be useful for their basic palliative care practice, describing characteristics of basic palliative care appropriate for integration into practice, and exploring specific considerations necessary when providing care to homeless or culturally diverse populations. The data from this study will be helpful in future education for healthcare providers and students and guide the development of policies that support palliative care at all levels.

Overview of Study

There are many studies that explore the knowledge and understanding that nurses have about palliative care and it is clear there is a deficit. However, there is no research on what basic palliative care looks like in practice. The IOM (2014) described who practices basic palliative care and other articles have suggested aspects of palliative care that is non-descript in how basic palliative care differed from specialist palliative care (Quill & Abernethy, 2013; Weissman & Meier, 2011; Wiencek & Coyne, 2014). These articles do not go into detail about how basic palliative care can be implemented and practiced in the acute care setting. Nurses working in the hospital setting encounter many patients that have at least one chronic life-limiting illness, as well as patients that are from homeless or culturally diverse populations who may have added challenges that require basic palliative care to be tailored to their unique health needs. In 2009,

39% of patients discharged from U.S. hospitals had two or more chronic illnesses and 33% had 4 or more (Steiner & Friedman, 2013). Nurses working in all areas of healthcare should thus have competencies in basic palliative care (American Association of Colleges of Nursing, 2016a; Institute of Medicine, 2014). Much of the literature describing nurses' understanding of palliative care explored the rote knowledge and definitions of palliative care. Palliative care is not provided in a universal way, so to understand and improve patient care in U.S. hospitals, further research is needed to gain a deeper understanding of how nurses working in U.S. hospitals perceive basic palliative care and how they see it as applicable to their practice. Current studies focus on the knowledge and understanding of basic principles of palliative care rather than seeking a more in-depth understanding of nurses' experiences and perceptions about basic palliative care. This study sought to describe basic palliative care in the acute care setting with consideration for specific homeless and culturally diverse populations.

Design

This qualitative study employed focus group and individual interviews for data collection. Focus group interviews are different from individual interviews in that the data is gathered and analyzed from the perspective of the interaction among the group members rather than through a conversation between the researcher and interviewee (Richie, Lewis, McNaughton Nicholls, & Ormston, 2014). One major advantage of focus group interviews is the chance for the participants to hear what others in the group think, take time to reflect, and offer their point of view (Richie et al., 2014). Hearing others' experiences may also trigger responses about experiences that participants may have forgotten (Richie et al., 2014; Stevens, 1996). Focus group interview data allowed for the collection of rich data by allowing participants to discuss, interact, and move to a deeper level of discussion (Richie et al., 2014; Stevens, 1996).

Inclusion of individual interviews increased the credibility of the data collected in the focus group interviews (Amankwaa, 2016). The opportunity to participate in an individual interview versus a focus group interview setting may have been more comfortable for some participants that do not like group settings or felt freer to express themselves in one-on-one situations.

Theoretical Frameworks

This study was guided by critical and transformative learning theories. Nursing is a profession that has historically involved gendered dynamics due to the interactions between what was historically a predominantly male medical profession and a predominantly female nursing profession. One study explored the experiences of nurses working with physicians and needing to challenge physician decisions (Churchman & Doherty, 2010). Nurses described challenging physicians as a battle and avoided confrontation when physicians were known to have bad temperaments (Churchman & Doherty, 2010). As in the past when nurses were expected to act subordinate, nurses continued to "play games" with physicians in ways that make the physicians do what they wanted without hurting physician egos (Churchman & Doherty, 2010). It was important to explore the beliefs and perceptions of nurses, working within an interdisciplinary setting, with an understanding of this history of oppression through a critical theory lens.

The populations that nurses care for in the acute care setting may also have different experiences based on their socioeconomic or cultural background. Some homeless people have limited trust in health care professionals or do not have optimal housing to receive traditional palliative care (Cagle, 2009; Song et al., 2007). There is little research on the experiences of the culturally diverse populations' experiences with palliative care; however, in one study nurses described feeling uneasy and helpless when faced with unfamiliar situations related to palliative

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care (Henry & Timmins, 2016). Viewing how palliative care can be provided to these

populations through a critical theory lens helped to bring challenges and barriers to the forefront.

In addition, nurses have had many experiences with patients that shape their

understanding, beliefs and perceptions. A frame of reference was described as a "structure of

assumptions and expectations through which we filter sense impressions" (Merriam, Caffarella,

& Baumgartner et al., 2007, p. 132). A point of view was one dimension of a frame of reference

in which Mezirow described as beliefs, attitudes, and judgements (Merriam et al., 2007).

Transformative learning theory guided the exploration of these experiences and further

development of understanding by valuing experiences and critical reflection. Dialogue used in

this study helped to uncover acute care nurses' practices and beliefs about basic palliative care

through storytelling and sharing of experiences.

Research Questions

This study aimed to respond to the following research questions:

1) What characteristics of palliative care do acute care nurses identify as appropriate for

basic palliative care nursing practice?

2) What aspects of palliative care do acute care nurses feel they need more knowledge

about?

3) What are the specific considerations acute care nurses find necessary when providing

palliative care to homeless and culturally diverse populations?

4) How can basic palliative care be integrated into acute care nurses' general practice?

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Conclusion

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With the growing number of aging adults with chronic illness, generalist healthcare

providers have the potential to help alleviate suffering and improve the quality of life for patients

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by being competent in basic palliative care. Studies have shown the lack of knowledge among the general public (McIlfatrick et al., 2013) and healthcare providers (Al Qadire, 2014; Finnerty & Gregory, 2010; Gardiner et al., 2011; Gott et al., 2011; Huijer et al., 2009; Hynes et al., 2015; Mahon & McAuley, 2010; Proctor et al., 2000; Spence et al., 2009) about palliative care. However, there are no studies that focus on how basic palliative care is operationalized in practice. Studies used hospice and palliative care interchangeably without distinctions for specialist or generalist palliative care practice. Literature about providing basic palliative care for homeless and culturally diverse populations also lacks in specifying how nurses work to meet specific needs that these populations may present. This study attempted to fill that gap in the literature by inviting acute care nurses to participate in focus group and individual interviews to discuss their experiences with palliative care. Participants were also asked what type of education they felt they would need to integrate basic palliative care into their nursing practice. The results from these interviews will enable the design of an orientation and continuing education class on basic palliative care for nurses. Results from this study will also be helpful to nursing faculty and students by describing what basic palliative care looks like in practice to better prepare new nurses entering the profession. Lastly, the results of this study are important to policy development at local and national levels as access and coverage for palliative care is not universal.

The IOM (2014) and the American Association of Colleges of Nursing (2016a) have recently highlighted the need for generalist healthcare providers to have competencies in basic palliative care to meet the needs of the patients. The ANA (2017) has charged nurses with leading the transformation of palliative care through education, research, practice, administration, and policy change. Through interviews with acute care nurses, the aim of this

study was to engage in dialogue about the experiences that have shaped nurses' knowledge and skills related to palliative care, identify what knowledge and skills acute care nurses felt would be useful to learn for their basic palliative care practice, describe characteristics of basic palliative care appropriate for acute care nurses to integrate into practice, and explore specific considerations acute care nurses find necessary when providing care to homeless or culturally diverse populations.

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Chapter 2: A Review of the Literature

Millions of Americans are afflicted with one or more chronic diseases. The Center for Disease Control and Prevention (CDC) (2015) reported that almost half of adults had one chronic disease and a quarter of adults had more than two chronic diseases in 2012. One in three Medicare beneficiaries was reported to have five or more chronic diseases (Cubanski et al., 2015). Not surprisingly, seven of the top 10 leading causes of death are chronic diseases, including heart disease, cancer, and chronic lower respiratory diseases (CDC, 2015). As the baby boomer generation continues to age, six in 10 adults over the age of 65 will have one or more chronic disease by 2030 (Institute of Medicine (IOM), 2012). These statistics require health care providers to take notice and focus on a palliative approach to care for people with chronic diseases that improves quality of life.

Palliative care is appropriate for people who have chronic or life-threatening illness and are still receiving curative treatments (Morrison & Meier, 2015). In a report about palliative care services in the United States, 1-2 million people admitted to U.S. hospitals that would benefit from palliative care services do not receive these services (Morrison & Meier, 2015). While palliative care services have grown rapidly, there is still a lack of specialists and services that are able to reach all those in need (IOM, 2014). Most of the growth of palliative care services has been in hospital settings. Community-based palliative care services outside of the hospital setting is still lacking (Meyers, Kerr, & Cassel, 2014; Morrison & Meier, 2015).

There is also very little research regarding palliative care and certain patient populations. For example, homeless people experience higher prevalence of chronic disease and a shorter life expectancy; however, there has been little attention paid to this population in the palliative care literature. Also, people of culturally diverse backgrounds may experience additional challenges when seeking healthcare, such as language barriers.

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The IOM's (2014) report, *Dying in America,* recommended including palliative care curricula in medical and nursing schools to ensure generalists' ability to provide basic palliative care, reserving specialists for complex cases. The American Nurses Association (ANA) (2017) has also charged nurses with leading the way in transforming palliative care through research, education, administration, policy, and practice. This chapter reviews the literature to determine what factors play a role in fulfilling the IOM's (2014) and ANA's (2017) recommendations that all healthcare providers are competent to practice basic palliative care and how nurses play a crucial role in integrating basic palliative care into practice.

Method of Search

The search of literature was conducted using four different databases; the University of Wisconsin – Milwaukee's online library, CINAHL, Medline, and Academic Search Complete. All searches included reviewing the titles and abstracts for relevance to the topic. Following that, articles were thoroughly reviewed and included in an extensive evidence table. The first search used the phrases "palliative care" AND "nurse understanding", with the limitations set to include articles from the years 2007-2015. From this search, 30 articles were selected to be read and reviewed. The search using CINAHL and Academic Search Complete included articles from the years 2008-2016, limiting the search to academic journals, and used multiple variations of phrases including: "understanding" AND "palliative care", "understanding" AND "palliative care" AND "nursing", "acute care setting" AND "basic palliative care", and "experience" AND "basic palliative care". From these searches, 38 articles were selected to be read and reviewed. Further searches were performed using the Academic Search Complete database using the terms "beliefs" and "perceptions"; eleven articles were reviewed. Lastly, a search using the terms "palliative approach" AND "acute setting" resulted in 36 articles, five of which were reviewed

for inclusion. Articles that were referenced from other articles and articles that the author had read in previous work were also used in this review.

Articles were included if a study pertained to nurses' knowledge, beliefs, and experiences of palliative care in any practice setting, nurses' experiences caring for the terminally ill or palliative care patients, and intervention studies to improve knowledge. Studies that included other disciplines as well as nursing were included as were articles about factors influencing palliative care. There were no limitations of the geographical location of the studies. Other reviews of the literature were excluded, and only primary studies were included. Articles written in languages other than English were excluded.

An additional search was done to explore the experiences of palliative care and homeless and culturally diverse populations. Academic Search Complete, CINAHL, and Medline databases were used. Search terms included, "palliative care" AND "homeless", and "palliative care" in combination with a variety of ethnicities. There was very little research in either of these populations pertaining to palliative care. There were some emerging interventional studies addressing advanced care planning with homeless people and fears homeless people had around healthcare and dying. Otherwise, there has been little to no recent studies examining nursing experiences with palliative care and these populations. The few studies and literature reviews that exist on these topics will be included in this discussion.

Key Concepts

The key concepts that emerged from the review of the literature were basic understanding of palliative care, nursing characteristics, and workplace environment. Each of these concepts describes the knowledge, beliefs, and experiences nurses had working in palliative care or in non-specialist nursing roles. Key concepts identified in the literature on

homeless populations were related to barriers which included lack of housing and social support, medication management, and the past experiences homeless people had with health care professionals, end of life, and serious illness. Literature on culturally diverse populations was scarce and included topics of pain outcomes, adaptation to living in the U.S., and how nurses care for patients from diverse backgrounds.

Basic Understanding of Palliative Care

　　Palliative and Hospice Terms. Palliative care is a health care service that focuses on management of symptoms and improved quality of life when a person is faced with a life-threatening illness (American Nurses Association & Hospice and Palliative Nurses Association, 2014). The terms palliative care and hospice care are often used interchangeably; philosophically, both types of care are similar (Meghani, 2004).

　　Factors that make palliative and hospice care unique from other types of care include the holistic approach to caring for the ill person and including family in the unit being cared for (Ferrell & Coyle, 2010; American Nurses Association & Hospice and Palliative Nurses Association, 2014; Meghani, 2004). The ethical standard for hospice and palliative nursing addressed the importance of caring for the patient in a way that "protects patient autonomy, dignity, rights, values, and beliefs" (American Nurses Association & Hospice and Palliative Nurses Association, 2014, p. 45). Meghani (2004) described the holistic approach of palliative care to include relieving people of pain and suffering in the areas of "physical, emotional, social, spiritual, and relational" (p. 158). The standards and scope of palliative nursing identified the need for incorporating both the patient's and family's needs and preferences in the creation of a holistic plan of care (American Nurses Association & Hospice and Palliative Nurses Association, 2014).

Palliative care from a global perspective. In the United States, coverage and accessibility to different types of care are generally dictated by health insurance coverage. Hospice benefits are covered by Medicare and have specific criteria for eligibility (Meghani, 2004). Eligibility for hospice under Medicare requires that a person be terminally ill, and that life expectancy is 6 months or less (Centers for Medicare & Medicaid Services, 2016a). Under these benefits, patients must agree to discontinuing life-prolonging treatments (Meghani, 2004). Palliative care as defined by the World Health Organization (WHO) (2015) is care applicable early in the disease process and "in conjunction with other therapies that are intended to prolong life." Recently, under the Affordable Care Act of 2010, a new model of care is being experimented with under the Medicare hospice benefit. The Medicare Care Choices Model began in 2016 and is a five-year experiment that will be implemented over 2 years (Centers for Medicare and Medicaid Services, 2016b). The new model allows Medicare and hospice benefit eligible patients to receive palliative and supportive care while continuing to receive curative treatments (Centers for Medicare and Medicaid Services, 2016b). The purpose of the introduction and limited duration of this model was to evaluate if these services "improve the quality of life and care received by Medicare beneficiaries, increase patient satisfaction, and reduce Medicare expenditures" (Centers for Medicare and Medicaid Services, 2016b). The Medicare Care Choice Model is limited to those with diagnoses of cancer, chronic obstructive pulmonary disease, congestive heart failure, and HIV/AIDS (Centers for Medicare and Medicaid Services, 2016b). In the United States, palliative care is also available to people with health insurance other than Medicare; however, not all insurance plans provide this specific benefit, and services may be covered under chronic care coverage (Minnesota Network of Hospice and Palliative Care, n.d.).

Globally, palliative care has grown in the last couple of decades. Many countries have some type of palliative care policy or strategy in place (African Palliative Care Association, 2016; Australian Department of Health, 2015; Van Beek et al., 2013). In Europe, Germany, France, Belgium, and Spain are the only countries that have specific laws regarding palliative care (Van Beek et al., 2013). Germany was the first to have a palliative care law in 1997 and Spain was the latest with a law passed in 2011 (Van Beek et al., 2013). The United Kingdom, the birthplace of hospice care, has many national and regional initiatives in place (Van Beek et al., 2013). One example is the implementation of the Gold Standard Framework (GSF) (Van Beek et al., 2013). The GSF is used in primary care to improve quality of life for patients and their caregivers in the last year of life (Walshe, Caress, Chew-Graham, & Todd, 2008). The program offers training in various settings including hospitals and dementia care settings (National Gold Standard Framework Centre, 2016).

Many African countries have developed policies or strategic plans related to palliative care. Rwanda and Swaziland developed palliative care policies or guidelines while Malawi is in the process of developing a national policy (African Palliative Care Association, 2016). Other nations have included palliative care into their national policies on HIV/AIDS (African Palliative Care Association, 2016).

The African Palliative Care Association (2016) utilized the WHO's palliative care definition, while other countries with policies on palliative care created their own, used a variation of the WHO definition, or did not offer a definition (Van Beek et al., 2016). For example, Belgium defined palliative care as total care for a person suffering from an illness that is no longer responding to treatment (Van Beek et al., 2013).

Despite the WHO's definition of palliative care, many researchers, providers, and patients continue to use the term interchangeably with hospice or end of life care. This may reflect the way in which palliative care is implemented in their geographical location. This use of terminology is reflected in the studies included in this review; the search term that was used was "palliative care," but many studies use palliative care to refer specifically to end of life care.

Nurses' understanding. The research surrounding nurses' understanding of palliative care included many different data collection methods, such as in-depth individual interviews (Bezerra do Amaral, Rosario de Menezes, Martorell-Poveda, & Cardoso Passos, 2012; Brzostek, Dekkers, Zalewski, Januszewska, & Gorkiewicz, 2008; Cameron & Salas, 2009; Campbell, 2011; Ewing, Farquhar, & Booth, 2009; Johansson & Lindahl, 2012; Kaasalainen et al., 2014; Mahon & McAuley, 2010; Mak, Chiang, & Chui, 2013; Marchessault, Legault, & Martinez, 2012; McKeown, Cairns, Cornbleet, & Longmate, 2010; Robinson, Gott, Gardiner, & Ingleton, 2015; Roche-Fahy & Dowling, 2009; Walshe et al., 2008), focus group interviews (Burt, Shipman, Addington-Hall, & White, 2008; Ewing et al., 2009; Gardiner, Cobb, Gott, & Ingleton, 2011; Gott, Seymour, Ingleton, Gardiner, & Bellamy, 2011; Hynes et al., 2015; Johnson et al., 2011; O'Shea, 2014; Phillips, Davidson, Jackson, & Kristianson, 2008; Raunkiaer & Timm, 2010; Spence et al., 2009; Valente, 2011; Verschuur, Groot, & van der Sande, 2014), surveys or pre- and post-tests (Al Qadire, 2014; Brazil, Brink, Kaasalainen, Kelly, & McAiney, 2012; Brzostek et al., 2008; Chan et al., 2014; David & Banerjee, 2010; Dillworth et al., 2016; Fink, Oman, Youngwerth, & Bryant, 2013; Huijer, Abboud, & Dimassi, 2009; Kang et al., 2010; McDonnell, McGuigan, McElhinney, McTeggert, & McClure, 2009; Nguyen, De Witt, Hughes, Rasmussen, & Weckmann, 2015), and observation (Cameron & Salas, 2009). Studies focused on nurses and a variety of other healthcare disciplines. In one study, recent nursing graduates and

experienced nurse practitioners were asked to self-assess their understanding of the term palliative care; 41% of the recent graduates and 49% of nurse practitioners rated their understanding as very good, and 50% and 46% as good, respectively (Brzostek et al., 2008). In this study, the researchers did not ask nurses to differentiate between palliative and hospice care and relied on self-assessment of knowledge; however, the self-assessments positively correlated with the participants' ability to correctly identify palliative care presented in a collection of case studies (Brzostek et al., 2008). Conversely, many studies have shown that nurses have difficulty distinguishing palliative care from hospice or end of life care (Al Qadire, 2014; Fink et al., 2013; Finnerty & Gregory, 2010; Gardiner et al., 2011; Gott et al., 2011; Huijer et al., 2009; Hynes et al., 2015; Mahon & McAuley, 2010; Marchessault et al., 2012; Monterosso, Ross-Adjie, Rogers, Shearer, & Rogers, 2016; O'Shea, 2014; Reimer-Kirkham, Sawatzky, Roberts, Cochrane, & Stajduhar, 2016; Spence et al., 2009; Verschuur et al., 2014). In many of these studies, nurses were asked what palliative care was and which patients would be appropriate to receive palliative care. The most frequent answer in Finnerty and Gregory's (2010) study was comfort and end of life. Nurses in Mahon and McAuley's (2010) study commonly answered that symptom management, excluding curative treatments, defined palliative care. Following an educational introduction to palliative care, nurses continued to define palliative care as comfort and end of life (Finnerty & Gregory, 2010). The most common answer for when palliative care should be started was when there was a terminal illness and it was the patient and family's choice (Finnerty & Gregory, 2010). This answer did change following the educational intervention to progressive chronic illness, which is aligned with the WHO's definition of palliative care (Finnerty & Gregory, 2010; WHO, 2015). Participants in Mahon and McAuley's (2010) study commonly responded that criteria for which palliative care would be appropriate were those factors related

to illness, the degree of suffering, and end of life care. A few participants believed that anyone with a cancer diagnosis should be eligible for palliative care (Mahon & McAuley, 2010). Nurses believed palliative care was appropriate when curative treatments no longer benefited the patient and was often considered late in the illness trajectory (O'Shea, 2014). Huijer, Abboud, and Dimassi's (2009) study found that 69.1% of the nurse participants believed palliative care should be initiated when the disease could not be cured. Intensive care nurses felt that physicians had difficulty identifying patients that were palliative care appropriate (McKeown et al., 2010). While the nurses in one study had difficulty defining palliative care, they believed that it should be started earlier in the illness trajectory (Verschuur et al., 2014).

Key principles of palliative care are that it does not prolong or hasten death and it should enhance quality of life (WHO, 2015). However, non-clinical nurses (for example, managers and administrators) in Huijer et al.'s (2009) study had the highest rates of mistakenly believing that an outcome of palliative care was to prolong life. Oncology nurses in this study were the least likely group of nurses to believe that "living with dignity and respect" was an outcome of palliative care and did believe that "palliative care destroys hope and leads to despair and depression" (Huijer et al., 2009, p. 348). These beliefs are in direct contradiction to the actual principles of palliative care regardless of the common confusion between hospice and palliative care.

Two studies used the Palliative Care Quiz for Nursing (PCQN) to assess nurses' understanding of palliative care (Al Qadire, 2014; Brazil et al., 2012). The PCQN includes three conceptual categories in both forms of the PCQN used in these studies; they include: palliative care philosophy, pain and other symptoms, and psychosocial and spiritual care (Brazil et al., 2012). The majority of nurses in Al Qadire's (2014) study had not received any palliative care

education whereas it was not reported if nurses in Brazil, Brink, Kaasalainen, Kelly, and McAiney's (2012) study had previous education. Overall mean scores on the PCQN were 8.3 (Al Qadire, 2014) with a possible score of 20. The mean scores for pain and symptom management, psychological and spiritual care, and philosophy and principles of palliative care were 5.6 (possible score=13), 0.8 (possible score=3), and 1.1 (possible score=4), respectively (Al Qadire, 2014). Nurses in Brazil et al.'s (2012) study were from four different long-term care homes. Percentage of correct answers to items on the PCQN was ranked by the authors (Brazil et al., 2012). Two items were answered incorrectly more frequently among the four care centers. A statement about the philosophy of palliative care and its compatibility with aggressive treatment was incorrectly answered false or 'I don't know' by a large majority of participants at each home (Brazil et al., 2012). Statements that indicated appropriate symptom management in the end of life were also answered incorrectly by nurses in this study (Brazil et al., 2012).

Similar to the poor knowledge about palliative care found in Al Qadire's (2014) and Brazil et al.'s (2012) study, McDonnell, McGuigan, McElhinney, McTeggert, and McClure (2009) surveyed 359 nurses working in nursing homes. The authors of this study found that only 25% of the registered nurses understood who palliative care was appropriate for and what its purpose was (McDonnell et al., 2009). Only 18% of nurses understood the importance of including families in palliative care (McDonnell et al., 2009). One characteristic of both palliative and hospice care is the provision of bereavement care to families following the death of the patient; only two registered nurses in this study understood this aspect of palliative care (McDonnell et al., 2009).

The lack of understanding about palliative care also occurred in relation to the timing of palliative care referrals. Referrals for consultation from any specialty were generally made by a

physician or non-physician providers, such as nurse practitioners (Dunn, 2010). Nurses felt that physicians did not communicate with patients appropriately when discussing prognosis which led to a delay in referrals to palliative care (Dillworth et al., 2016). However, when identifying who should recognize palliative appropriate patients, Reimer-Kirkham, Sawatzky, Roberts, Cochrane, and Stajduhar's (2016) study found a need for change in who identified patients as having a palliative need from physicians to nurses. Consultation for palliative care services were at times seen as a failure on the providers' ability to care for the patient (Gardiner et al., 2011; McKeown et al., 2010). The age of the patient and presence of familial support played a role in the timing of palliative care referrals. It was more difficult to initiate palliative care services when a patient was young or if an older adult did not have family support (Gardiner et al., 2011). Some nurses recognized that integrating a palliative approach was appropriate at diagnosis of a life-limiting disease or condition rather than waiting for curative treatments to be exhausted (Monterosso et al., 2016; O'Shea, 2014). Patients with non-malignant disease were also less likely to be referred to palliative care than patients with a diagnosis of cancer (Gardiner et al., 2011). Dalkin, Lhussier, Philipson, Jones, and Cunningham's (2016) study found similar results of patients with non-malignant disease being 11 times less likely to be registered in a particular palliative care program. The participants cited unpredictable illness trajectories as the reason for not registering patients with non-malignant disease (Dalkin, Lhussier, Philipson, Jones, & Cunningham, 2016). Participants expressed a concern that many times the focus of care was curative, and this also delayed a palliative care referral (Gardiner et al., 2011; McKeown et al, 2010).

Lastly, nurses working in settings where they were expected to provide palliative care expressed a desire for early referrals in order to develop relationships with patients and families

(Verschuur et al., 2014). Early referrals did not occur because of the difficulty in identifying patients who were appropriate. One study focused on determining palliative care needs among inpatient populations (Szekendi, Vaughn, Lai, Ouchi, & Williams, 2016). Nineteen percent of the inpatients were assessed according to the study's definition of palliative care to be appropriate. Of this 19%, 60.9% were not referred or did not receive palliative care services (Szekendi et al., 2016). Kydd's (2015) review discussed the problem with healthcare professionals having multiple definitions or understandings of palliative care. Confusion of terms or definitions can be a major factor in referring patients at appropriate times and patients' acceptance of palliative care (Kydd, 2015).

The IOM (2014) identified three levels of care that fall under the concept of palliative care: hospice, basic or primary palliative care, and specialist palliative care. There are not and will not be a sufficient number of specialists available to provide all palliative care services that would be appropriate; therefore, it is important for primary healthcare providers to be competent in basic palliative care (IOM, 2014). Basic palliative care is defined by the IOM (2014) as

> 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 populations but are not certified in palliative care (p. 1-6).

It is clear from the results of these studies that nurses working in various settings and countries do not have a basic knowledge of palliative care to fulfill the IOM's recommendation that "all clinicians across disciplines and specialties who care for people with advanced serious illness should be competent in basic palliative care" (p. 4-25).

Need for education. Not surprisingly, many study participants recognized a need for more education in palliative care (Cameron & Salas, 2009; Fink et al., 2013; Huijer et al., 2009; Marchessault et al., 2012; McKeown et al., 2010; Monterosso et al., 2016; Reimer-Kirkham et al., 2016; Roche-Fahy & Dowling, 2009). While in some studies, nurses reported receiving palliative care education (Fink et al., 2013; Huijer et al., 2009), many also requested more education in this area (Cameron & Salas, 2009; Fink et al., 2013; Huijer et al., 2009; Marchessault et al., 2012; McKeown et al., 2010; Monterosso et al., 2016; Roche-Fahy & Dowling, 2009). Education in symptom management was the most requested topic (Fink et al., 2013; Marchessault et al., 2012; Monterosso et al., 2016; Reimer-Kirkham et al., 2016; Roche-Fahy & Dowling, 2009). Other areas that nurses requested education in related to palliative care included end of life communication, business management (Fink et al., 2013), and medication administration (Roche-Fahy & Dowling, 2009). Additionally, nurses in Reimer-Kirkham et al.'s (2016) study identified needed education in "self-reflection about attitudes towards pain and death" (p. 2194). Nurses in this study also expressed needs in initiating conversations with patients and families about goals of care, ethical-legal issues, and providing psychological, social, and spiritual care (Reimer-Kirkham et al., 2016). Studies also indicated a need for general palliative care education (Fink et al., 2013, Marchessault et al., 2012; Monterosso et al., 2016; O'Shea, 2014). Homecare nurses expressed that education would benefit patients (Marchessault et al., 2012). The use of shadowing specialists and role-playing was suggested by health care professionals as tools for educating on palliative care (Monterosso et al., 2016).

Nursing Characteristics

There were three themes that were identified in the literature that are relevant to nurses providing palliative care; nurses' confidence in their own knowledge and skills, nurses' experience in practice, and the nurse-patient relationship.

Confidence in skills and knowledge. There was a difference in confidence levels reported in the literature depending on whether the nurses participated in a study that included educational interventions. Many studies included multiple disciplines, mainly registered nurses, physicians, and nursing or care assistants (Cameron & Salas, 2009; Dee & Endacott, 2011; Ewing et al., 2009; Finnerty & Gregory, 2010; McDonnell et al., 2009; Phillips et al., 2008). Studies that elicited responses from participants without providing education about palliative care found feelings of inadequacy in knowledge of palliative care (Cameron & Salas, 2009; Ewing et al., 2009), skills (Dee & Endacott, 2011; Hynes et al., 2015; McDonnell et al., 2009) and knowledge of how palliative care work was relevant to other members of the healthcare team (Gott et al., 2011). Cameron and Salas (2009) interviewed a registered nurse and physician about concerns regarding their experiences in providing palliative care. The major concern for these healthcare professionals was the sense that they had inadequate knowledge about palliative care (Cameron & Salas, 2009). This was partially explained by the training process at this particular research site (Cameron & Salas, 2009). Initially when the palliative care services were started, employees were trained in palliative care; however, training was not continued when there was employee turnover (Cameron & Salas, 2009). Skills such as decision making and communication were difficult when there was not a clear clinical pathway for the patient (Dee & Endacott, 2011), when nurses were uncertain about how to respond in conversations about prognosis or dying (Hynes et al., 2015), or when answering patients' questions (Cameron & Salas, 2009). Some nurses did not feel comfortable talking with patients about dying or engaging in patient

and family interactions (McDonnell et al., 2009; Monterosso et al., 2016), were not confident in their symptom management skills (Monterosso et al., 2016), and often referred to specialist palliative care providers for advice in symptom management (McDonnell et al., 2009). Nurses in Reimer-Kirkham et al.'s (2016) study reported a general lack of confidence in fulfilling patients' palliative needs. However, oncology nurses in one study felt they were skilled in bringing up difficult topics of conversation that nurses in other studies have found difficult and challenging (Valente, 2011).

Palliative care related skills were a source of feeling inadequate for some nurses. Eighty-four percent of the registered nurses in one study had experience caring for a patient with a syringe driver, a device often used in palliative care (McDonnell et al., 2009). However only two-thirds felt competent in this skill and less than half felt competent assessing the patients' need for this device (McDonnell et al., 2009). In one study, a lack of confidence in skills and knowledge led to more referrals to specialists when the cases were not complex (Ewing et al., 2009). Palliative care specialists in this study identified this as a good opportunity to provide education to generalist providers (Ewing et al., 2009).

Nurses felt inadequate when dealing with patients' physical and existential needs (Johansson & Lindahl, 2012). Nurses described "finding oneself, both as person and professional nurse" was helpful when assisting patients and families with these needs (Johansson & Lindahl, 2012, p. 2038). Many times, nurses felt uncertain about the work they did, craved validation, and felt inadequate when they could not provide what patients' and families needed (Johansson & Lindahl, 2012).

Alternatively, studies that did include some type of intervention showed good results for improving nurses' confidence in the different areas of palliative care (Finnerty & Gregory, 2010;

Kang et al., 2010; Milic et al., 2015; Phillips et al., 2008). Participants who attended some sort of

palliative care education reported sharing the information they had learned with peers and

colleagues (Finnerty & Gregory, 2010; Phillips et al., 2008). Knowledge gained from palliative

care interventions also empowered nurses to take responsibility for their role in the care team

(Milic et al., 2015; Phillips et al., 2008) and improved the use of skills (Milic et al., 2015). A

higher percentage of participants who attended an 8-hour workshop reported "very good" to

"excellent" level of skills after the workshop than before (Milic et al., 2015). Confidence in

utilizing skills in communication also increased after the workshop and at a 3-month follow-up

(Milic et al., 2015). Nurses in Phillips, Davidson, Jackson, and Kristianson's (2008) intervention

study reported they were more inclined to reach out to specialists, prevent unnecessary transfers

to hospitals at end of life, and changed pain assessments from a reaction to a routine intervention

after participating in a tailored palliative care education session.

Experience. The experience that a nurse had was also an important factor that was

evident in the literature. Benner (1982) described the expert nurse as one that no longer relied on

guidelines to understand patients. Instead, the expert nurse used what was described as intuition

to understand patients (Benner, 1982). Nurses in Dee and Endacott's (2011) study described

similar experiences as being able to recognize that a patient was dying yet lacked the quantifiable

data to support this knowledge. One participant in this study stated "there are times that you just

know" when a patient was dying (Dee & Endacott, 2011, p. 189). This type of knowing was

described as a challenge in addition to a beneficial skill; since there was no evidence, it was

difficult to introduce the specific pathway for these patients (Dee & Endacott, 2011). Nurses in

this study also described the benefit of experience as a reference to draw from in similar patient

situations (Dee & Endacott, 2011). Nurses in Johansson and Lindahl (2012) described intuitive knowing as having good self-knowledge and knowledge of others.

One study showed that nurses with more experience scored better in a variety of areas within palliative care (Thacker, 2008). Thacker (2008) found significant differences among years of experience when analyzing data on nurses' perceptions of advocacy behaviors in end of life care in an acute care setting. This study reported that experienced and expert nurses, as defined by Benner, conveyed the importance of communication, relationships with patients and family, and nurse beliefs and compassion with greater frequency than novice nurses (Thacker, 2008). Nurses in Valente's (2011) study noted a need for role modeling to enable new nurses to better communicate sensitive information and advocate for patients' wishes to other members of the healthcare team. Benner (1982) described the expert nurses' actions as a way of being and reacting to illness. Patients admitted to an acute care hospital described hospital staff as "experts in managing illness" and this created a feeling of safety (Robinson et al., 2015, p. 706).

Conversely, there were studies that did not find any differences in the knowledge or attitudes of nurses based on expertise. Al Qadire's (2014) study did not identify any statistical significance based on age, education level, years of experience, or area of experience with nurses that were surveyed with the PCQN. Nor were there any statistically significant differences regarding those nurses who had previous education on the topic of palliative care (Al Qadire, 2014). It is worth noting that Al Qadire's (2014) study was conducted in Jordan where palliative care is in its infancy, which may have played a role in the results of that study.

Nurse-patient relationships. Palliative care is a holistic approach to caring for patients and their families. Creating relationships with patients and family members is an important part of nursing itself. Many studies discussed the benefits and challenges the role of nurse-patient

relationships can play in palliative care (Cameron & Salas, 2009; Chan et al., 2014; Dee & Endacott, 2011; Ewing et al., 2009; Huijer et al., 2009; Hynes et al., 2015; Johansson & Lindahl, 2012; Kaasalainen et al., 2014; Mahon & McAuley, 2010; McDonnell et al., 2009; Milic et al., 2015; Richardson, MacLeod, & Kent, 2012; Roche-Fahy & Dowling, 2009; Zhou, Stoltzfus, Houldin, Parks, & Swan, 2010). Nurses described their palliative care role as a privilege (Burt et al., 2008; Johansson & Lindahl, 2012; Marchessault et al., 2012). Richardson, MacLeod, and Kent's (2012) article discussed the concept of empathy and its role in nursing. The Steinian approach to empathy is "recognizing a lived experience, clarifying another person's emotional state and then standing side-by-side with that person" (Richardson et al., 2012, p. 692). This description was how nurses in the literature described relationships with palliative care patients. Some nurses described meeting patients as "giving much of oneself both as a fellow human being and as a professional nurse" (Johansson & Lindahl, 2012, p. 2038). Cameron and Salas's (2009) study about the experiences of palliative care nurses in Chile, described "going the extra mile" for patients. This included providing much more than nursing care to patients; in some cases, nurses gave clothes to patients and families and made extra visits or called patients during off time on weekends (Cameron & Salas, 2009). Some nurses in Kaasalainen et al.'s (2014) study also reported going the extra mile by doing laundry for low-income patients. Creating close relationships with patients and families was beneficial in assessing patients (Dee & Endacott, 2011; Johnson et al., 2011; Mahon & McAuley, 2010), in making decisions about care (Kaasalainen et al., 2014; Mahon & McAuley, 2010), and to the quality of care (Johansson & Lindahl, 2012; Kaasalainen et al., 2014; Roche-Fahy & Dowling, 2009). Knowing the patient well allowed providers to compare the patient's condition from past to present (Dee & Endacott, 2011) and to know what expectations the patient may have regarding healthcare (Mahon &

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McAuley, 2010; Walshe et al., 2008). When there was a relationship between the patient and healthcare provider, decisions could be based on more than clinical data alone (Mahon & McAuley, 2010). Nurses who formed relationships with the patients and families could help them during difficult transitions of care, such as moving from palliative care to hospice care (Kaasalainen et al., 2014). Nurses also favored referrals early in the illness process in order to have time to build relationships with patients and families (Johnson et al., 2011). Rural nurses in Canada found that there was a strong sense of community in their area of nursing, which enhanced trusting relationships with members of those communities (Kaasalainen et al., 2014). Nurses perceived relationships as an important role in the patients' perception of comfort (Roche-Fahy & Dowling, 2009).

Nurses recognized the importance of managing relationships with patients by balancing engagement with detachment and distancing themselves at times (Johansson & Lindahl, 2012; Roche-Fahy & Dowling, 2009). The roles of nurses in palliative care was recognized as emotionally demanding (Johansson & Lindahl, 2012; Roche-Fahy &Dowling, 2009). Nurses reported that close relationships can cause problems of uncertainty when having difficult conversations or when the busyness of healthcare overshadows the importance of the relationship (Hynes et al., 2015). Nurses reported experiencing feelings of failure when they were unable to respond to patient suffering due to outside influences; this feeling was heightened when there was a close relationship with the patient (Hynes et al., 2015). Nurses in McDonnell et al.'s (2009) study suggested the need for support systems to help nurses cope with these demands. Nurses felt there was a risk of becoming too attached to patients they cared for (Johansson & Lindahl, 2012). To protect themselves, nurses described creating a distance between themselves and the patients (Johansson & Lindahl, 2012) and suppressing their emotional responses

(O'Shea, 2014). They sometimes felt helpless and sad if a patient suddenly died and sometimes blamed themselves after the death (Mak et al., 2013). The physicality of care and existential needs patients had created professional insecurity among nurses that affected nurses personally (Johansson & Lindahl, 2012). Nurses also felt burdened by bearing witness to suffering, some of which they felt was futile care (O'Shea, 2014). Lastly, some nurses felt they could not provide adequate care for patients near death and blamed task orientation and inflexible organizational policies (Mak et al., 2013).

While nurses experienced emotional distress and burden from caring for palliative care patients, they also felt satisfied and grateful for the work they did (Burt et al., 2008; Johansson & Lindahl, 2012; Marchessault et al., 2012). Nurses felt each patient was unique and worked hard to make them feel that way (Johansson & Lindahl, 2012). Nurses also felt that work in palliative care encouraged them to reflect on their practice which resulted in professional and personal growth (Marchessault et al., 2012).

The roles nurses filled in palliative care was not surprising given the descriptions they provided in discussions about relationships with patients and the satisfaction in providing palliative care. Community nurses in Burt, Shipman, Addington-Hall, and White's (2008) study described their roles in palliative care as coordinators. They felt they were essential to providing, organizing, and coordinating care to ensure patients' needs were met (Burt et al., 2008). Nurses in other studies identified themselves as advocates for patients (Dillworth et al., 2016; O'Shea, 2014; Roche-Fahy & Dowling, 2009; Verschuur et al., 2014). Nurses felt their roles were to empower patients and encourage patients to express their fears and concerns (Roche-Fahy & Dowling, 2009). Nurses also felt the role of advocate was important in alleviating suffering,

viewing the patient holistically, and expressing concerns if they felt the patients' needs were not being addressed (O'Shea, 2014).

To summarize, when reviewing the literature on nurses' experiences and knowledge working in palliative care there are three main themes that emerged: confidence in skills, level of experience, and nurse-patient relationships. Studies that were descriptive in nature and did not include an intervention showed nurses lacked confidence in skills, regardless of how often they used those skills (McDonnell et al., 2009) and sought referrals to specialists when they were uncertain (Ewing et al., 2009). In most studies, nurses felt more confident in their work when they had education and continuing education about palliative care (Finnerty & Gregory, 2010; Milic et al., 2015; Phillips et al., 2008).

Nursing experience was evident in how a nurse cared for and understood patients. Dee and Endacott (2011) and Johansson and Lindahl (2012) described intuition when discussing how an experienced or expert nurse understood the patient holistically. These descriptions were compared to Benner's (1982) novice to expert model of how a nurse developed professionally.

Lastly, the nurse-patient relationship was an important factor in nursing but also palliative care nursing. Nurses found benefits in building relationships with patients and their families early in the interaction (Johnson et al., 2011; Kaasalainen et al., 2014).

Workplace Environment

In this review of literature, many different settings were represented, including rural community settings, acute care hospitals, nursing homes, government and privately-run hospitals, specific hospice centers, and specialist hospital wards. There were five main themes identified in the literature in relation to workplace environment: time, mixed patient assignments, resources, support, and teamwork.

Time. Time was an important factor in how nurses were able to care for patients and interact with colleagues. Dalgaard and Delmar (2008) conducted a grounded theory study to understand the connection between time and quality of palliative care. The result of this study resonated with many other studies and how nurses in those studies described issues with time. The researchers identified clock time, which referred to time dictated by the clock, and personal time, which was one's own time to navigate (Dalgaard & Delmar, 2008). The lack of clock time occurred when there was an overabundance of tasks and required time saving strategies. These strategies may have included routine care for a patient without taking into consideration their individuality (Dalgaard & Delmar, 2008). Nurses resorted to 'doing' rather than 'being' (Dalgaard & Delmar, 2008). The agenda of the nurse became more important than the agenda of the patient (Dalgaard & Delmar). When there was an imbalance of clock time and personal time and when the nurse attempted to control clock time, nurses experienced stress and the inability to reflect on their practice (Dalgaard & Delmar, 2008). The results of this may also be manifested by outbursts among colleagues to let out frustrations but did not include any type of engaging or therapeutic conversation (Dalgaard & Delmar, 2008). In situations where there was adequate clock time, nurses' experiences caring for patients was vastly different. Nurses with balanced clock and personal time engaged patients and were flexible in adapting to patient needs (Dalgaard & Delmar, 2008). With a balance of time, nurses were able to engage with colleagues in a more professionally stimulating way in which opinions were shared, and feedback was given (Dalgaard & Delmar, 2008). These types of situations promoted professional growth (Dalgaard & Delmar, 2008).

The challenge of time was mentioned in much of the literature (Burt et al., 2008; Dillworth et al., 2016; Ewing et al., 2009; Gardiner et al., 2011; Gott et al., 2011; Marchessault

et al., 2012; McDonnell et al., 2009; O'Shea, 2014; Phillips et al., 2008; Reimer-Kirkham et al.,
2016; Roche-Fahy & Dowling, 2009; Spence et al., 2009; Zhou et al., 2010). Community nurses
reported prioritizing palliative patients over non-palliative patients when time was short (Burt et
al., 2008). Nurses felt that they were expected to create time to spend with palliative care patients
in a fast-paced setting of an acute care ward (Roche-Fahy & Dowling, 2009). Health
professionals working with COPD patients discussed how limited time with patients allowed
them to only address immediate issues (Spence et al., 2009). In one clinic, nurses reported that
they were only given enough time to perform physical checks and medication review (Hynes et
al., 2015). As a result, nurses recommended a support clinic where patients could receive
supportive care outside of regular clinic time; this recommendation was rejected by management
(Hynes et al., 2015). Nurses felt frustrated with task-oriented work environments (Mak et al.,
2013) and limited time and felt better care could be provided without these limitation (Klarare,
Hagelin, Furst, & Fossum, 2013). Rural nurses in Kaasalainen et al.'s (2014) study noted that the
increase in the quantity of work decreased the quality of work or care given to patients.
Specialist palliative care team members identified lack of time as a reason for referrers to consult
their team to provide psychological support; the specialist on this team did not see this as an
appropriate reason for consultation (Ewing et al., 2009). District nurses in the United Kingdom
felt that increasing demands compromised their ability to provide palliative care, specifically in
what they described as "time-consuming psychosocial" care (Gott et al., 2011, p. 236). Time
restraints were the reason for missed team meetings (Phillips et al., 2008), not having meetings at
all (Cameron & Salas, 2009), or a barrier to advanced care planning (Zhou et al., 2010).

Mixed patient assignments. In some settings, nurses were required to care for both
palliative care patients and non-palliative patients (Cameron & Salas, 2009; Hynes et al., 2015;

Johansson & Lindahl, 2012). Nurses who had other types of patients besides palliative care patients were not able to be fully engaged in palliative care (Cameron & Salas, 2009). Nurses caring for palliative care patients in acute care settings experienced problems with high bed occupancy and rapid patient turnover (Hynes et al., 2015). Some health care professionals did not feel palliative care in the acute care setting was reasonable or that it fit in with the curative culture of the hospitals (Gott et al., 2011). This study clearly used the term 'palliative care' as a type hospice or end of life care. Nurses in Johansson and Lindahl's (2012) study experienced both positive and negative aspects of caring for palliative care and acutely ill patients. In a positive way, caring for both types of patients created a balance between curing and alleviating; however, nurses described being split physically and spiritually (Johansson & Lindahl, 2012).

Resources. There was a lack of resources mentioned in many of the studies (Cameron & Salas, 2009; Kaasalainen et al., 2014; McDonnell et al., 2009; Phillips et al., 2008; Roche-Fahy & Dowling, 2009). Shortage of staff was a major resource that was lacking and resulted in heavy workloads (Alexander et al., 2015; Cameron & Salas, 2009; Gardiner et al., 2011; Kaasalainen et al., 2014; McDonnell et al., 2009). Phillips et al. (2008) described a small number of staff who were trained in palliative care; this created an imbalance in the ability to provide palliative care services (Phillips et al., 2008). Nurses described difficulties reaching medical staff on off hours (Kaasalainen et al., 2014) or getting medical teams to recognize the need for palliative care and to write a referral (Hynes et al., 2015). Johnson et al.'s (2011) study participants saw the hierarchy among healthcare professionals as a barrier to referrals for palliative care. Allowing nursing and other allied health providers to request referrals was helpful to avoid late referrals to palliative care (Johnson et al., 2011). DeMiglio and Williams' (2012a) study of community based palliative care teams' shared care model found it difficult to find funding for non-

physician roles. Additionally, the study participants found it difficult to have physicians participate in the shared care model; some reasons that the participants gave for the shortage was the lack of interdisciplinary training physicians received and the possible loss of autonomy physicians felt (DeMiglio & Williams, 2012a).

Cameron and Salas's study (2009) identified the lack of resources as a barrier to meeting patient needs. Services and medications were free for patients, while access to equipment was a challenge (Cameron & Salas, 2009). Inadequate privacy was also lacking in some settings, such as acute care hospitals or nursing homes (McDonnell et al., 2009; Roche-Fahy & Dowling, 2009). Patients and residents in acute care hospitals and nursing homes often did not have a private room, or rooms were cluttered and did not offer a peaceful setting for adequate end of life or palliative care to occur. In these circumstances, nurses attempted to create a calming environment (Roche-Fahy & Dowling, 2009). McKeown, Cairns, Cornbleet, and Longmate (2010) interviewed intensive care unit (ICU) staff about their experiences in providing palliative care. Negative aspects included uncomfortable environments, aggressive interventions, and lack of privacy (McKeown et al., 2010). Recommendations from this study included single private rooms for palliative patients who received care in the ICU (McKeown et al., 2010).

Support. Another workplace environmental factor that influenced the experiences of nurses providing palliative care was the lack of support from their organizations and feelings of isolation from the rest of the healthcare team (Cameron & Salas, 2009; Dee & Endacott, 2011; Hynes et al., 2015; Johansson & Lindahl, 2012; McDonnell et al., 2009; Milic et al., 2015; Phillips et al., 2008; Roche-Fahy & Dowling, 2009; Thacker, 2008; Valente, 2011). McDonnell et al. (2009) found that 43% of nurses did not feel support when caring for a patient in the last 24 hours of life. In some cases, nurses felt that their opinions were not valued (Dee & Endacott,

2011) and other members of the healthcare team did not understand the value of the work they did (Johnson et al., 2011). Rural, community, and specialist nurses found their work isolated them from other team members (Kaasalainen et al., 2014; Marchessault et al., 2012; Phillips et al., 2008), while some nurses felt their roles in palliative care were not recognized (Burt et al., 2008). Lack of role recognition was in part due to lack of communication about the plan of care which some nurses felt resulted in disjointed care (Kaasalainen et al., 2014).

Nurses found support in managers and colleagues (Johansson & Lindahl, 2012; Thacker, 2008). Nurses in Valente's (2011) study found that social workers and psychologists could be helpful allies when working with physicians. Seventy-one percent of nurses in McDonnell et al.'s (2009) study recommended support for staff through counseling, debriefing, bereavement, appreciation from management, and time to grieve the loss of a patient. Other suggestions to provide support for nurses working with palliative care patients were to foster a workplace culture where nurses were actively involved with communication about prognosis and goals of care (Milic et al., 2015) and to provide support for new staff (Roche-Fahy & Dowling, 2009).

Teamwork. An important aspect of palliative care is interdisciplinary teams. One underlying assumption of palliative care is that care is provided by an interdisciplinary team and is collaborative (American Nurses Association & Hospice and Palliative Nurses Association, 2014). Monterosso, Ross-Adjie, Rogers, Shearer, and Rogers' (2016) study participants acknowledged that palliative care was multidisciplinary and inclusive of family. Nurses in O'Shea's (2014) study felt that when all team members were on the "same page", there was a more cohesive approach to the care provided to palliative care patients. However, nurses also felt that when there were multiple services involved with the care of a complex patient, care could become fragmented (O'Shea, 2014). Healthcare providers in Gardiner, Cobb, Gott, and

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Ingleton's (2011) study identified varying interpretations of roles between specialist and generalist providers. Palliative care specialists believed that all health care professionals should provide basic palliative care while many generalists were unfamiliar with the term "generalist palliative care" (Gardiner et al., 2011). Moreover, specialists noted that they were referred many times for skills that could be provided by the generalists (Gardiner et al., 2011). Unsurprisingly, generalist providers lacked understanding of palliative care and did not recognize their role in the provision of palliative care (Gardiner et al., 2011). Other healthcare providers in the study felt that with the existence of specialist palliative care, past roles were taken from them (Gardiner et al., 2011). In one study, nurses felt they improved the collaboration among the team of physicians, patients, and families (Valente, 2011).

Varying perceptions of the level of knowledge and skill other team members possessed affected the confidence and structure of the team (Reimer-Kirkham et al., 2016). In one study that included many disciplines, only one participant could describe what other professionals did, while all other participants' descriptions were vague (Klarare et al., 2013). Literature varied about who should lead specialist or non-specialist palliative care teams. Some study participants felt physicians should lead the team, while others felt it should be the team member that possessed leadership skills (Klarare et al., 2013). Wittenberg, Goldsmith, and Neiman (2015) surveyed nurses with varying nursing degrees about palliative care team leaders and communication. Twenty percent identified physicians as team leaders (Wittenberg, Goldsmith, & Neiman, 2015). Another study asked nurses what changes needed to happen within their teams for improved communication (Wittenberg, Ferrell, Goldsmith, Buller, & Neiman, 2016). Team roles, structure, and processes were the most expressed needs for change (Wittenberg et al., 2016). The strongest collaborative skill that nurses reported having was the ability to remind the

team about outcomes and patient preferences (Wittenberg et al., 2016). The weakest collaborative skill was the ability to cultivate team building activities (Wittenberg et al., 2016). Nurses also felt that the most difficult role within a team was to report observed errors in care (Wittenberg et al., 2016).

There were suggestions about the types of team behavior that were beneficial to a functioning team. All members should have a common goal or shared values to connect team members together (DeMiglio & Williams, 2012b; Klarare et al., 2013; McVey, McKenzie, & White, 2014; Pereira, Fonseca, & Carvalho, 2012). Providing support to all team members was essential (Klarare et al., 2013). One study allowed time for all team members to attend a professional support group (Klarare et al., 2013). Klarare, Hagelin, Furst, and Fossum's (2013) study described the following characteristics to being on a team; respect, listening skills, consideration of all opinions, clear role descriptions to avoid duplicate work, competition, and challenging behavior that could affect patient care.

Hierarchy. Historically, nurses have been seen as a subordinate assistant to medical physicians (Bell, Michalec, & Arenson, 2014; Churchman & Doherty, 2010). In one study, the experiences of nurses challenging physicians indicated that these subordinate roles or a hierarchy still existed (Churchman & Doherty, 2010). Nurses described challenging physicians as a battle and avoided confrontation when physicians were known to have bad temperaments (Churchman & Doherty, 2010). Nurses continued to "play games" with physicians in ways that make the physicians do what they wanted without hurting physician egos, as they did in the past (Churchman & Doherty, 2010). Another study of nurses' relationships with physicians reported that 87.5% of nurses believed that physicians understood the role of nurses and stated that they found it easy to approach physicians; however, 81% stated that they would approach a nurse

before approaching a physician (Fernandes et al., 2010). Many of these nurses reported a friendly relationship with physicians, yet, 27% believe there was still hierarchy between nurses and physicians (Fernandes et al., 2010).

Most of the data in the literature related to workplace environmental factors in nurses' experiences working with palliative care are not positive. Many study participants felt their practice was dictated by time constraints (Hynes et al., 2015; Roche-Fahy & Dowling, 2009) or they were split between providing care to non-palliative patients in addition to palliative care patients (Johansson & Lindahl, 2012). Lack of resources for staff and to meet the needs of patients was another issue addressed in the literature (Cameron & Salas, 2009; Kaasalainen et al., 2014; McDonnell et al., 2009). Lastly, many nurses described feeling undervalued in the work they provide to palliative care patients (Dee & Endacott, 2011) and feeling isolated from other healthcare members (Kaasalainen et al., 2014; Marchessault et al., 2012; Phillips et al., 2008). Studies have shown that hierarchies among nurses and physicians still exist and may likely play a role in the functionality of palliative care teams.

Specific Populations and Palliative Care

This literature review was conducted for a study that explored the perspectives of acute care nurses providing basic palliative care for homeless and culturally diverse populations. When the nurses were asked about culturally diverse populations, many referred to the large Hmong population that was cared for in their hospitals. Literature on palliative care and homeless and Hmong people is limited.

Homeless. Homeless individuals are more likely to experience poor health, including chronic illness, which can be both the cause and the result of their homelessness (National Coalition for the Homeless, 2009). The life expectancy for homeless people is estimated to be 42

years to 52 years compared to 78 years in the general population (National Coalition for the Homeless, 2009). Homeless people also struggle with substance use and mental health issues (Substance Abuse and Mental Health Services Administration, 2017). The main themes in the literature regarding homeless people and palliative care are prevalence of illness and problems accessing palliative care directly related to the status of homelessness.

  Prevalence of illness. One systematic review found a significantly higher rate of diabetes among the homeless population (8.0%) compared to the general population (5.2%) (Bernstein, Meurer, Plumb, & Jackson, 2015). Bernstein, Meurer, Plumb, and Jackson's (2015) review also compared prevalence of hypertension; while the results were not statistically significant, there were slightly more homeless individuals with hypertension (27%) than in the general population (25%). Both groups were noted to have upward trends in prevalence of both chronic conditions (Bernstein et al., 2015). Nikoo et al.'s (2015) study found the most common chronic conditions among homeless people were neurological conditions, infectious diseases, and musculoskeletal issues. Forty percent of the participants in Nikoo et al.'s (2015) study identified as aboriginals; 95% of this population reported at least one chronic illness and half of them reported three or more chronic illnesses. Nikoo et al.'s (2015) study found conflicting data from Bernstein et al.'s (2015) review, noting that homeless individuals were half as likely to have diabetes than the general population; however, they were just as likely to have hypertension as the general population. Homeless people were two to four times as likely to have chronic conditions such as arthritis and chronic obstructive pulmonary disease as the general population (Nikoo et al., 2015). The likelihood for homeless people to have infectious disease compared to the general population was even higher (Nikoo et al., 2015).

In addition to physical illnesses, substance use and mental health issues are also prevalent among homeless people. Studies identified mental illness or substance use as the top admitting diagnoses to hospitals for homeless people (Dirmyer, 2016; Doran et al., 2013; Russolillo, Moniruzzaman, Parpouchi, Currie, & Somers, 2016). Substance use and mental illness have been causes and effects of homelessness (Narendorf, 2017). In some cases, stopping the use of medications for mental illness contributed to homelessness (Narendorf, 2017). In other cases, substance use was a method of managing mental illness after a person became homeless (Narendorf, 2017). Still other homeless people described an onset or worsening of mental health symptoms once they became homeless (Narendorf, 2017). Substance use was also a barrier to homeless people accessing traditional palliative care facilities (McNeil & Guirguis-Younger, 2011). Few facilities tolerate the continued use or even the history of substance use by their residents.

The concerns surrounding reportedly high incidence of substance use created problems with medications to control symptoms such as pain (Cagle, 2009; MacWilliams, Bramwell, Brown, & O'Connor, 2014; Song et al., 2007). One practical problem with providing medications to homeless people was the lack of safe storage on the street or in a shelter (Cagle, 2009; MacWilliams et al., 2014). Shelters may not be willing to store medications for homeless people or may have difficulty doing so safely (Cagle, 2009; MacWilliams et al., 2014). Prescribing staff may identify this population as "drug seeking" or worry about dependence (Cagle, 2009; Song et al., 2007). The debate about whether dependency should be a concern with a person at end of life is noted (Cagle, 2009). Regardless of whether dependency is a relevant concern, a person with substance use often developed a high tolerance to pain medications

making it difficult to relieve symptoms effectively (Cagle, 2009; MacWilliams et al., 2014) particularly in the context of homelessness.

Barriers related to homelessness. Barriers identified in the literature affected providing palliative or hospice care to the homeless population. Key concepts in the literature were related to lack of housing and social support (Cagle, 2009; Song et al., 2007), issues regarding medication management (Cagle, 2009; MacWilliams et al., 2014; Song et al., 2007), and past experiences with health care professionals, end of life, and serious illness (Huynh, Henry, & Dosani, 2015; Song et al., 2007). One of the key principles of palliative care is the care of patient and family and the support of family as caregivers (American Nurses Association and Hospice and Palliative Nursing Association, 2014). Regardless of how one defined family, homeless people rarely have social support making it difficult for family caregivers to participate in care for homeless individuals (Huynh et al., 2015). Homeless people expressed varying desires to reunite with families at end of life or times of serious illness (Ko, Kwak, & Nelson-Becker, 2015; Song et al., 2007). Reasons cited for not wanting family involved were abandonment by family, not wanting to be a burden on family, and not wanting to reveal their homeless status (Ko et al., 2015; Song et al., 2007). Homeless people form relationships within the homeless community; however, homeless people described these relationships as a means to resources or to avoid loneliness (Bower, Conroy, & Perz, 2017). Some homeless people were able to develop meaningful relationships with other homeless people (Bower et al., 2017). These relationships however, would not supply the assistance in palliative care as one of a housed family member or friend would.

Lack of housing was another issue that arose when providing palliative or hospice care to homeless people (Cagle, 2009). Regardless of where homeless people lived, on the streets or in a

shelter, there was a lack of privacy and space that limited the interventions that were available (Cagle, 2009). Cagle's (2009) review also indicated that hospice workers may not feel safe going to areas where homeless people are located due to the higher incidence of substance use. One program in Canada was attempting to provide care where the homeless were located (Cipkar & Dosani, 2016); however, the program experienced barriers such as resources and funding (Cipkar & Dosani, 2016). In addition to lack of housing, there was also a lack of facilities that provided palliative or hospice care for the homeless population (Song et al., 2007), though Cagle (2009) noted that residential hospice facilities for homeless people would be more cost efficient than providing this care in a traditional palliative care setting or hospital. Beresford (2017) identified only five facilities in the U.S. that provided hospice for the homeless population. However, this did not include palliative care.

Homelessness also affected access to services. In the review by Huynh, Henry, and Dosani (2015), studies in the U.S. and Canada found that people identified as low socioeconomic status had less access to palliative care resources and hospice services, referral rates were lower for people living in lower socioeconomic areas despite those areas having higher incidence of cancer, and patients were more likely to die in institutions.

Lastly, the experiences that homeless people have had with health care professionals, loved ones at end of life, and personal experiences with serious illness have created barriers for this population. There was a distrust of health care professionals among the homeless population (Cagle, 2009; Song et al., 2007). Stigma associated with homelessness affects the dignity and respect that health care providers may or may not show to homeless people in their care (Cagle, 2009). Homeless people who participated in Song et al.'s (2007) study described feeling disrespected by service providers including police, social service workers, and medical

professionals. In previous experiences of serious illness or end of life care for a loved one, there was a feeling of loss of control over the situation, decisions regarding care, and an unresponsiveness to suffering (Song et al., 2007). Homeless people in Song et al.'s (2007) study expressed fears of dying anonymously and not being remembered. They also feared a disrespectful burial, either unmarked or nonconsensual cremation (Song et al., 2007).

There were three studies included in this review that addressed advanced care planning with the homeless population. Advanced care planning is an important aspect of palliative care to ensure that patients' preferences are known and honored. Leung, Nayyar, Sachdeva, Song, and Hwang's (2015) and Song et al.'s (2008) studies determined the rate of completion of advanced directives in the homeless population. Leung et al.'s (2015) study had a completion rate of 50.2%. The majority of participants stated that completing the advanced directive gave them peace while 16.3% reported participation in the process gave them anxiety (Leung, Nayyar, Sachdeva, Song, & Hwang, 2015). Those that completed the document were less likely to feel uncomfortable with talking about end of life (Leung et al., 2015). Forty-four percent of participants in Song et al.'s (2008) study completed advanced directives. This study had two groups; one group had access to counselors to assist in completing the advanced directive while the other only had a self-guide to complete the document (Song et al., 2008). The group that had access to a counselor had a higher completion rate (59%) than the self-guided group (30%) (Song et al., 2008). There was a decrease in worry about death by participants that completed advanced directives from 50% prior to completion to 12.5% at a 3-month follow-up (Song et al., 2008).

Despite the many barriers related to providing palliative and hospice care to the homeless population, there is a great need as this population tends to have high mortality and morbidity

rates than the general population. There are some programs that attempt to bring palliative and hospice care to homeless populations; however, such programs are affected by barriers related to funding (Cipkar & Dosani, 2016; Huynh et al., 2014). Additionally, there are insurance coverage issues unique to countries, such as the United States, that do not have universal coverage. The Affordable Care Act of 2010 provided Medicaid expansion to cover adults of low income and potentially homeless populations (Garfield & Damico, 2016). While there are hospice benefits available through Medicaid (Medicaid.gov, n.d), there are 19 states that have not accepted the Medicaid expansion, continuing to leave many people uninsured (Kaiser Family Foundation, 2016).

Hmong population. There was no literature to my knowledge that specifically addressed the Hmong population and palliative care needs. The Hmong people started immigrating to the U.S. following a long history of oppression and migration that started in China in the 16th and 17th centuries (Minnesota Historical Society, n.d.). From China, the Hmong people moved to Laos, Myanmar, Thailand, and Vietnam (Minnesota Historical Society, n.d.). After supporting the U.S. in the Vietnam War, many Hmong were left in Vietnam to be targeted and killed. Many fled to Thailand for refuge, and ultimately led to their resettlement in the U.S., Canada, France, and Australia (Cobb, 2010). Despite Hmong people living in the U.S. for over 30 years, little research exists that focuses on how to provide palliative care or end of life care for them. Literature that does exist focuses mostly on the traditional beliefs about illness and death (Gerdner, Cha, Yang, & Tripp-Reimer, 2007; Schriever, 1990; Vawter & Babbitt, 1997). However, literature that was found addressed the challenges immigrant and refugee populations may experience in the U.S. healthcare system, palliative care, and end of life care.

Immigrant and refugee populations may have various stressors related to adapting to life in a new country. In general, recent Burmese, Bhutanese, and Iraqi refugees attributed language barriers to adequate communication with health care providers and lack of interpreter use by physicians (Hauck, Maxwell, Maxwell, & Reynolds, 2014). This group of refugees also expressed stress due to separation from family, food insecurity, and additional needed support with health care and Medicaid (Hauck et al., 2014). Periyakoil, Neri, and Kraemer's (2016) study found that 72.2% of multiethnic participants reported some barriers to high quality end of life care. The three most common barriers were related to finances and insurance issues, physician behaviors, and communication between patients and physicians (Periyakoil, Neri, & Kraemer, 2016). The authors recommended that all physicians have a competency in palliative care (Periyakoil et al., 2016). Bell, Kuriya, and Fischberg's (2011) study compared pain outcomes among patients receiving inpatient palliative care consults. This study found that 71% of all racial groups reported a decrease in pain to mild or no pain after consultation (Bell, Kuriya, & Fischberg, 2011). There was no evidence of racial disparity among non-white and white patients and pain outcomes (Bell et al., 2011).

There is little research on the experiences of nurses caring for diverse palliative populations. Studies that focused on the nurses' experience providing palliative care for patients of various ethnic backgrounds included how nurses provided cultural care (Huang, Yates, & Prior, 2009) and how religion played a role in providing specialist palliative care (Henry & Timmins, 2016). Huang, Yates, and Prior's (2009) study identified multiple themes: nurses' views and understanding of culture and cultural care; philosophy of cultural care; previous experiences; and organizational approach. Nurses' views and understanding of culture included the importance of religion (Huang et al., 2009). Nurses also understood that culture influenced

how people lived, behaved, made decisions, and shaped people's attitudes, values, and beliefs (Huang et al., 2009). Nurses in this study also recognized that a person of a specific culture does not mean the person follows all the traditional beliefs of that culture (Huang et al., 2009). However, nurses' beliefs about specific cultures did shape behaviors and attempts at providing cultural care (Huang et al., 2009). The nurses' philosophy of cultural care included being aware and sensitive to other cultures, being respectful and proactive, and being competent in communication skills (Huang et al., 2009). Previous experiences, professionally and personally, also shaped the way nurses approached appropriate cultural care (Huang et al., 2009). Having personal experiences provided nurses with a heightened awareness to different cultures (Huang et al., 2009). Lastly, the organization's dedication to a caring environment that provided assistive services for staff and patients allowed for cultural adaptation between patients and staff (Huang et al., 2009).

Henry and Timmins (2016) looked at nurses' experiences in caring for diverse populations in a specialist palliative care unit. Nurses in this study reported that allowing and assisting patients to practice specific religious and death rituals was important; although nurses felt uneasy, inexperienced, and helpless with unfamiliar situations (Henry & Timmins, 2016). The nurses felt tension at times when religious beliefs clashed with professional beliefs surrounding the use of pain medication to alleviate suffering (Henry & Timmins, 2016). Nurses adapted and accepted that patients may not want all aspects of palliative care and resorted to offering but not imposing aspects of care (Henry & Timmins, 2016). One way that nurses in this study provided palliative care in situations of uncertainty was to approach patients cautiously as to not offend (Henry & Timmins, 2016). Lastly, nurses felt that being resourceful by seeking more knowledge about different religious groups would be helpful (Henry & Timmins, 2016).

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Gap in the Literature

The studies in this review examined the knowledge and experiences nurses and other health care professionals had in palliative care practice. There is a clear lack of knowledge accompanied by a recognized need for education by nurses. The IOM (2014) and American Association of Colleges of Nursing (AACN) (2016a) recommendations are for all health care providers to have a competency in basic palliative care. While it is clear that nurses and other health care professionals need further education in palliative care, the term basic or general palliative care needs an in-depth description. The IOM (2014) has recommended that all health care professionals have a basic competency in basic palliative care. The IOM (2014) definition gives health care professionals a description of who should be providing this non-specialist care; however, there is a lack of understanding of what this care looks like in practice. Literature described the lack of knowledge and lack of confidence nurses had in providing palliative care. Research in the literature does not describe the skills nurses should have to be competent in basic palliative care. Terminology used in the literature, differences between basic palliative care, specialist palliative care, and end of life or hospice care is often unclear.

There is a shortage of palliative care specialists needed to meet the needs of all patients who are appropriate for receiving palliative care. However, it is unnecessary and unreasonable to expect generalist nurses to provide palliative care at the specialist level when it would be more efficient for them to have a basic competency and utilize specialists for more complex patients. An integrated model of palliative care would help to incorporate basic palliative care into practice. Working alongside specialists in an integrated model has resulted in more appropriate referrals and aided in skill building among generalist practitioners (Firn et al., 2016). Generalist

and specialist palliative care providers working together would also help to describe basic palliative care in the acute care setting which does not exist in the current literature.

There is also a gap in the literature when considering palliative care for specific populations, such as homeless people and people with different cultural or ethnic backgrounds. Perspectives of nurses that may care for these populations within the hospital were not addressed in the literature. Since there is a lack of community resources for homeless people to access, the hospital setting is where individuals receive most of their healthcare. Research with culturally diverse populations and palliative care was scarce and non-existent with the Hmong population. There were few studies focusing on certain aspects of end of life or palliative care, such as pain, religion, and barriers and even fewer on the nurses' perspective of providing care to these populations. At least 13% of the U.S. population are immigrants (Zong & Batalova, 2016) and over 69,000 are refugees (US Department of State, 2015). In addition to the general population of chronically ill individuals in need of palliative care, it is important to examine the different populations and determine if there are any considerations to include in educating nurses in basic palliative care based on socioeconomic status or culture.

The study for which this review was conducted aimed to engage in a dialogue with acute care nurses to describe basic palliative care in the acute care setting with consideration for homeless and culturally diverse populations. Focus group and individual interviews were used to engage acute care nurses in dialogue regarding their experiences providing basic palliative care in an acute care setting. The results of this study can help inform future education, research, and policy changes to increase the competency of acute care nurses in their practice of basic palliative care.

Many challenges were described in the literature about the work environment and effects that result from the emotional type of care that is palliative care; however, while many of these cannot be solved with nursing interventions alone, nurses do need tools to provide basic palliative care in situations that are not always ideal. Nurses also need to extend their roles as advocates beyond the patient experience and advocate for themselves when they are feeling less valued within the team framework. Literature highlighted the negative impact that nurses feel working within a team with other disciplines that do not always understand others' professional roles. These types of team dynamics can affect the quality of care provided by the team as a whole.

In addition to education on basic palliative care, nurses need to advocate to other healthcare providers when basic palliative care is appropriate and when a specialist palliative care provider is needed. The CARES (AACN, 2016a) document and course material from the ELNEC-Core course (AACN, 2016b) will be helpful tools in determining the content for educating acute care nurses in basic palliative care. The acute care nurses that participated in this study shared experiences and perceptions about basic palliative care to describe the current state basic palliative care in the acute care setting.

Conclusion

The review of literature pertaining to nurses' experience in palliative care show many deficiencies that need recognition and attention before the IOM's (2014) recommendation of generalists providing basic palliative care can be achieved. There remains confusion with the terms hospice, palliative, and end of life care. While the philosophy is the same, patients with life-threatening illness should be able to have access to palliative care without foregoing curative treatments (WHO, 2015). In some cases, palliative care is appropriate to start at diagnosis to help

alleviate symptoms, provide emotional and spiritual support, and create goals that are aligned

with the patients' wishes. The research clearly indicated a lack of knowledge of palliative care,

poor confidence levels in providing palliative care, and workplace environments that do not

support the type of environment that is ideal for palliative care to be provided by generalist

practitioners. However, studies that included educational interventions did show improvement in

most of these areas. Education in palliative care is necessary in the training of nurses as well as

continuing education once in practice. Support systems are necessary to support nurses in

providing palliative care that is often very rewarding but also emotionally draining. To realize

the recommendations of the IOM (2014) and the ANA's (2017) call to action, basic palliative

care needs a better description to guide nurses to integrate it into the challenging acute care

setting. A closer look at various populations that may have additional needs, such as the

homeless or cultural diverse populations, helped to describe how basic palliative care is delivered

in the acute care setting with populations that have unique needs.

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Chapter 3: Methodology

Chronic disease affects millions of Americans. In 2012, the Centers for Disease Control and Prevention (CDC) (2015) reported that half of adults had one chronic disease, while one in three Medicare beneficiaries had five or more chronic diseases (Cubanski et al., 2015). These statistics are expected to increase as the baby boomer generation continues to age (Institute of Medicine (IOM), 2012). Chronic diseases can cause premature death, multiple hospitalizations, and limit activities of daily living (CDC, 2016). Many chronic diseases, such as heart failure and chronic obstructive pulmonary disease, can be terminal. Despite the prevalence of chronic illness, healthcare providers have found it difficult to discuss the terminality of disease, including transitioning to palliative or hospice care (Barclay, Momen, Case-Upton, Kuhn, & Smith, 2011; Broom, Kirby, Good, Wootton, & Adams, 2014; Dea Moore & Reynolds, 2013; Slort et al., 2011; van Gurp et al., 2013). The tendency has been to manage the disease rather than discuss end-of-life issues (Barclay et al., 2011), even when options such as palliative care would be appropriate alongside disease management.

In addition to the older, chronically ill, adult population that would benefit from palliative care, the homeless and culturally diverse populations would benefit and may need additional considerations when receiving palliative care. Homeless populations have high mortality and morbidity rates compared to the general population and may be more susceptible to poor health due to living conditions (Cagle, 2009). Some chronic conditions have been studied to determine prevalence in the homeless population compared to the general population (Bernstein, Meurer, Plumb, & Jackson, 2015) and to determine what conditions were most common among the homeless (Nikoo et al., 2015). Bernstein, Meurer, Plumb, and Jackson's (2015) systematic review determined there was a statistically significant higher rate of diabetes among the homeless compared to general population. Nikoo et al.'s (2015) study found the most common

physical conditions among homeless are neurological, infectious, and musculoskeletal. The homeless population also has a higher incidence of substance abuse and mental health issues that may make symptom relief in chronic or life-threatening illness more difficult (Cagle, 2009; MacWilliams, Bramwell, Brown, & O'Connor, 2014). Another challenge that faced this population was the limited spaces in which palliative care can be provided. Limited social support, housing, and long-term care facilities for homeless people forced this population to seek health care in the hospital setting. Due to these factors, providing palliative care to the homeless population may be more challenging; it is necessary to consider these factors when planning education for acute care nurses. Culturally diverse populations may also require various considerations when providing palliative care. Though there is very little research in this area, there are religious and cultural differences that nurses may need to consider when providing these populations with palliative care in an acute care setting.

The World Health Organization (WHO) (2015) has defined palliative care as care that has a holistic approach, focusing on the physical, spiritual, and psychological aspects of the patients' well-being. According to the WHO (2015), palliative care includes: relief of multiple symptoms related to the illness, affirm life and realize death as normal, integrate psychological and spiritual aspects of care, support families during illness and bereavement, enhance quality of life, begin early in the illness trajectory, use with curative therapy, and neither hasten nor postpone death. Palliative care can be provided by a patient's primary care provider but is most often provided by a team that specializes in palliative care (IOM, 2014). Palliative care is ideally initiated at the time of diagnosis of a life-threatening illness (IOM, 2014; Wittenberg-Lyles, Goldsmith, & Ragan, 2011). This ideal for palliative care has not yet been realized in the United States (U.S.) or in most countries. Klinger, Howell, Zakus, and Deber (2014) reported that

patients received hospice or palliative care in only 41% of the deaths reported in the U.S.; 16-30% in Canada; 23% in England; and 12% in Germany.

Palliative care has evolved into a specialized type of medical and nursing care (IOM, 2014). However, with the growing, aging population, the IOM (2014) estimated an insufficient number of palliative care specialists to provide needed care. Therefore, the IOM, National Consensus Project (NCP), American Nurses Association (ANA), and the Hospice and Palliative Nurses Association (HPNA) support the call for all nurses to have the knowledge and skills to provide basic palliative care to chronically ill patients (American Association of Colleges of Nursing (AACN), 2016).

Literature on nurses' understanding of palliative care identified a lack of knowledge and a consistent confusion between the terms palliative and hospice care (Al Qadire, 2014; Finnerty & Gregory, 2010; Gardiner, Cobb, Gott, & Ingleton, 2011; Gott, Seymour, Ingleton, Gardiner, & Bellamy, 2011; Huijer, Abboud, & Dimassi, 2009; Hynes et al., 2015; Mahon & McAuley, 2010; Proctor, Grealish, Coates, & Sears, 2000; Spence et al., 2009). Many schools of nursing include palliative care in the curriculum (Dickinson, 2007); however, a recent review found that nursing schools were using inaccurate and outdated content (Ferrell, Malloy, Mazanec, & Virani, 2016). The AACN (2016) recently revised their competencies for undergraduate nursing students. The guidelines, Competencies and Recommendations for Educating Undergraduate Nursing Students (CARES), suggest ways for schools of nursing to integrate palliative care into existing curriculum (AACN, 2016). This is an important step in educating future nurses to approach chronically ill patients with a palliative approach; however, there are 2.6 million nurses in the workforce in the U.S. who lack the knowledge, skills, and confidence to incorporate basic palliative care into their practice (AACN, 2011).

Research Purpose

The goal of this study was to describe basic palliative care in the acute care setting with consideration for homeless and culturally diverse populations. Through focus group and individual interviews, acute care nurses had the opportunity to discuss their understanding of and experiences with basic palliative care and reflect on aspects of their practice that may overlap with basic palliative care. The WHO (2015) definition of palliative care was used in this study; specifically, the idea that implementation of palliative care can occur simultaneously with life-prolonging treatment and before hospice is indicated or accepted. The research questions for this study were:

1) What characteristics of palliative care do acute care nurses identify as appropriate for basic palliative care nursing practice?

2) What aspects of palliative care do acute care nurses feel they need more knowledge about?

3) What are the specific considerations acute care nurses find necessary when providing palliative care to homeless or culturally diverse populations?

4) How can basic palliative care be integrated into acute care nurses' general practice?

Qualitative Perspective

A qualitative approach was used for this study. Qualitative research depends on the human experience and recognition that those realities are complex (Munhall, 2001). The data gathered in qualitative research offers a description of these realities and human experiences (Munhall, 2001). Creswell (2013) suggested many instances where qualitative research is indicated rather than quantitative research. The reasons for using a qualitative approach for this

study were the need to hear the voices of nurses and to gain a complex, meaningful, and detailed account of acute care nurses' experiences and understanding of basic palliative care.

To understand what acute care nurses knew about basic palliative care in relation to their own experiences, data had to include their stories of patient care. Through nurses' experiences, the description of basic palliative care for the acute care setting was possible.

Theoretical Framework

The theoretical framework that guided this study was from a critical theory perspective. Critical theory, namely Habermas' and Mezirow's theories, used the components of experience, reflection, dialogue, and action as an approach to emancipation (Mezirow, Taylor, & Associates, 2009; Rodgers, 2005). The aims of this study were to engage acute care nurses in dialogue about their experiences that have shaped their knowledge and skills related to basic palliative care, to identify what knowledge and skills acute care nurses felt would be useful to their practice, to identify specific considerations for providing basic palliative care to homeless or culturally diverse populations, and to describe basic palliative care in the acute care setting. This study utilized dialogue and reflection to learn about the experiences and uncover the understanding that acute care nurses had regarding basic palliative care concerning the populations they cared for. Young (2008) described a critical theory approach as the researcher working within a group "respecting the expertise of the participants and collaborating on an issue of concern" as a way to improve practice (p. 97). The discussions that occurred in the focus group and individual interviews provided the researcher and participants with knowledge of what is known, how it is understood, what more is desired for acute care nurses to have a better understanding and possibly empower nurses to change their practice to include basic palliative care. Critical theory emphasizes language, power relations, and knowledge associated with social processes (Rodgers,

2005). The dialogue in these focus group and individual interviews also explored caring for homeless and culturally diverse populations who may not have resources to fully access palliative care or may need alterations in typical care based on living situation or culture. It was expected that nurses with experience caring for these populations had some beliefs about palliative care needs for these populations.

Mezirow described transformative learning theory as a way to make sense out of experiences (Merriam, Caffarella, & Baumgartner, 2007). A frame of reference consisted of habit of mind and point of view (Merriam et al., 2007). Habit of mind was a broad set of assumptions a person may filter experiences through to make meaning (Merriam et al., 2007). A point of view was a set of "specific beliefs, feelings, attitudes, and value judgments" (Merriam et al., 2007, p. 133). As nurses shared their experiences, some of these points of view were uncovered as they discussed the types of basic palliative care and general nursing care they provided to patients.

Additional components of Mezirow's transformative learning theory included holistic orientation, awareness of context, and authentic relationships (Mezirow et al., 2009). Mezirow et al. (2009) described a holistic orientation as the acknowledgment of affective knowing. Affective knowing and the emotions attached to an experience are often triggers for reflection and possible transformation of beliefs, attitudes, or perspectives (Mezirow et al., 2009). Relationships between nurses and patients are an important part of nursing. Palliative care nurses felt privileged to take care of patients during emotionally difficult times for patients and their families (Offen, 2015). Nurses in Johansson and Lindahl's (2012) study felt they were "giving much of oneself both as a fellow human being and as a professional nurse" (p. 2038). Affective knowing is a large part of the work that nurses do, and it was appropriate to consider this type of

knowledge in the study as nurses were asked to share their experiences. Awareness of context included the personal and professional experiences, situations connected to the learning environment, and societal factors that influenced experience (Mezirow et al., 2009). It was not unusual that nurses in the focus group and individual interviews shared experiences outside their practice. Many nurses cared for family and friends in times of need. Those experiences also shaped the experiences within their practice and knowledge about a specific topic, such as palliative care. Therefore, personal and professional experiences with palliative care were welcomed during the focus group and individual interviews. It is also important to note the context and social factors that may have influenced the experiences of the nurses participating. The nurses all worked within the same healthcare system, as does the researcher, so they shared a commonality. The nurse participants also worked in healthcare at a time in history where one of the largest generations continues to transition into older adulthood, and in a time when technology allows people to live longer with chronic disease. All these factors are important to acknowledge. Lastly, authentic relationships to Mezirow et al. (2009) generally referred to teacher and learner. This concept can easily transfer to researcher and participants. Habermas also expressed the importance of free and equal expression to develop understanding (Rodgers, 2005). The researcher needed to create a space where participants were free to express their ideas and beliefs without fear of doing so. In this study, one inclusion criterion was that participants are "floor" nurses, meaning they did not have any authority over other nurses and managers were not included in the study. This helped to ensure that nurses felt safe and comfortable expressing themselves without fear of repercussions. It was also made clear that discussions within the focus group and individual interviews were somewhat confidential; while it was impossible to ensure for the focus group interviews, it was stressed that the conversations within the focus group

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interviews should be treated with respect. Clear explanations of the purpose of the study

supported participants to speak freely and authentically.

<div align="center">**Design**</div>

The research design for this study was qualitative. This study sought to describe basic

palliative care for the acute care setting with consideration for homeless and culturally diverse

populations. The use of a qualitative research design fit the need for understanding the voices

and experiences of the participants. The use of focus group and individual interviews allowed the

participants to discuss and reflect on their knowledge and practice.

Data Collection

Focus group and individual interviews were the sources of data for this study. Focus

group interviews are different from individual interviews in that the data is gathered from an

interaction among the group members rather than the researcher and interviewee (Richie, Lewis,

McNaughton Nicholls, & Ormston, 2014). Focus groups can occur in many different forms with

a varying number of participants (Richie et al., 2014). The typical focus group interviews use a

standard format of 6-8 participants per group and discussions lasting from 1.5-2 hours in length

(Richie et al., 2014). Other formats for focus groups can include second meetings 1-2 weeks

following the first to reflect on the discussions that arose in the first meeting (Richie et al., 2014).

Researchers may also request participants to do various tasks between meetings; such as keep a

journal or discuss the subject matter with others (Richie et al., 2014).

Advantages to using focus group interviews included data collected from a communal

voice, and participant interactions that influenced and supported each other through dialogue

(Mkandawire-Valhmu, 2010; Stevens, 1996). By interacting and listening to other opinions,

participants had time to reflect on what others had to say as they formed their own perspective

(Richie et al., 2014). Stories from other participants triggered memories of one's own personal experiences that added richness to the dialogue (Richie et al., 2014; Stevens, 1996). Preston, Ogenchuk, and Nsiah (2014) described an enriched transformational learning experience when students had an environment to openly discuss feelings and experiences. Focus group interviews allowed for this type of interaction as opposed a single conversation between two people as in individual interviews. This study utilized the typical format of a goal of 6 participants per focus group with each session lasting 1.5-2 hours in length. The goal was to have two focus group interview sessions at each of the three acute care hospitals within the specific healthcare organization and an additional pilot focus group of four participants; setting the targeted sample size at 36-40 participants.

Individual interviews were added to the source of data collection following the last focus group interview. Individual interviews strengthened the credibility of data gathered in the focus group interviews (Amankwaa, 2016). Participants who did not feel comfortable participating in a group had a chance to share their experiences in a setting more comfortable to them in an individual interview.

The process that the focus group interviews were conducted followed a 5-stage process described in Richie, Lewis, McNaughton Nicholls, and Ormston (2014). Stage 1 was scene-setting and ground rules. In this stage, the researcher welcomed participants and made a personal introduction outlining the purpose of the research study. During this stage, the importance of confidentiality and voluntary participation was explained (Richie et al., 2014). An explanation of what was expected in respects to the format of discussion, liberty to speak freely, and the necessity of audio recording was also conveyed in stage 1 (Richie et al., 2014). Stage 2 usually started with turning on the recorder and allowing participants to introduce themselves (Richie et

al., 2014). In this study, introductions were made prior to audio recording. Stage 3 began the discussion about the opening topic (Richie et al., 2014), in this case palliative care and basic palliative care. During this stage, it was important for the researcher to encourage everyone to participate. Richie et al. (2014) warned that if not everyone spoke up during this stage; quieter participants found it difficult to join the discussion later. Stage 4 consisted of the main discussion; ideally participants were excited and fully participated in the conversation. During this stage the researcher actively listened to what was being said, continued to engage by asking questions to further encourage comments and discussion based on what had been said (Richie et al., 2014). Again, during this stage it was important to include all participants and explore unclear comments (Richie et al., 2014). The researcher also allowed for silence to occur; this allowed participants to reflect on what had been said and shaped further discussion topics (Richie et al., 2014). Stage 5 was the final stage where the researcher started to end the group discussion with a final topic (Richie et al., 2014). Richie et al. (2014) advised to make the final topic a positive one, such as suggestions for improvement. This study ended by asking participants if there were other topics that were not discussed that they felt should have been or if there were further comments anyone had before ending the interviews. The individual interviews were conducted in a similar way between the researcher and participants.

Prior to conducting the focus group and individual interviews, a pilot study was done to develop and enhance the interview guide. Pilot studies are important in the development of a topic or interview guide (Richie et al., 2014). Using a pilot group to test interview questions allowed the participants and researcher to include issues that they believed were important (Richie et al., 2014). Testing interview questions on a pilot group also allowed questions to be revised if they were not cultivating the information needed to answer the research questions

(Richie et al., 2014). A small group of three participants were used as the pilot group in this study. Richie et al., (2014) noted that data from the pilot group can be included in the final data set of qualitative studies and was done so in this study.

Demographic data was collected from the study participants. Information regarding years of experience, prior education and experience in palliative care, facility and type of unit employed at, nursing degree attained, and race/origin information was collected. The form used to collect demographic information is in Appendix A.

Sampling

The participants for this study were acute care nurses from three different acute care hospitals within one healthcare organization. Nurses working within this healthcare organization had varying experiences with diverse populations. One hospital was in the downtown area of a large metropolitan city; whereas the other two hospitals were in the suburbs of the same metropolitan city. Data from the 2015 community health nursing assessment identified White as the dominating race served at these three hospitals; however, Black and Asian populations were the second and third known races served by these hospitals (Wilder Research, 2015). One of the three hospitals were across the street from a homeless shelter and was more likely to serve the homeless population than the other two hospitals. From May 2015 to April 2016, there were 136 inpatient visits by patients identified as homeless determined by the patient's address matching one of four area shelters (HealthEast Acute Care Homeless SJ Visits, 2016).

The sample was purposive. According to Richie et al. (2014), purposive samples are those that are chosen because of a particular characteristic that enables the researcher to have a detailed understanding of the themes being studied. In this study nurses were recruited for their experience working in an acute care setting for a further understanding of their knowledge about

basic palliative care. In regard to the size of the sample, Richie et al. (2014) recommended that there are 6-12 groups and 6-8 participants per group. There are several issues to consider when choosing the sample size for a qualitative study. The hetero- or homogeneity of the group may indicate the needed size (Richie et al., 2014). For example, if there was more diversity among the participants it would be necessary to have a larger sample; whereas if the groups are more homogeneous, a smaller sample will suffice (Richie et al., 2014). The selection criteria should be considered when deciding on a sample size. Generally, if there are many criteria, the sample size should be larger (Richie et al., 2014). The presence of interlocking criteria, requiring paring criteria with one another, would require a larger sample size (Richie et al., 2014). Other factors that would require a larger sample size are the inclusion of special interest groups, multiple samples within one study, and what type of method was used to collect data (Richie et al., 2014). Lastly, the available resources and budget available for the study would have an impact on the sample size (Richie et al., 2014). This study recruited with the goal of having 6 focus groups; 2 groups from each hospital. The size of the groups followed Richie et al.'s (2014) recommendation of 6 members per group. The inclusion criteria for this study were minimal. Participants for this study had to be nurses that currently worked in an acute care setting, cared for adult patients, and were able to read, speak, and understand English. Nurses with an RN diploma, associate, bachelor's, or graduate degree could participate; however, nurses working mainly in intensive care units, emergency departments, or who were in a position of management or advanced practice were excluded. Nurses in intensive care units, emergency departments, and advanced practice roles were excluded because based on their location of practice or level of practice, they may have had different experiences and perspectives about palliative care than a nurse working in an acute care setting. Nurse managers or those in supervisory roles were

excluded to allow nurses in the focus group interviews to feel they could express themselves freely without fear of consequence from management. There was a need to reschedule and add additional focus group and individual interviews; qualitative research allows for this to make the study more complete (Richie et al., 2014). The total number of anticipated participants was 40, including those in the pilot group.

Data Analysis

The data analysis process for qualitative research was a thematic approach (Richie et al., 2014). Analysis began as soon as the first set of data was collected (Merriam & Tisdell, 2016). Unlike quantitative research, qualitative researchers gain insight into additions or alterations they need to make for the next interview by reviewing the previous interview (Merriam & Tisdell, 2016). By reviewing data as it was collected, the researcher was able to start the process of identifying possible themes (Merriam & Tisdell, 2016). During this process the researcher made notes, writing down possible themes, and reflecting on the process and data (Merriam & Tisdell, 2016).

Managing data began once all the data had been collected. During the initial stage of analysis, labels or notations were made throughout the data set to help organize and identify specific areas (Richie et al., 2014). These notations represented initial themes and subthemes (Richie et al., 2014). Richie et al. (2014) suggested creating a hierarchy of themes and subthemes to construct a framework to use throughout the data set.

Indexing and sorting was the next step to data analysis. Indexing was the process of labeling parts of the transcripts with corresponding themes or subthemes (Richie et al., 2014). Sorting involved taking parts of the transcripts that had the same themes and organizing them together into a separate document (Richie et al., 2014). This allowed the researcher to view a

specific thematic set all in one place (Richie et al., 2014). During the indexing and sorting phase the researcher reviewed and made changes that needed to be made in the framework, making sure to make notes about changes for future reference (Richie et al., 2014). Richie et al. (2014) recommended creating a matrix for each theme. The matrix allowed the researcher to review each theme and subthemes as a whole with the data appropriately categorized within the matrix (Richie et al., 2014). The creation of the matrices could be done either by reviewing data in the sorted thematic data or by reviewing transcripts and entering data from transcripts into the matrices (Richie et al., 2014). Data in this study was reviewed by sorted thematic data. Summarizing participant voices in each subtheme of the matrix was the next and final step in managing the data (Richie et al., 2014). Enough information was added to make sense of the theme without having to refer to the transcript (Richie et al., 2014).

The next stage of data analysis was abstraction and interpretation (Richie et al., 2014). This stage allowed the researcher to further examine the data and find "patterns of meaning" (Richie et al., 2014, p. 279). At the beginning of this stage, the original research questions and objectives for the study were reviewed to ensure that interpretation of the data was closely linked (Richie et al., 2014). The description phase of this stage was to understand and highlight the actual language the participants used and the context in which they were spoken (Richie et al., 2014). The researcher sifted through the data to identify elements that were similar or different and examined the possible need to reorganize or rename themes and subthemes (Richie et al., 2014). Once the data was categorized, themes started to emerge that moved from the words used in the raw data to theoretical concepts (Richie et al., 2014). The categories needed to be comprehensive and include all the data that related to the category for the phenomenon to be fully described (Richie et al., 2014). The researcher then started to create an explanation of the

data. This study explored how acute care nurses experienced basic palliative care in the acute care setting. This explanation included explicit, implicit, personal characteristics, dispositions, norms, and contexts in which themes had been identified (Richie et al., 2014).

Richie et al. (2014) discussed the pros and cons of analyzing focus group interviews as a whole or as participant-based group analysis. This study analyzed data by treating the group as a whole. It was important to pay close attention to areas of conflict or agreement, non-verbal communication during the focus groups, the level of participation by all the group members, and how attitudes and beliefs evolved during the focus group interviews (Richie et al., 2014, p. 340-341; Stevens, 1996). Stevens (1996) offered questions that were helpful during the analysis of focus group interviews. The following questions were used for reflection in field notes following focus group interviews and during the analysis phase of this study (Stevens, 1996):

- o How well did the group adhere to the issues presented for discussion?
- o Why, how, and when were related issues brought up?
- o What statements seemed to evoke conflict?
- o What were the contradictions in the discussion?
- o What common experiences were expressed?
- o Were alliances formed among group members?
- o Was a particular member or viewpoint silenced?
- o Was a particular view dominant?
- o How did the group solve disagreements?
- o What topics produced consensus?
- o Whose interests were being represented?
- o How were emotions handled?

Results from focus group interviews can serve an ongoing purpose, for example, plan interventions (Stevens, 1996). The results from this study will serve as a guide to designing an educational intervention on basic palliative care for nurses currently in practice. Additionally, findings from this study will help to guide nursing education and develop policy affecting local and national levels. Palliative care is restricted by insurance coverage; however, with the greater

knowledge of palliative care by current and future nurses, these practices can be provided as a part of basic care, benefiting many more patients regardless of insurance.

Focus group and individual interviews served the purpose of this study to describe basic palliative care in the acute care setting. Participants had the opportunity to express, explore, and transform their perspective on basic palliative care in the acute care setting through discussions with their peers or through reflection in individual interviews.

Scientific Rigor

In quantitative research, the methods for evaluating a study examine validity and reliability (Bloomberg & Volpe, 2008). While these terms are sometimes applied to qualitative methods, literature on trustworthiness often cite Lincoln and Guba (1985) as the standard for establishing trustworthiness through credibility, transferability, confirmability, and dependability (Amankwaa, 2016; Connelly, 2016; Cope, 2014). Creswell (2013) looked at validation strategies, reliability and evaluation, to determine the worth of a qualitative study. These different evaluative methods included similar strategies for ensuring high quality research studies that were trustworthy and credible.

Member checking is a validation strategy that Creswell (2013) described as a crucial technique for establishing credibility. To ensure that participants were comfortable with and in agreement of the portrayal described in the final analysis of this study, two participants volunteered to read the final analysis and correct any misconceptions before dissemination of the data findings. The use of individual interviews also increased the credibility of this study by having multiple data sources to compare and contrast.

One strategy for validating a qualitative study is through the use of rich, thick descriptions of the process and data (Creswell, 2013). Providing such a detailed description of

the data and the process by which the researcher collected and analyzed the data allowed the reader to clearly see how relationships were discovered and how the themes were identified. This is described as transferability (Amankwaa, 2016; Bloomberg & Volpe, 2008; Connelly, 2016; Cope, 2014). Bloomberg and Volpe (2008) emphasized that qualitative research is not expected to be generalizable; however, it can be transferable. Transferability refers to seeing how relationships are created and how they could be applied to other populations (Bloomberg & Volpe, 2008). Charmaz' (2006) criteria of usefulness resembled transferability, as does Creswell's (2013) evaluation questions. Charmaz (2006) offered the following questions to reflect on, to determine the usefulness of a study (p. 182):

- o Does your analysis offer interpretations that people can use in their everyday lives?
- o Do your analytical categories suggest any generic processes?
- o If so, have you examined these generic processes for tacit implications?
- o Can the analysis spark further research in other substantive areas?
- o How does your work contribute to knowledge? How does it contribute to making a better world?

These questions and attention to a rich, thick description of the data collection and analysis process were used in this study to ensure transferability and usefulness.

Audit trails were used to establish confirmability in this study (Amankwaa, 2016). A detailed record of raw data, field notes, and notes during theme construction described the authenticity of findings from the interviews (Amankwaa, 2016). The use of direct quotes was also a way to enhance confirmability and was used in the subsequent manuscripts reporting on the findings of this study (Cope, 2014).

Creswell (2013) referred to reliability in qualitative research to include recording interviews and engaging in intercoder agreement. The interviews in this study were audio recorded and transcribed by the researcher. This strategy ensured adequate reproduction of what

participants said during interviews for the analysis process. While this study did not involve the engagement of an intercoder agreement procedure as described by Creswell (2013), there was one other qualitative researcher that reviewed the transcripts and thematic framework to ensure that conclusions made sense and were appropriate. This was also referred to as dependability (Amankwaa, 2016).

> Reflexivity was defined by Bryant and Charmaz (2007) as
>
> the researcher's scrutiny of his or her research experience, decisions, and interpretations
>
> in ways that bring the researcher into the process and allow readers to assess how and to
>
> what extent his or her interests, positions, and assumptions influenced the research (p.
>
> 609).

Bloomberg and Volpe (2008) described reflexivity as a way to ensure credibility by keeping personal biases of the researcher transparent. The exercise of journaling, memo-writing, and field notes during data collection and analysis were used to enhance reflexivity in this study. Field notes were taken immediately following each focus group and individual interview to portray accurate reflections and recollections of the experience.

Reflexivity is the researcher's ability to scrutinize decisions made about the study (Bryant & Charmaz, 2007). Richie et al. (2014) highlighted the importance of reflexivity as it related to making the researcher's assumptions, biases, and values transparent. In this study, the purpose was to describe basic palliative care in the acute care setting with consideration for homeless and culturally diverse patient populations. As the researcher, I had assumptions regarding possible responses from participants based on the literature review conducted in preparation for the study as well as my own experiences working in acute care. Many of the assumptions from my experiences had been supported in the literature. There was a lack of time and resources that I

believed would be expressed in the interviews as barriers to integrating a new skill set into nurses' practice. However, I also read the literature and experienced the late involvement of palliative care and the use of specialists for reasons I believe general practitioners, nurses, and physicians, were capable of addressing. Therefore, I did recognize a bias in the belief that nurses as well as other health care team members needed more education in basic palliative care; however, I did not possess a clear understanding of what that looked like and as the literature review demonstrated, there was no clear practical description of basic palliative care in the acute care setting. In regard to the needs of homeless and culturally diverse populations, I believed nurses had experience working with these populations and could speak to those experiences to provide insight into what unique needs these populations may have had in palliative care situations that may have differed from the general population.

Ethical Issues and Resolutions

Munhall (2001) offered basic and more in-depth ethical issues to consider when engaging in qualitative research. For this study, approval was granted from the Institutional Review Boards of the University of Wisconsin-Milwaukee, where the researcher is a graduate student, and from the healthcare organization from which the participants were recruited. Informed consent was obtained from all the participants before the focus group and individual interviews began.

More thoughtful ethical issues to be considered included the purpose of the study and the use of participants in the study (Munhall, 2001). One question that Munhall (2001) posed was "toward what goal and for what end?" was this study's purpose. By reflecting on this question, the researcher better defined the entire purpose of the study and the purpose of the participants' involvement. In defining this purpose, the researcher also reflected on his or her assumptions.

For example, in this study the researcher may have had the assumption that palliative care was beneficial and should be utilized at the time of diagnosis of a life-threatening illness and throughout the healthcare system. Reflecting on this assumption, the researcher considered whether the purpose of the research was to understand acute care nurses' understanding or to emphasize that palliative care was best for all patients and therefore, all practitioners should have a basic understanding. The researcher then concluded that having an open mind during the data collection and analysis process was essential for focusing on the research question that was guiding this study: What characteristics of palliative care do acute care nurses identify as appropriate for basic palliative care nursing practice? Having an open mind, focusing on the question at hand and setting aside any bias helped to describe basic palliative care in the acute care setting and how nurses may or may not connect it to their own practice. Recognizing and reflecting on assumptions and possible biases was important for conducting an ethical study that used human participants to explore a phenomenon.

Conclusion

In conclusion, this study was a qualitative study, utilizing focus group and individual interviews to gather data from acute care nurses working in a hospital setting. The purpose of this study was to describe basic palliative care in the acute care setting with consideration for specific homeless and culturally diverse populations. In this study, the Hmong population emerged as the culturally diverse population that the participants had the most experience working with, and therefore, based their experiences. Results from this study will shape educational needs for acute care nurses already in the workforce to reach the goal of the IOM (2014) and the American Associations of Colleges of Nursing (2016) to have all healthcare professionals have a basic competency in basic palliative care. In addition, this study itself was a

start to the ANA's (2017) call to action for nurses to lead the way in transforming palliative care. Findings from this study may also help to shape future policy regarding palliative care at a local and national level.

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Chapter 4: Helping Families Navigate Progressive Illness

Abstract

As the population of chronically ill, older adults increases, there is a growing need for palliative care. The Institute of Medicine recommends that healthcare providers have a basic competency in palliative care. However, the description of basic palliative care and how providers should be educated are not clear. The purpose of this study was to describe the dimensions of basic palliative care from the perspective of acute care nurses. Through focus group and individual interviews, nurses described basic palliative care under the themes of *"helping families navigate progressive illness"* and *"empowering families."* Nurses helped families navigate by educating and role modeling. Nurses empowered families by *"giving options", "being present",* and *"advocating."* The study findings point to the educational needs of future and current nurses on their role in providing basic palliative care to improve the quality of care for seriously ill patients and their families in the acute care setting.

It is estimated that by 2030, 60% of adults over 65 years of age will have one or more chronic illnesses (Institute of Medicine, 2012). In recent years, palliative care has been found to be beneficial for patients diagnosed with other chronic and progressive illnesses, such as heart failure and chronic obstructive pulmonary disease (Meghani, 2004). Not only is palliative care appropriate for patients with chronic illness, the World Health Organization (WHO) (2015), American Nurses Association (ANA) and Hospice and Palliative Nurses Association (HPNA) (2014) recognized that families and patients together are the center of care delivery. Eggenberger, Meiers, Krumwiede, Bliesmer, and Earle (2011) found that including family as the recipient of care helped to promote the overall health of the patient and the well-being of the family.

Hospital specialist palliative care programs have increased in the last 20 years due to the already increasing prevalence of chronic disease (Institute of Medicine, 2014). However, the Institute of Medicine (IOM) (2014) identified a shortage of palliative care specialists required to care for the growing number of patients and families that could benefit from this supportive care. The IOM (2014), therefore, recommended that all healthcare providers have a basic competency in palliative care. The definition of basic palliative care is non-specialist providers of palliative care (IOM, 2014). The IOM definition does not specify the dimensions of care involved in basic palliative care, nor does it describe the difference between care provided by specialists and non-specialists.

The hospital setting can be a place where serious illnesses are diagnosed, and symptoms related to illness are managed (Wallace, Cooney, & Walsh, 2013). Given the shortage of palliative care specialists, the practice expectation is for non-specialists to provide basic palliative care to patients and families. To ensure that quality of care is provided for both patients

and families, basic palliative care should be an option in the acute care setting. However, we know little about acute care nurses' perspective on providing basic palliative care.

The purpose of this study was to examine acute care nurses' perceptions of their practice of basic palliative care with a focus on unit of care defined as patient and family. This study utilized the perspective of acute care nurses to provide a description of what constitutes basic palliative care in the acute care setting. There are many healthcare providers that patients and their families interact with in a hospital setting; however, nurses are a constant presence in the care provided in a hospital setting. Therefore, this study engaged acute care nurses in dialogue about their experiences, identified knowledge and skills they felt would be useful for their practice, and described principles of basic palliative care appropriate for acute care nurses' practice.

Literature Review

Family as a Unit of Care

Palliative care aims to improve the "quality of life of patients and their families facing the problems associated with life-threatening illness" (WHO, 2015). Families are greatly affected by the presence of chronic illness in one of its members. In the literature, family interactions with healthcare professionals have sometimes been reported as negative by patients and families, especially in regard to communication (Caswell, Pollock, Harwood, & Porock, 2015; Robinson, Gott, & Ingleton, 2014). This sometimes occurred when families were not included in planning care. A study conducted by Eggenberger et al. (2011), found that families' level of uncertainty decreased when families were included in the plan of care. Hospitalized patients who had high levels of burden related to symptoms and control of illness-related symptoms was one area that patients and families reported as most dissatisfied within the hospital setting (Robinson et al.,

2014). Symptom management is an important aspect of palliative care. Patients in Robinson,

Gott, Gardiner, and Ingleton's (2015) study expressed relief when they were admitted to the

hospital because they felt safe believing that the hospital setting could help them understand their

symptoms. Additionally, patients felt that being admitted to the hospital provided their family

members who served as caregivers at home, with relief (Robinson, Gott, Gardiner, & Ingleton,

2015). It is evident that families play an important role in the life of a loved one living with

chronic illness.

Prevalence

The prevalence of palliative care needs in hospitalized patients has been documented in

the literature and palliative care has an important role in the acute care setting. Studies identified

up to one-third of inpatients met the criteria but over half the patients did not receive a referral

for specialist palliative care services (Creutzfeldt, Wunsch, Curtis, & Hua, 2015; Ryan et al.,

2013; Szekendi, Vaughn, Lai, Ouchi, & Williams, 2016). Each of the studies identifying patients

with palliative care needs used different criteria to determine the patients' need (Creutzfeldt et

al., 2015; Ryan et al., 2013; Szekendi et al., 2016). One study focused on intensive care unit

(ICU) admissions, age, diagnosis of advanced cancer, cardiac arrest, or intracranial hemorrhage

with mechanical ventilation (Creutzfeldt et al., 2015). Ryan et al. (2013) utilized the Gold

Standards Framework prognostic tool and the Sheffield Profile for Assessment and Referral of

Care Index to identify non-ICU patients that had palliative care needs. Lastly, Szekendi, Vaughn,

Lai, Ouchi, and Williams (2016) mainly used diagnosis of poor-prognosis cancer, and advanced

stages of congestive heart failure and chronic obstructive pulmonary disorders to determine if

patients from any inpatient unit had a palliative care need. The lack of consistent and universal

criteria for basic or specialist palliative care has been identified as a barrier to utilization of these types of services in hospitals (Szekendi et al., 2016).

Multiple barriers continue to exist for accessing and receiving palliative care despite the United States, Canada, United Kingdom, and Australia identifying palliative care in the hospital setting as a priority (Milligan, 2012). Major barriers include nurses' limited knowledge of palliative care (Szekendi et al., 2016) and the inability to recognize the palliative care needs of patients (Milligan, 2012). Other barriers included lack of a standard definition of palliative care, subjective referral criteria associated with a limited life expectancy, lack of training in basic palliative care, and a curative culture (Szekendi et al., 2016).

Theoretical Framework

Critical and transformative learning theories guided this study. Both theoretical frameworks utilize experience, reflection, and dialogue as a way of understanding social processes and to uncover knowledge informed by frames of reference (Mezirow, Taylor, & Associates, 2009; Rodgers, 2005). From a theoretical perspective, transformative learning theory explained how people make sense out of their experiences (Merriam, Caffarella, & Baumgartner, 2007). Mezirow noted that future actions are shaped by an interpretation of past experiences (Merriam et al., 2007). These concepts can be used to understand how a person's experiences shape their perspective. As a method, these components were utilized to gain an understanding of acute care nurses' experiences with basic palliative care in the acute care setting. Dialogue allowed various points of view to be expressed as it related to providing basic palliative care to patients and families of diverse backgrounds. Furthermore, from a critical theory perspective, differences of opinions and knowledge among members of a health care team can be influenced by power relationships. Therefore, the method of data collection needed to uncover assumptions

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and premises related to dimensions of basic palliative care with patients and their families and examine how systemic issues related to how power may affect practice.

Methods

Design

This study used qualitative inquiry to guide the design and analysis of data. A qualitative approach examines phenomena of interest from a complexity perspective (Munhall, 2001). The aim of the study was to describe acute care nurses' experiences providing basic palliative care. Therefore, a qualitative approach provided a means to gain an in depth understanding of the nurses' experiences as defined by them. Focus group and individual interviews were conducted to gather rich data about acute care nurses' experiences to understand how basic palliative care operates in the acute care setting. Using focus group interviews gave the researcher an opportunity to analyze the interactions among the nurse participants. Focus group interviews also enabled the participants to listen to and reflect on their own as well as others' experiences (Richie, Lewis, McNaughton Nicholls, & Ormston, 2014). Individual interviews enhanced credibility of the data gathered in the focus groups and was inclusive to participants who felt more comfortable in a one-on-one interview.

Setting and Sample

Nurses were recruited from one healthcare organization that included three acute care hospitals in a Midwestern city. The inclusion criteria for this study were registered nurses (a) currently working in an acute care setting, (b) who cared for adult patients, (c) were able to read, speak, and understand English, and (d) held any degree that allowed them to work as a registered nurse. Nurses were recruited through employee emails, flyers, social media, and word of mouth.

Data Collection

The study was approved by institutional review boards (IRBs) at both the University of Wisconsin-Milwaukee and the Midwestern healthcare system. A semi-structured interview guide was used for the focus group (See Appendix B). First, a pilot focus group was conducted to refine the interview guide. This data was included in the final data analysis.

Focus group interviews were held at each of the three hospitals in a private conference room. All focus group interviews were arranged by me except for one which was held during the first hour of a unit council meeting for a specific unit; this time was donated by the manager of the unit to this study. Written consent was obtained prior to the start of the interviews. Participants also completed a demographic survey that included information related to age, race, gender, experience and education in palliative care, and work information such as years of experience, place of employment, and specialty area of nursing (Appendix A).

The individual interviews were added after the focus group interviews were completed as a strategy for obtaining saturation and to validate the data gathered in the focus group interviews. The individual interviews followed the same procedure for recruitment as the focus group interviews. Nurses who participated in a focus group interview were not eligible to participate in an individual interview. All interviews were audio recorded for accuracy and transcription. Following each focus group and individual interview, the researcher either wrote or recorded field notes.

Data Analysis

I transcribed the audio recordings from all interviews. Analysis followed a constant comparison and thematic approach. Analysis of the data began following completion of the first focus group interview and simultaneously with further data collection (Merriam & Tisdell, 2016). Data from the first focus group interview was compared to the data from the pilot focus

group to determine if the pilot focus group data should be included. Transcripts were reviewed multiple times, noticing and revising themes. The process of indexing and sorting as described by Richie, Lewis, McNaughton Nicholls, and Ormston (2014) was used to organize themes and subthemes. Sections of the transcripts were sorted into a matrix, this allowed data related to the identified theme to be further reviewed for consistency. Another researcher familiar with qualitative methods reviewed the thematic matrix and transcripts for consistency with themes and subthemes.

Four strategies were used to assure trustworthiness; credibility, transferability, confirmability, and dependability (Amankwaa, 2016; Connelly, 2016; Cope, 2014). Credibility is the ability to express confidence in the findings of a study (Amankwaa, 2016). Member checking was used in this study to ensure credibility of themes that were identified from the data. All focus group participants were asked prior to the start of the interviews if they would volunteer to review a summary of the findings once data collection was complete. Two participants were randomly chosen to review a summary of the themes and subthemes once focus group data analysis was complete. Each member validated the accuracy of the summary. Individual interviews were added as data source triangulation and the data was found to be similar to focus group interviews, further adding to the credibility of the data collected in the focus group interviews.

Transferability is accomplished when there is a thick description of the study process, participant details, and a description of the context of study (Amankwaa, 2016). This study involved collection of in-depth data about the participants' backgrounds and experiences, a description of the location of the three hospitals and patient populations (see Tables 1 and 2), and

a detailed description of the process through which data were collected through focus group and individual interviews. A sample of the semi-structured interview guide was also provided.

Confirmability describes the neutrality of findings as authentic to participants and not shaped by researcher bias (Amankwaa, 2016). The main way of establishing confirmability is through audit trails and direct quotes (Amankwaa, 2016; Cope, 2014; Polit & Beck, 2006). Audit trails and the use of direct quotes were used in this study to enhance confirmability. Digital and written notes on the emerging themes were used throughout the analysis process.

To assess dependability defined as consistency of findings (Amankwaa, 2016), an expert qualitative researcher reviewed the design, process, and findings of this study throughout the duration of the study to enhance dependability of the study.

Results

Sample Description

The study involved seven focus group interviews (n=26) and eight individual interviews with a total of 34 nurse participants. Focus group participation ranged from three to six participants per group. Most nurses in this study had 6-15 years of nursing experience, and 15 held a bachelor's degree in nursing. The majority of study participants (n=32) identified as female, and 26 were between the ages of 30-56 years. Twenty-eight participants identified their race as White, four as Black, and two as Asian. Half of the participants (n=17) had not received formal education in palliative care. The majority of nurses (n=24) answered yes to having a personal experience with palliative care. More than half of the nurses (n=16) that answered yes described the personal experience as one that was work-related and not an experience outside of work, such as caring for a family member (See Table 3).

Major Themes

Participants described their basic palliative care practice as comprising of two units of care dimensions, *"helping families navigate progressive illness"* and *"empowering families."* Families are considered part of the unit of care in palliative care and it was evident from the nurses' narratives that families were central to their nursing care. A diagram of these themes along with their subthemes is depicted in Figure 1.

Helping families navigate progressive illness. The overarching theme of "*helping families navigate progressive illness"* described how nurses viewed their role in palliative care in an acute care setting. Nurses described helping families and patients navigate through a progressive disease process or end of life experience by using education and role modeling. Nurses described educating patients and families on different types of care, decision-making, and how families could participate in the care of the patient. Nurses discussed families as part of the unit being cared for with the patient, one nurse stated:

> We've spent a lot of time talking about patient which is who it's about but also, I think helping the family navigate, that this [type of care] is what the patient wants realistically, this is what can happen with what we're doing.

Nurses also discussed what palliative care could be in relation to educating patients and families. One nurse described what a course of illness could look like if palliative care was started at diagnosis,

> If you're starting palliative care at the time you're getting a diagnosis and it's going to progress in a certain fashion, I feel like if you're educating the family of this is the way it's gonna go and this is what you may see, then getting to that point, getting to that point where it's end of life, that that palliative care is just holding them in your hand and ushering them down the road and then going ok now this is the end of the story. To where

it's not as scary, I mean it's always going to be sad and it's always going to be whatever

but I feel like if you're cradling the family along with palliative care, you're telling 'this

is what you're going to see and this is where it's going to go' and you see those things,

it's not as scary or it's expected, it's not such a big dramatic turn for the family or for the

patients themselves.

Nurses also helped families as they were required to make decisions for the patient. One

nurse described talking with family members about what they felt the patient would want.

Determining whether the patient and family had ever discussed the patient's wishes was a way of

taking the burden off the family by trying to help them to execute what the patient would have

wanted. This nurse felt this guidance role was necessary "because…I feel like families are facing

this massive decision of 'I'm killing my family member'."

In end of life circumstances, nurses found that "families sometimes I think in the

beginning just don't know how to interact with the person anymore, so I think we have to lead

them through that as well." One nurse described teaching family members a certain relaxing

hand massage technique and found that "really makes them feel good that they can do something

to help him or her." Another nurse described advising families to

continue to hold their hand, talk to them, to share memories, and as a family and stories,

thank them, say whatever you feel the need to say in your heart and then also letting them

know you're going to be okay when they're gone is important.

In cases that a palliative care team was consulted, one nurse noted that specialists initiate

education about the care and disease. Nursing staff on the unit were there to then reiterate and

remind during the remainder of the patient's hospital stay. Other nurses felt that one way to

educate and help families navigate was to "translate from doctor speak." Nurses in this study

often brought up their role in answering questions after a physician had told patients and families something about their illness. One nurse stated that "there is a 95% chance that as soon as [the physician] leave, they're going to ask me a question about what [the physician] just told them." Nurses also advised patients and family members to write down questions for the physician when the nurses were unable to answer all their questions.

Empowering families. The theme of *"empowering families"* described how nurses help patients and families navigate through serious illness in ways other than education and role modeling. The word 'empower' means to "make (someone) stronger and more confident, especially in controlling their life and claiming their right" (English Oxford Living Dictionaries, 2017). Nurses in this study described situations of empowering families and patients in three different ways: "*giving options*", "*being present*", and "*advocating*." The first two subthemes applied to both patients and their family members, while advocating referred to how nurses helped advocate for the patient with families and other healthcare providers.

Giving options. The subtheme of "*giving options*" described how nurses help patients and families see all their options. The options may include those that the patients and families may not be aware of or those that other members of the healthcare team have not offered to them. Nurses felt that patient knowledge was power. By keeping families informed about what was happening with the patient and what could be expected in the course of illness or the end of life experience, nurses felt they could empower patients and their families. One nurse described it as "kind of giving power back to the family so they are involved, they don't feel, you know, run by their disease or something, so they have some control, giving them back some control." Another nurse talked about a situation where an older adult patient was deciding whether or not to have a feeding tube placed. The nurse described knowing the patient's role as caregiver for his

spouse. The nurse said, "I looked at him. I said, 'you know you can get the feeding tube but you can decide when to stop using it.' Letting him know yes you can have this option…" This nurse let the patient know that even if he chose to have the feeding tube, the patient was also in charge of deciding when to stop using it. The nurse gave permission to the patient to take control of the situation.

"Giving options" also applied to giving patients and their families time to think about the options and "to know that there's not a wrong choice." One nurse stated that she "really affirm to them that these decisions are their own…their life and their death is gonna be their own." One nurse felt as though he might be crossing a line when he informed the patient that they could request a different doctor because pain was not being adequately addressed for this patient. The nurse said, "I felt I was doing a disservice if I didn't tell them that they have that option to make that request." The nurses in the study felt that patients and families do not always know all their options; the nurses felt it was their job to make patients and families aware of all the options. Another nurse felt that not offering palliative care soon enough was an injustice to their patients. This nurse believed that patients, as well as staff, were not well-educated on the difference between palliative and hospice care, did not offer palliative care soon enough or provide education on the difference between palliative and hospice care. By doing this the nurse described providers as not considering quality of life and were focused solely on quantity of life.

Being present. The second subtheme of *"empowering families"* was *"being present"* with patients and families. Nurses described *"being present"* as a way of supporting patients and families and creating a space for them to open up or talk about their situations if they chose to do so. At times this meant "just being quiet with them." One nurse made the statement that "There's a life in the bed and we need to make sure we're hearing what's going on with that life." This

statement referred to listening to the patient and making sure they had a chance to be heard rather than always having the focus of nursing care be task-oriented. Allowing a patient to be heard aligns with the definition of empower.

Another nurse described patients needing someone to hold their hand and as this nurse talked, he held another participant's hand to demonstrate this simple action. He went on to say, "Sometimes somebody is, that we just hold your hands…that's just only what they needed at that particular time, you know hold your hands…they be able to pour out their mind." One nurse shared "just being there talking to him and understanding him, why he was feeling the way he was…when he finally opened up to me, he cried, and it made me cry too." When relaying this story, the nurse started to cry.

Another nurse described caring for an anxious patient who was preparing for surgery, "I'm there for the patient first and I felt like I need to show her I was taking her seriously and wasn't going to minimize her concerns." This nurse felt that her patient was concerned about dying in surgery, and even though the nurse was unsure of how to respond she could see it was important to the patient and wanted to validate her concerns and answer her questions the best she could.

Other nurses described "*being present*" for family members after a loved one had just died or was actively dying. One nurse described how she had a patient who was actively dying on her shift. She went in that room to do her charting so she was available to the family and the patient's husband "started telling me the day that he fell in love with her, you how they'd had gone to a dance…I think he was just so much at peace and felt really supported ….because we made time for them." The nurse became tearful as she told this story. Nurses talked about how

family members just thanked them for being there and hugged them after their loss. After a sudden death, one nurse described sitting with the newly widowed wife for an hour.

Advocating. Being an advocate for patients is a basic practice of nursing. Not surprisingly, nurses in this study discussed "*advocating*" for their patients as part of their role in basic palliative care. Nurses described "*advocating*" for patients in regard to end of life decisions, decision making, and pain control. One nurse described this aspect of palliative care as:

> …trying to be more so on the patient's side when you have all those doctors and family
> and whatever, looking at you going 'we want you to live, we want you to do this.' And
> it's just you and patient on the other side going 'nope this is what she said she wants.'

Nurses felt that at times family members did not understand what the patients' wishes were or were afraid of losing their loved one. In these cases, nurses felt that it was their job to stand by the patient and support their decisions despite having family and other healthcare members urging the patient in one way or another.

Other nurses described themselves as a buffer or middleman between the providers and patients. Nurses described providers who were insistent on patients having surgery, procedures, or receiving blood, and nurses having to be the voice for the patient who was saying no. In some cases, they were successful and other times they were not. One nurse described a patient that was competent and clear about her wishes to be comfortable and forego any procedures. The physician was persistent. The nurse described talking to the physician outside of the room; she explained how she felt "like you're the middleman a little, trying to ease the path I mean, especially for advocating for my patient's wishes that were so clear and strong and that can be really uncomfortable and hard." Another nurse said, "if we're talking about quality of life and

goals and how we make someone feel comfortable and improve their quality of life, doing things the way they want them done is part of that." One nurse made it her personal goal to do whatever she could to get a patient comfortable and home, where he wanted to be at the end of his life.

Pain control was another topic discussed when nurses talked about "*advocating*" for their patients. Nurses felt very comfortable reaching out to physicians to adjust pain medication regimens to help alleviate pain for the patient. Sometimes, this was an easy task, and at other times, it was not. One nurse said, "So I kept advocating for the patient you know the doctor was kind of stonewalling him."

Nurses talked about how they were able to advocate for patients when there was a clearly written advanced directive. One nurse described the presence of an advanced directive as a way to help the family come to terms with the patient's wishes. The nurse said, "we were able to point to this and the daughter said, 'ok I realize now that all the treatment I'm seeking is for me and not for her'." Others told of patients who talked with nurses about family not understanding their decisions, and one patient told a nurse "tell them to let me go."

Discussion

In this study, nurses were asked to discuss their understanding and knowledge regarding basic palliative care in their nursing practice. Many of the nurses in this study described situations in which a patient was at or nearing the end of their life. While palliative care can be initiated at diagnosis (WHO, 2015), the experiences of these nurses in an acute care setting indicated that palliative care was mainly utilized as end of life care in the hospitals in which they worked. Only one nurse from a cardiac unit described palliative care being utilized earlier in the illness trajectory. When the nurses talked about palliative care, they often referred to the specialist palliative care team. However, through storytelling, exploration of the care they

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provided, and an understanding of the IOM's (2014) definition of basic palliative care, many

nurses came to recognize their role in providing basic palliative care. Nurses in this study felt

that they were already practicing basic palliative care without having an official name for it. The

evolution of the nurses' understanding of basic palliative care and their role is an example of the

way a transformational learning theory framework uncovered aspects of practice that may not

always be visible.

Nurses described how they help families and patients as they navigate their progressive

and often life-limiting illness and end of life. Nurses felt that education was a key aspect of

helping families and patients understand what was happening and what would happen in the

future based on their nursing experiences.

The results of this study are similar to other studies where the nurses' role was to support

family of dying patients and ensure the family could be with the patient (Caswell et al., 2015;

Namasivayam, Lee, O'Connor, & Barnett, 2014). Nurses in Caswell et al. (2015) were not

observed explaining what could be expected as a patient was dying. However, the nurses in this

study felt that it was important to inform the patients and families about what to expect in the

illness trajectory and dying process. Nurses in this study also supported families being with their

loved one by role modeling how to participate in cares.

The standards of palliative care include the family in the unit of care (American Nurses

Association & Hospice and Palliative Nurses Association, 2014). Other studies have also

identified family as an important aspect of caring for patients receiving palliative care (Caswell

et al., 2015; Namasivayam et al., 2014). Nurses in this study clearly included families in their

discussion about how they provided basic palliative care in their practice setting.

In addition to helping patients and families navigate through progressive illness by educating and role modeling, nurses described empowering patients and families by "*giving options", "being present"*, and "*advocating*." Nurses offered options to patients and families in order to aid them in decision making or help them see options that were not provided by physicians. In some cases, nurses gave options patients did not know they had, such as requesting a different physician when symptoms, such as pain, were not being adequately controlled or having a feeding tube placed but also deciding how long to use it. Family members of an ill person in one study believed that the healthcare they received depended on how well the patient knew their illness and options (Arestedt, Benzein, & Persson, 2015). The standards of palliative care assume that educating patients about options and decision-making is part of the healthcare providers' role (American Nurses Association & Hospice and Palliative Nurses Association, 2014). Most nurses in this study felt obligated to offer patients and families options so they were fully informed to make decisions about their care.

Nurses also described that just being present with patients allowed them the opportunity to express themselves or for families to share stories about their loved one. These results are supported by Robinson et al.'s (2014) integrative review which showed how families felt cared for when nurses were attentive, approachable, friendly, and regularly checked in. Many theories of hospice and palliative care include the concept of nursing presence (Dobrina, Tenze, & Palese, 2014). Presence was a way for nurses to give time and space to patients and families to express themselves (Dobrina et al., 2014). Nurses in this study shared experiences of being quiet with patients to allow them to talk if they wanted or to just be with another person in silence.

"*Advocating*" for patients was sometimes very difficult for nurses, and at times nurses felt they were stepping over the line with other providers. However, nurses felt it was their duty

to stand by the patient and support their wishes when other healthcare providers and family were pushing for further treatment options. Advocacy is an important role for all nurses. Many studies have reported that nurses working in palliative care situations value their role as patient advocates (Dillworth et al., 2016; Finnerty & Gregory, 2010; O'Shea, 2014; Roche-Fahy & Dowling, 2009; Thacker, 2008; Verschuur, Groot, & van der Sande, 2014). Shannon (2016) described one definition of advocacy as a "liaison between the patients and doctors" (p. S44). Nurses in the current study talked about how it was their job to be on the side of the patient when their wishes and preferences conflicted with physicians or family members.

"Advocating" was specific to patients as opposed to other themes that applied to both families and patients. Nurses' comments toward patient advocacy are similar to those reported in Arbour and Wiegand (2014). Critical care nurses reported educating and supporting families through the dying process of a loved one but advocated for patients (Arbour & Wiegand, 2014). Nurses described patients who needed an advocate to help the family understand the patient's wishes (Arbour & Wiegand, 2014). Nurses in the current study expressed that when there was conflict between patient and family wishes, they attributed it to the family's fear of losing their loved one. Other instances of advocacy in the literature referred to family being advocates for their loved one (Arestedt et al., 2015; Fahlberg & Dickmann, 2015; Shield, Wetle, Teno, Miller, & Welch, 2010). The results of the current study may reflect the experiences of patients and families in conflict with treatment preferences or goals of care. These experiences may contribute to the sense of duty to advocate for the patient in the absence of family advocates.

The results of this study provide examples and experiences of acute care nurses providing basic palliative care. The IOM's (2014) definition of basic palliative care described who provides palliative care; however, it lacked a clear description for nurses and future nurses of how this

type of care is provided in the acute care setting. Authors in the literature list topics of what basic palliative care entails, such as pain management and goals of care discussion (Quill & Abernethy, 2013; Weissman & Meier, 2011; Wiencek & Coyne, 2014). Listing topics does not describe the depth of caring that the nurses in this study discussed. The topics listed in the literature also overlap extensively with specialist palliative care noting that specialists attend to "complex cases" (Quill & Abernethy, 2013; Weissman & Meier, 2011; Wiencek & Coyne, 2014) and are task-oriented. '*Helping families navigate progressive illness'* and '*empowering families'* as described in this study can help to provide a better picture of what is expected when providing basic palliative care in the acute care setting. The results of this study may also guide future education for current practicing nurses and nursing students.

Limitations

The main limitation was that the study participants were from the same healthcare organization. Seventy percent of the participants were from one of the three hospitals and 47% were from an orthopedic unit. Many of the patients cared for in the acute care setting may come from or go to long term care settings or transitional care settings at discharge. It would thus be beneficial for future studies to explore what basic palliative care might look like in such settings as a way of determining the unique practices and educational needs for nurses practicing in these settings. Nevertheless, this study does offer some interpretations that could be applied to everyday nursing practice in settings other than acute care, such as long-term care facilities and nursing homes.

Almost all the participants identified as female, and the majority was White. The make-up of nurses in the United States does not reflect the patient population. It is a priority of many institutions to increase the diversity of nurses in the profession (American Association of

Colleges of Nursing, 2015). The ethnicity and gender of nurses in this study reflects nurses in the state in which the study was conducted; however, this limitation highlights that ethnic minority nurses' perspectives and experiences are underrepresented.

Nurse managers were excluded from this study because I believed that nurses might be more comfortable and free to talk about experiences without an authority figure present. However, unknown to me at the time, one nurse manager did participate in the focus group interview that was arranged and held during the unit council meeting on one particular unit. This nurse's presence did not seem to limit the other nurses' participation and this deviation from the IRB protocol was reported to both institutions that approved the study. The data obtained from this focus group was discussed with other expert researchers and was determined to be valuable as it did not seem to inhibit other nurses from fully participating in the interview. Therefore, data from this focus group was included in the data analysis of this study.

Implications for Nursing

The results of this study describe how nurses believe they practice basic palliative care in the acute care setting. While none of the nurses in this study had ever heard the phrase "basic palliative care", many described situations where they provided aspects of palliative care, many without formal education in palliative care. A number of the nurses in this study also expressed a desire for more education in palliative care. By recognizing the benefit of basic palliative care, healthcare organizations can improve the quality of life for patients with chronic, progressive illnesses. With a projected shortage of palliative care specialists (IOM, 2014), non-specialist providers will deliver the majority of basic palliative care. Through focused education, nurses could become more confident and better prepared to offer palliative care in their generalist nursing practice. Education in basic palliative care would benefit patients served in all settings.

The results from this study can assist in developing education specifically designed for the basic palliative care provider.

This study has implications for education and policy. The American Association of Colleges of Nursing (2016) has issued guidelines for implementing concepts of palliative care into nursing curriculum. Findings from this study can help to make those objectives more practical by providing real-life examples for nurses in acute care settings, especially novice nurses and nursing students. For currently practicing nurses, education and policy changes at the organizational level are important. Each organization has a different way of including palliative care in the care provided to patients in the acute care setting as well as other care settings, such as long-term care. It is important for organizations to design education that is congruent to the setting and patient populations they care for. Providing education to all providers of care, including nursing assistants, physicians, nurses, chaplains, pharmacists, and social workers, is important so that the care team uses the same language with patients and has the same criteria for including basic palliative care in the plan of care. Inclusion of all disciplines may benefit the patients by having a more cohesive team understanding basic palliative care. Policy changes at an organizational level should include standard assessment tools for providers to use in assessing for palliative care needs. Education in this area should also become a priority for all new employees as well as current employees.

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Chapter 5: Nurses' Perceptions of Basic Palliative Care in the Hmong Population

Abstract

Introduction: The purpose of this study was to describe basic palliative care from the acute care nurses' perspective with consideration for culturally diverse populations. Nurse participants focused their responses based on their experiences with Hmong patients. The concept of cultural safety was explored to improve basic palliative care practice in acute care settings. **Method**: A qualitative approach was utilized. Thirty-four nurses, recruited from three acute care hospitals, participated in either focus group or individual interviews. **Results**: Assisting tradition, understanding culture, and language barriers were identified as themes unique to providing basic palliative care to Hmong patients. **Discussion**: Nurses in this study experienced uncertainty and inadequacy of resources when caring for patients from a Hmong background. Nurses also recognized the strong family ties in this specific population and the importance of supporting tradition while in the hospital. Educating nurses on the practice of cultural safety would benefit Hmong patients and patients of various cultural backgrounds to receive quality palliative care.

Non-white racial groups experience disparities in health that lead to earlier onset and higher severity of disease in the United States (U.S.) (Williams, Mohammed, Leavell, & Collins, 2010). African Americans, Asian Americans, Hispanics, American Indians, and Alaskan Natives suffer higher mortality rates and are disproportionately affected by chronic diseases, such as diabetes and heart conditions (Health and Human Services, n.d.). Palliative care is appropriate for people experiencing symptom burden associated with serious illness; however, the use of palliative care with ethnically diverse patient populations has been lower than with White patients (Johnson, 2013). The purpose of the current study was to describe basic palliative care from the acute care nurses' perspective. One specific aim from the larger study was to create dialogue with nurses about basic palliative care experiences with culturally diverse populations. The term 'culturally diverse' was used in this study with the assumption that nurse participants would consider ethnic diversity when asked about culturally diverse patients. Nurses in this study did consider ethnic diversity but specifically discussed their experiences with the Hmong population.

Significance and Background

The Institute of Medicine (IOM) (2014) has recommended that all healthcare providers have a basic competency in palliative care. Basic palliative care is defined as non-specialist providers who practice palliative care from various disciplines (IOM, 2014). Not only should healthcare providers be competent in basic palliative care, but they should also have the skills to provide basic palliative care to people of different ethnicities, religions, and beliefs about illness and dying.

Culturally diverse populations experience many stressors including interactions with the health care system and at times a limited ability to receive high quality end of life care (Hauck,

Maxwell, Maxwell, & Reynolds, 2014; Periyakoil, Neri, & Kraemer, 2016). Johnson's (2013) review of racial and ethnic disparities suggested that barriers to palliative care for racially and ethnically diverse populations include a lack of knowledge about palliative care, cultural beliefs, and attitudes towards disclosing terminal diagnoses. Organizational barriers to palliative care with these populations may include a lack of diverse staff, interpreters, and community outreach (Johnson, 2013). Research in non-hospice palliative care is limited due to inconsistencies with billing for palliative care (Johnson, 2013).

The state in which this study was conducted is home to the second largest Hmong population in the U.S. (Pfeifer, Sullivan, Yang, & Yang, 2012). Hmong patients in this study were considered the minority group compared to the nurse participants; the Hmong patients had different cultures, life experiences, and language that may contribute to the differentiation of power in the nurse-patient relationship.

The Hmong people originated in China (Minnesota Historical Society, n.d.). In the late 1700's and 1800's, Chinese rulers suppressed Hmong people, resulting in the Hmong people migrating to Laos, Myanmar, Thailand, and Vietnam (Minnesota Historical Society, n.d.a). During the Vietnam War (1954-1975), Hmong soldiers were trained and fought alongside the U.S. against North Vietnam. Once the U.S. withdrew from the region in 1973, many Hmong were systematically targeted and killed. As a result, many of them fled as refugees to camps in Thailand. The U.S. government resettled some of the Hmong as refugees in the U.S. starting in the 1980's as well as other countries such as Canada, France, and Australia (Cobb, 2010). The circumstances surrounding their assistance to the U.S. during war, followed by a lack of support when the U.S. left the region, has caused distrust among Hmong people, which also impacts their trust of healthcare providers in the U.S. (Lee & Vang, 2010). The literature on the experiences of

Hmong populations with palliative care, specifically, is quite limited. The literature that does exist focuses mostly on traditional beliefs and customs related to illness and death (Gerdner, Cha, Yang, & Tripp-Reimer, 2007; Schriever, 1990; Vawter & Babbitt, 1997).

Cultural Diversity and Safety Terminology

Competently caring for patients of various diverse backgrounds is an important aspect of nursing and palliative care nursing. The definition of palliative care incorporates the "needs, preferences, values, beliefs, and culture" of patients and their families (American Nurses Association & Hospice and Palliative Nurses' Association, 2014). In the literature, the most commonly used phrases that speak to healthcare provider attention and sensitivity to cultural differences are cultural sensitivity and cultural competence (Evans et al., 2012). However, the concept of cultural safety may be more appropriate. The concept of cultural safety originated in New Zealand and much of the nursing literature on this concept is based on studies in New Zealand, Australia and Canada. Cultural safety is different from cultural competence and cultural sensitivity (Papps & Ramsden, 1996). In applying a cultural safety framework, the term 'culture', is contested and focuses less on specific traditions and more on how people differ from one another based on race and class status, sexual orientation, and age (Richardson, Yarwood, & Richardson, 2017). Cultural safety also emphasizes the role of power relations in healthcare (Papps & Ramsden, 1996). For example, a patient who does not feel safe in the healthcare setting may not seek care until their illness has progressed; which demonstrates a feeling of powerlessness of the patient within the system (Papps & Ramsden, 1996). Cultural safety requires the power disparities within the nurse-patient relationship to be recognized (Richardson et al., 2017). Richardson, Yarwood, and Richardson (2017) described cultural safety as recognizing "social, economic, and political positions of groups in society" (p. 2). Woods and

Schwass (1993) (as cited by Richardson et al., 2017) created a framework to use for practicing in a culturally safe way. The framework included acknowledging a difference between the nurse and patient, avoiding disempowering the patient, respecting and preserving the rights of patients, attempting to share power with the patient, understanding the origins of inequalities in healthcare, and realizing that power is biased to the healthcare provider (Richardson et al., 2017, p. 2). Nurses can work towards practicing cultural safety through self-reflection and having an awareness of how their beliefs and systems can influence relationships with patients (Richardson et al., 2017).

Method

Design

The aim of this qualitative study was to explore the experiences of acute care nurses in providing basic palliative care to culturally diverse patients. Due to the setting of the study and the responses of the participants, the data represents providing basic palliative care to the Hmong population more specifically. The University of Wisconsin - Milwaukee and the healthcare organization from which the participants were recruited approved this study through their respective institutional review boards.

The theoretical frameworks guiding this study included critical and transformative learning theories. Experience, reflection, and dialogue are key components of these theories that aid in understanding social processes (Mezirow, Taylor, & Associates, 2009; Rodgers, 2005). Due to the potential for oppression or unequal experiences of people not of the majority culture, a critical theory lens was applied in analyzing acute care nurses' perspectives and experiences in caring for diverse populations. Transformative learning theory helps nurses to uncover knowledge from their practice and understand their actions. Through self-reflection, a tool used

to engage in cultural safety, transformative learning theory guided nurses in uncovering their experiences and beliefs about basic palliative care with Hmong patients.

Sample and Setting

Acute care nurses were recruited from three hospitals within the same healthcare organization. Nurses were chosen as the participants for this study rather than other healthcare providers because they spend the most time with patients and their families during hospital admission. Nurses were eligible to participate if they worked as a registered nurse in an adult acute care setting. Nurses also needed to be able to read, write, and speak English. Nurse managers and nurses working in the intensive care unit and emergency departments were not included in this study.

The three acute care hospitals from which nurses were recruited serve a variety of patient populations. One hospital was in a downtown metropolitan area, while the other two hospitals were in suburbs of the metropolitan area. The majority of patients served at all three hospitals identified as White, with Blacks and Asians accounting for between 2.8%-8.6% (J. Pennington, Senior Director of Community Health, Policy, & Measurement, personal communication, December 9, 2016). English was the most common language spoken by patients; Hmong was the second common language spoken by patients at two of the hospitals, and the third most common language spoken by patients at the third hospital (See Table 4). The patient demographics served at these three hospitals are reflective of the state's racial demographics (see Table 1).

Data Collection

A pilot focus group was utilized to refine the semi-structured interview guide used in this study (Appendix B). Following the pilot focus group interview, six additional focus groups were conducted. Data collected in the pilot focus group interview was found to be valuable and was included in the final data analysis. Eight individual interviews were added later in the data

collection process to further enhance the credibility of the study findings by confirming the

findings of the focus group interviews and ensuring saturation. Nurses participated in either a

focus group or individual interview. Nurses participating in all of the interviews provided written

consent. Focus group interviews were conducted in a private conference room at each of the

three hospitals. Individual interviews were conducted at a private location agreed upon by the

participant. All participants completed a demographic form (see Appendix A).

Data Analysis

A thematic approach was used for data analysis. All interviews were audio recorded and

transcribed by the researcher. For thorough analysis of the data and identification of themes,

interviews were reviewed multiple times. The process of indexing and sorting was used to

organize themes and subthemes (Richie, Lewis, McNaughton Nicholls, & Ormston, 2014).

Trustworthiness was established by focusing on credibility, transferability,

confirmability, and dependability (Amankwaa, 2016). Member checking was the strategy used to

enhance the credibility of this study. Participants in the focus group interviews were asked to

volunteer for member checking. Once data from the focus group interviews had been analyzed, a

summary was sent to two randomly chosen participants to confirm that the analysis accurately

portrayed what was discussed during the focus group interviews. Each of these participants

confirmed the accuracy of the data analysis. Field notes were written or recorded after each

interview; this approach helped to enhance confirmability as it allowed for documentation of

theme construction using raw data. In this study, participant demographics were obtained (See

Table 3), which allowed for the transferability of the findings to other similar settings and

contexts. Dependability was established by consulting with an external qualitative researcher

throughout the design process and data collection. The external researcher also reviewed the raw data and the audit trail of theme construction.

Results

Sample

A total of 34 registered nurses participated in either a focus group or individual interview. There were seven focus groups consisting of 3-6 participants in each group and eight nurses participated in individual interviews. Twenty-four nurses participating in this study worked at one of the three hospitals. Thirty-two nurses identified as female and 28 were White. Most nurses (n=14) had 6-15 years of experience working as a nurse (See Table 3). The results presented in this manuscript reflect only those related to basic palliative care for Hmong patients. Other themes related to basic palliative care are reported elsewhere.

Major Themes

There were three major themes identified from the data concerning nurses' experiences providing basic palliative care to patients with a Hmong background; *"assisting tradition," "understanding culture,"* and *"language barriers."* A table of themes, subthemes, and exemplar quotes can be found in Table 5. These themes describe how the nurses in the study worked with patients and families to assist in rituals or how understanding the patient's culture affected the care provided. While the definition of palliative care indicates its' appropriateness early in and throughout the illness trajectory, most of the nurses' experiences with palliative care was focused on end of life care in the acute care setting.

Assisting tradition. *"Assisting tradition"* described how nurses assisted patients and families with carrying out specific rituals related to end of life in the acute care setting. This theme has two subthemes, *"family focused"* and *"closure."*

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Family focused. The subtheme, *"family focused"* described the strong family presence when caring for Hmong patients and how nurses believed this aspect of their culture may inhibit the use of palliative care services. One nurse said, "…in the Hmong population God bless them, they always have a lot of family around." A Hmong nurse participating in a focus group interview said, "in the Hmong culture it's all about family…very family oriented." Another nurse noted that it did not matter what caused the hospitalization, there were usually 40-50 people visiting. Some nurses found this challenging with limited space, "especially back then we had double rooms." One nurse described having to ask the spokesperson if they could leave so that the nurse could "do what we need to do." Another nurse noted that it could be overwhelming to have the amount of family and visitors that Hmong patients often have visiting them in the hospital, "you kind of get overwhelmed when they are [there] cause there can be like 50 people in the room." Nurses also noted that they have seen a change in this practice and that sometimes Hmong patients do not have anyone with them and attributed this to becoming "Americanized." One nurse said, "when you have a Hmong patient that's not doing well and there's no family it's very strange and you realize how lovely their culture is, how family oriented they are overall." In the context of palliative care, another nurse felt that

> The Hmong culture already, it's just like there is a whole other emotional and spiritual level to the palliative care that's brought with it and I feel like they already are embracing that within their…I've noticed the majority of the time that they already embrace that within their everyday life.

One nurse talked of how she cared for a Hmong patient who was receiving palliative care. The patient was dressed in her traditional "traveling clothes," the nurse said, "it was nice, it seemed

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like a really nice melding of what we think of as palliative care and also what the family and the patient would want for her travel for her journey at the end."

Nurses also felt that due to the large family support, Hmong patients usually did not accept some inpatient or alternative therapies, such as essential oils, while they were in the hospital. A few nurses commented that they did not see Hmong patients receiving inpatient palliative or hospice care services because "they [family] usually take them home." One nurse said that even if palliative care is part of the plan of care for a patient, "they [family] want to hold off on giving pain medication because they want to take the family member home because they like to take care of their own." This same nurse said that she had been working on the hospice inpatient unit for 13 years and could not remember caring for a Hmong patient that had died in the hospital.

One aspect of the *"family focused"* subtheme was how nurses described assisting families in traditional rituals. One nurse described helping families with traditions when a patient was dying. She spoke of helping a Hmong family dress the patient in a death robe. Another nurse spoke of entering the room of a dying patient to reposition the patient. The family was surrounding the bed praying and chanting. The nurse accepted that it was not a good time for her to do her tasks and said that she wanted to "allow them to do what they want based on their culture as long as it's keeping the patient comfortable." Nurses felt that it was important to inform patients and families of resources, such as calling spiritual care to assist in bringing a religious leader of the patient's faith or just letting them know that nurses were there to help in any way they could. One nurse shared a story about accommodating a patient's request to burn incense by moving the patient's bed off the unit to work around the hospital policy against

fragrances. This nurse created a space in which they could accommodate the patient and family needs in their end of life experience.

Closure. Nurses described participating or aiding in traditional rituals as a way of ensuring closure for the family. By honoring and assisting with traditional rituals, one nurse said, "It gives them closure." The nurses wanted families to "feel comfortable with everything." One nurse said, "Make sure that the patient dies and dies in the way that the family will be happy and not feel haunted." Other nurses described their understanding of different cultures by describing consequences the family may endure from not accommodating traditional end of life rituals. One nurse described this by saying,

> They have very, very strong rituals and beliefs and if we don't do them and then that family is going to be haunted or their spirits can't rest and so then somebody else in the family is going to become afflicted.

Nurses also felt that if the hospital setting did not honor these traditions, it could prevent patients from seeking medical help in the future. One nurse stated that some families may not bring their family member to the hospital "because they think when they come in sometimes we are in the way of them performing whatever they think is the right thing to do for their dying family."

Understanding culture. The theme "*understanding culture*" referred to nurses' understanding and uncertainty of certain aspects of their patients' culture. Two subthemes were identified under this theme, *"uncertainty"* and *"learning more."* Nurses shared aspects of their own culture that related to end of life goals and death in general. One Hmong nurse participant offered insight into Hmong cultural beliefs, such as dressing a dying patient in a funeral or death robe. This nurse also talked about how she was able to connect with a Hmong patient who had

not been open to talking with other nurses. She was able to talk to him in their native language and this created an atmosphere of trust.

   Uncertainty. The subtheme of *"uncertainty"* described how some nurses were unfamiliar with cultures that were different from their own and how this impacted the care they provided. One nurse was caring for a dying Hmong patient and because she did not understand the rituals the family was performing, she felt she could not make a connection, "I wish I had known more about that before I stepped into the room because it was just…felt like I couldn't really connect because I didn't know." Another nurse stated, "they have their whole thing that they do and I kind of let them do their thing and I sort of feel like I maybe don't totally understand it, so I don't want to get in the way of it, so I just kind of make sure they know I'm there to help them with my western medicine." This same nurse expressed that she would not know "what to do to facilitate their…rituals" and that she lets "the family lead the way."

   Nurses noted that they did not know a lot, specifically about the Hmong culture, when describing their experiences. In talking about the limited services that Hmong patients and families accept from hospital staff one nurse stated, "maybe we're not educating that population or it's just their culture." Another nurse told of a patient who was at the end of life, but the family refused palliative or hospice care to be involved. She felt that the patient suffered for weeks and ended the story by saying,

   I don't know a ton about their culture, I think that was a more of a cultural barrier too,

   with them but it was kind of unfortunate that they weren't willing to let us try these

   approaches or get other people involved.

Another nurse expressed her uncertainty about why Hmong patients and families refuse pain medication. She stated, "I would need to understand more of the Hmong population to be able to

fully understand why a lot of times they don't want the pain medications." This nurse did not want to make assumptions about why Hmong patients and families refused pain medications. She felt that she needed more information about their culture to understand the patient's needs.

One nurse felt that "there's a white standard of living and I think that the hospital really embodies that." She pointed out that using the terminology of "culturally diverse" is "assuming white is the standard." She felt this was especially exhibited with the Hmong populations and their requests for warm or hot water to drink. This nurse felt that other nurses did not respect Hmong patients' requests for warm or hot water when it was contraindicated in situations such as fever. The nurse felt this disregarded the patient's belief about what was needed to heal. In respects to palliative care, this nurse felt that "a form of palliative care [is] allowing someone to do what they want."

Learning more. The second subtheme, *"learning more,"* referred to nurses exploring the cultures of their patients when they wanted to know more. One nurse talked about how she asks the primary spokesperson for the patient "What can I do to support you? Is there anything culturally that I should be aware of that can make this a better experience for you?" She used these examples after another nurse in the focus group expressed discomfort in not knowing what to do when she did not understand cultural practices.

Another nurse described an experience with a Hmong patient who had broken a major joint. The patient did not want surgery because of a belief that evil spirits could enter his body during surgery. The nurse had not come across this belief before and to learn more, she searched for articles on such beliefs which helped to reinforce what she had learned from the patient. Nurses used information they knew about specific cultures to understand why certain treatment options were chosen.

Language barriers. "*Language barriers"* was the last theme that emerged from the interviews in the context of providing basic palliative care to culturally diverse patients. This theme had two subthemes: "*means to communicate"* and *"incomplete understanding."* This theme was not necessarily limited to the context of basic palliative care and many of the nurses' experiences described caring for other patients with limited English proficiency.

Means to communicate. The subtheme of "*means to communicate"* referred to the physical resources nurses have to communicate with patients with limited English proficiency. Nurses described the need to rely on communication devices to call a language line because in-person interpreters were not available. Nurses felt that communication devices were ineffective because patients and interpreters had difficulty hearing through them. The nurses thus did not feel confident that patients understood what was being said or explained to them. One nurse said, "Things can be misinterpreted… Because you can't hear right, it's better to have an actual person." Other nurses discussed that some languages do not have specific medical terms that can be easily translated and that this could also cause confusion. One nurse described how interpreters seemed rushed, which did not allow for the necessary time to overcome language barriers and understand what the patients were experiencing.

Nurses also described ways in which they described getting information to patients when there was difficulty with interpreters or understanding, even if the patient or family spoke English. One nurse found it helpful to draw pictures, especially with Hmong patients and families. She described how drawing a bursting appendix helped a family understand the severity of a patient's condition. Other nurses discussed using applications on their smart phones to help them interpret and communicate with patients instead of using the organization's language line.

Incomplete understanding. The last subtheme of "*incomplete understanding"* described nurses' feeling that even when they had adequate resources for interpretation, there was a gap between languages that created an "*incomplete understanding*" by the patient and their families. One nurse in a focus group interview described this by saying,

> Sometimes we explain things in English and if they have a family member or translator something like that…oftentimes they may do like the smile and nod thing and 'oh yeah ok I understand' but they really don't necessarily, or they might understand a portion and not feel comfortable asking clarification questions. I think that's a real concern.

Another nurse described a situation in which a patient and family indicated understanding of a procedure, but then refused that procedure when the nurse attempted to implement it. The nurse said, "when you talk to them it's 'sure, sure, sure' and shaking their head but then you go to do whatever you said and their just 'oh no', they totally did not understand what you were [saying]." Another nurse used the word 'noncompliant' but then said "I hate the word noncompliant cause … I feel like half the time it's not that they're being noncompliant, it's that there's some lack of information being translated with why it's not working." One nurse said, "it's like there's something that it's so culturally different that it's really hard to get the idea across…it doesn't come across in a way that they can sort of formulate into their culture at first." Another nurse felt that perhaps they do not have the "right language" to translate it correctly.

Nurses in one focus group talked about the different dialects within the Hmong culture and how that could make understanding difficult even when interpreters were present. The Hmong nurse in this group also said, "We don't have specific terms gear[ed] toward [diagnosis or medical terms]." This nurse gave examples of how some medical diagnoses are translated,

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"for hypertension we'll say high blood, which is (native word). It means like high blood…and they understand it or like diabetes is sweet blood."

Discussion

The nurses in this study talked about their experiences providing basic palliative care for patients of the Hmong population. Nurses discussed the importance of assisting patients and families with traditional rituals as a way of creating closure for families after the death of a loved one but also to build trust with the Hmong community. The nurses in this study also expressed uncertainty when working with patients and families with different cultural and ethnic backgrounds. However, some nurses sought out more information when confronted with situations they were not familiar with. Nurses felt that means to communicate with patients and families with limited English proficiency were inadequate.

Nurses described their roles in assisting patients and families in their rituals in an acute care setting. Nurses in this study described a willingness to work around hospital rules to provide appropriate palliative care. Schrank et al. (2017) spoke of bending rules as a way of doing what was best for the patient and their family. For example, one nurse in the current study described finding a way to allow family members of a dying patient to burn incense, despite the unit policy of being fragrance free.

One Hmong nurse participant was able to provide clarity for other nurses about cultural beliefs and practices in the Hmong culture. However, nurses in this study were mostly White, Christian women. The participants in this study reflect the nursing profession (American Association of Colleges of Nursing, 2015) and people in the U.S. as 70.6% identify as Christian (Pew Research Center, 2017). Fifty percent of Hmong people living in the U.S. identify as Christian; however, the historical spirituality of Hmong people are animism and ancestor worship (Minnesota Historical Society, n.d.b). Ensuring that staff within the organization reflect

the patient population is one organizational measure suggested by Schrank et al. (2017). The benefit of feeling a connection with someone like you is illustrated in the Hmong nurse's story in this study. A Hmong nurse participant believed that she was able to develop trust more easily with a Hmong patient than her White colleagues. She believed that this relationship enabled him to share his fears and goals related to a terminal diagnosis.

Nurses described some aspects of knowing about various cultures they often worked with in the acute care setting. However, other nurses expressed an uncertainty about cultures that created difficulties in connecting with patients. Vandenberg (2010) described looking for similarities to build a trusting relationship as one way of enhancing cultural safety. To build a trusting relationship, nurses need to focus their priorities on the patient's and family's needs. Understanding cultural traditions and beliefs can come from experience and knowledge about the culture, but with caution to avoid stereotyping or making assumptions about what an individual patient believes. Some nurses in this study noted that as later generations are raised in the U.S., their cultural practices may change as they adapt to a new environment. It may be more appropriate to provide staff with up to date articles on how to provide culturally safe care to patients of diverse backgrounds in addition to educating nurses on ways of assessing patient needs. Nurses in the focus group interviews also advised others when they expressed *"uncertainty."* One nurse described questions she asked when she was unsure of the beliefs and needs of patients from diverse backgrounds. This is one benefit of utilizing focus group interviews for data collection. Reflecting and sharing experiences such as this also helps to transform nurses' future actions as described in transformative learning theory.

The focus group and individual interviews strayed from the topic of basic palliative care as nurses spoke about how language barriers and the resources they have for interpretation felt

inadequate. Selman et al. (2017) found that the U.S. had a lack of interpreters which inhibited communication. Even with interpreter services, nurses in this study did not always feel that patients and their families understood information completely or asked questions that they had. Some nurses felt that some concepts did not translate, specifically with Hmong patients. In Cobb's (2010) study, the authors also identified that medical words do not exist in the Hmong language and that meanings are sometimes "lost in translation" (p. 80). In this study, a Hmong nurse participant gave examples of how diabetes was often translated as sweet blood.

The problem of inadequate interpreter services is indeed an organizational level problem that must be addressed (Schrank et al., 2017). Nurses in this study had suggestions for improving interpreter services in their healthcare system; one nurse suggested using iPads or some similar device so patients could see who was speaking and to improve the ability of the patient and interpreter to hear one another as well as see non-verbal communication cues.

There were four subthemes the emerged in this study that reflect some tenets of culturally safe nursing practice. Nurses who sought out more information about beliefs of a patient to gain a better understanding reflect the nurses' awareness of difference and an attempt to learn more to better serve the patient. Other nurses recognized the importance of the patient and family following certain rituals inside the hospital and felt a duty to respect and assist in completing those rituals. Lastly, some nurses used creative ways to overcome language barriers to decrease the uneven power that the lack of understanding gives the patient. Each of these examples do not demonstrate a strong culturally safe nursing practice; however, they illustrate ways in which some nurses are attempting to serve their patients and decrease the unequal power that is distributed among the parties.

Other subthemes seemed to increase the lack of power patients experienced, and although nurses recognized some of them, there were no actions that resulted to address this inequality. The nurses described a lack of or poorer forms of resources available for interpretation with Hmong patients. The nurses felt that these forms of communication were inadequate to serve the patients and themselves well. Inadequate resources in addition to the problem of translating certain medical terms has the potential for an incomplete understanding by the patient and their family, furthering the lack of power given to patients and their families. Lastly, uncertainty about different cultures, particularly the Hmong culture, made some nurses hesitant about assisting or contributing more to the care of the patient. While these nurses were aware of this, they did not describe seeking out or learning more about the culture in order to feel more confident in their care for these patients. Only one nurse recognized the lens of White culture being the standard to base care on in the acute care setting. Figure 2 illustrates these interactions of themes, subthemes as a move towards culturally safe care or culturally incomplete care.

Implication for Nursing Practice

To ensure culturally safe practice in the context of basic palliative care, it is necessary for nurses to approach patients as individuals rather than emphasizing the notion of culture and attempting to apply what they know or have learned about a group to everyone they encounter who might identify with that group. Nurses in this study described ways in which they had seen different cultural aspects change as people lived in the U.S. longer and altered some of their customs in order to adapt. The framework created by Woods and Schwass (1993) (as cited by Richardson et al., 2017) could assist nurses in becoming culturally safe in their nursing practice. The four principles include the nurse 1) acknowledging a difference between themselves and their patients, 2) identifying the power differential between nurse and patient and attempting to

share power, 3) understanding the roots of inequalities in health, and 4) appreciating that power is biased to the provider (Richardson et al., 2017). Teaching nurses to use these principles may guide them to provide care to their patients, so that the patients feel safe and an equal partner.

Limitations

There were some limitations to this study. Nurses participating in this study were all from one healthcare organization located in the Midwest. This limits our understanding of basic palliative care to nurses who have similar experiences working in one area. However, the experiences caring for patients in a hospital or other type of care setting with similar presentation of health issues are likely to be comparable.

The majority of the participants were White females and reflected the demographics of the nursing profession (American Association of Colleges of Nursing, 2015). There were four African native nurses, and two that identified as Asian. The experiences of the nurses in this study may reflect the majority of nurses from a predominantly White profession; however, it is lacking in bringing forth the voices and experiences of nurses from an ethnic minority background. The fact that there is a very small minority of nurses from racial, ethnic, and gender diverse backgrounds highlights the need for a great increase in a diverse profession and attention to implementing successful ways to include all backgrounds and genders into the nursing profession.

Nurses working in intensive care and emergency departments and nurse managers were excluded from participating in this study. Intensive care and emergency departments are more likely to have different experiences in palliative care than acute care nurses and were, therefore excluded. Nurse managers were excluded so that nurses would feel comfortable expressing themselves freely. However, one nurse manager participated in the focus group interview that was arranged by another manager. This was unknown at the time. The two institutional review

boards that approved the study were made aware of this deviation from the study protocol. Participation of the nurse manager in the focus group interview did not seem to affect the nurses' participation or willingness to discuss their experiences. Therefore, data from this focus group interview was found to be valuable and was left in the study.

Conclusion

This study was conducted in Minnesota, which is the second largest home to Hmong-Americans (Pfeifer et al., 2012). It should be of great concern that nurses working with Hmong patients feel uncertain in the care they provide because of the difference in culture. Furthermore, organizational structures that do not provide adequate or effective forms of interpretation should also be concerned when patients are not fully understanding what is happening to them in the hospital or what is expected of them when they leave the hospital. During times of serious illness, the hospital can be a confusing place even for someone that speaks and understands the dominant language and is from the dominant culture. For patients of differing cultures, it must be even more so confusing. To incorporate basic palliative care into nursing practice, an individualized form of care must also emerge so that patient differences are recognized, respected, and incorporated into the care provided. As nurses working in acute care settings are expected to have a basic competency in palliative care, their awareness and ability to enhance cultural safety is important as they care for an aging and more diverse population.

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Chapter 6: Homelessness and Basic Palliative Care

Abstract

Palliative care is known to be beneficial for people with chronic illnesses or facing life threatening illnesses. Palliative care is important for persons experiencing homelessness. This population has a higher prevalence of chronic illness and shorter life expectancy than the general population. This study aimed to identify acute care nurses' perceptions of what is needed to provide basic palliative care to homeless patients in an acute care setting. The study used a qualitative approach to analyze data from focus group and individual interviews. Thirty-four acute care registered nurses participated in this study. Four themes were identified: invisible patients, determining needs, coinciding obstacles, and building relationships. Nurses with basic palliative care skills can help homeless patients overcome obstacles by assisting with advanced directives, creating a plan of care that supports the homeless patient, and building trusting relationships through non-judgmental care.

Key words: palliative care, chronic illness, homelessness

According to data from the United States Census (2016), over half of a million people experienced homelessness in the United States (U.S.) in 2016. Homeless individuals are at greater risk for chronic illnesses than the general population (Beijer, Bruce, & Burstrom, 2016; Bernstein, Meurer, Plumb, & Jackson, 2015; Cagle, 2009; MacWilliams, Bramwell, Brown, & O'Connor, 2014; National Coalition for the Homeless, 2009). Life expectancy is 36 years less for a homeless person than a housed person (National Coalition for the Homeless, 2009). Homeless people also typically seek and receive health care in an acute care setting (National Coalition for the Homeless, 2014a).

In addition to physical illnesses, mental illness and substance use have a significant impact on the health of homeless people. According to the Substance Abuse and Mental Health Services Administration (2017), in 2016, over 200,000 homeless people had severe mental illness or chronic substance use disorder. Certain populations are at higher risk for homelessness and have higher risks for mental illness and substance use (Substance Abuse and Mental Health Services, 2017). Lesbian, gay, bisexual, and transgender (LGBT) youth have a high risk of homelessness, mental health, and substance use (Substance Abuse and Mental Health Services, 2017). Trauma amongst the LGBT population, including physical and sexual assault, is at higher rates than the general population (Substance Abuse and Mental Health Services, 2017). Additionally, rural populations who are homeless have limited shelter options (Substance Abuse and Mental Health Services, 2017). Rural homeless populations in some states have higher rates of mental illness compared to urban homeless populations (Substance Abuse and Mental Health Services, 2017). Amongst veterans, mental illness, commonly post-traumatic stress disorder, and the use of substances, are strong predictors of homelessness (Substance Abuse and Mental Health Services, 2017).

Palliative care offers support for patients with chronic and life-threatening illnesses, with services such as symptom management, advanced care planning, care coordination, and emotional support (National Consensus Project, 2013). Homeless people suffer more from chronic illness than the general population, and yet have fewer resources and support. The Institute of Medicine (IOM) (2014) has recommended that healthcare providers have a basic competency in palliative care. Basic palliative care was defined as palliative care provided by healthcare professionals without a specialization in palliative care (Institute of Medicine, 2014). Homeless individuals typically seek and receive care in acute care settings. Therefore, it is important to ensure that acute care nurses are prepared to provide basic palliative care to homeless people.

The aims of this study were to explore 1) acute care nurses' experiences in providing basic palliative care and 2) any considerations acute care nurses found to be necessary when providing basic palliative care to homeless patients from a critical and transformative theory perspective.

Two theoretical frameworks guided this qualitative study. Exploring nurses' experiences through a critical theory lens helped to gain greater insight into the homeless population, who often experienced discrimination and stigma. Homeless individuals were likely to experience their personal power shifted to the providers within the healthcare structure. Transformational learning theory utilizes individual's experiences and reflections to uncover beliefs and attitudes (Mezirow, Taylor, & Associates, 2009). Mezirow identified a "structure of assumptions and expectations" that are used to filter impressions as frame of reference (Merriam, Caffarella, & Baumgartner, 2007). Point of view was one aspect of the frame of reference that included a person's beliefs, attitude and judgements (Merriam et al., 2007). Nurses' actions and attitudes

toward basic palliative care for homeless patients can start to be uncovered through their

storytelling of experiences caring for homeless patients.

Background

Literature on homeless patients has focused on the lack of social support (Bower,

Conroy, & Perz, 2017; Narendorf, 2017), causes of homelessness (Bower et al., 2017; Dirmyer,

2016; Doran et al., 2013; Narendorf, 2017; Piat et al, 2015) and access to healthcare (Doran et

al., 2013; Russolillo, Moniruzzaman, Parpouchi, Currie, & Somers, 2016). Literature addressing

the palliative care needs of homeless people was limited. However, literature that did exist

included challenges with managing medications (Cagle, 2009; Hakanson et al., 2016;

MacWilliams et al., 2014; Song et al., 2007), experiences with death and dying, serious illness,

and interactions with healthcare professionals (Huynh, Henry, & Dosani, 2015; McNeil &

Guirguis-Younger, 2011; Song et al., 2007; Tobey et al., 2017).

Lack of Social Support

Lack of social support for the homeless communities on the part of family and friends has

been reported (Bower et al., 2017). Bower et al.'s (2017) study described homeless individuals'

experiences of rejection by family and lack of companionship as missing links in their network.

The authors of this qualitative study interviewed homeless people to gain a better understanding

of social networks and isolation among the homeless community (Bower et al., 2017). Some

homeless people were rejected or separated from family and friends because of their

homelessness, while others became homeless because of broken relationships with family and

friends (Bower et al., 2017). Narendorf's (2017) study focused on young adults' experiences

with homelessness, mental health, and substance use issues. Young adults described being

kicked out of their home by family and friends (Narendorf, 2017). Some reasons for this were

related to behavior problems associated with substance use or mental illness (Narendorf, 2017).

Other young adults in this study experienced unstable living conditions in foster care from a

young age (Narendorf, 2017).

Some homeless people were unable to find healthy relationship options within the

homeless community. This was due to not fitting in with other homeless people (Bower et al.,

2017). Distancing or not connecting with the homeless community was also related to the

backgrounds from which people came before becoming homeless (Bower et al., 2017). For

example, participants in Bower et al.'s (2017) study who experienced marginalization prior to

homelessness found a sense of belonging in the homeless community. Alternatively,

professionals who became homeless resisted forming relationships with other homeless people

(Bower et al., 2017). Those who made strong social connections within the homeless community

found these relationships beneficial. Some recognized the need to make connections to gain

access to resources or just to avoid loneliness (Bower et al., 2017). Bower et al.'s (2017) study

participants also acknowledged the temporary nature of relationships due to the possibility of

housing placement that created geographic distance between people. There was also some

distrust of others in the homeless community due to fear of being a victim of theft (Bower et al.,

2017).

The lack of social support that homeless people experienced was a barrier to receiving

palliative care. Family and social support are important aspects of palliative care (American

Nurses Association & Hospice and Palliative Nurses Association, 2014). Lack of social support

makes it difficult to find caregivers outside of the healthcare system to support homeless

individuals during an illness experience (Huynh et al., 2015). Some homeless people desired

reunification with family members during an illness or at end of life, while others were not

willing to reach out to estranged family for fear of further rejection (Hakanson et al., 2016; Song et al., 2007). Ko, Kwak, and Nelson-Becker's (2015) study found that homeless people had a desire to make amends as a way of creating closure with significant others. This was one aspect of what homeless people described as a good death (Ko, Kwak, & Nelson-Becker, 2015). A support house in Sweden provided shelter and palliative care to people who had been denied housing due to drug and alcohol use (Hakanson et al., 2016). Staff who provided care to the residents found it important that they treat the patients with dignity and respect in order to build trusting relationships (Hakanson et al., 2016). Staff described serving as stand-in family for patients by participating in everyday activities with them (Hakanson et al., 2016). Such activities included eating meals together, watching television, or taking walks (Hakanson et al., 2016). Often staff who had the closest relationships with the patient were the ones that sat with, talked with, and were present at the time of death.

Causes of Homelessness

In addition to broken or unstable family structures, many other factors play a role in homelessness. The reasons why people experience homelessness include; lack of affordable housing, poverty, lack of affordable health care, domestic violence, early childhood adverse experiences, mental illness, and addiction (Fazel, Geddes, & Kushel, 2014; National Coalition for the Homeless, 2014b).

Homelessness can be a cause of both substance use and mental illness, but it can also be a result of either of these (Narendorf, 2017). Participants in Narendorf's (2017) study attributed homelessness to the onset or exacerbation of symptoms of mental illness. Others described substance use as the contributing factor to homelessness and mental illness (Narendorf, 2017). In some cases, substance use was also a way to cope with or manage mental illness because

homelessness made it difficult to manage symptoms with prescription medications (Narendorf, 2017). Other participants described stopping medications prescribed for mental illness, which, led to the use of other drugs and resultant homelessness (Narendorf, 2017).

Homeless people admitted to acute care settings were often admitted for substance use issues or mental illness. Some studies have identified mental illness and substance use as the top two diagnoses for inpatient admissions for homeless people (Dirmyer, 2016; Doran et al., 2013; Russolillo et al., 2016). Doran et al.'s (2013) study found that of those patients readmitted to the hospital, 36% was a result of substance use. A study by Dirmyer (2016) had similar results; homeless patients with neuro-psychiatric conditions were more likely to be readmitted than patients with respiratory conditions, injury, or cardiovascular conditions.

The structural causes of homelessness, such as lack of affordable housing, health care, and employment opportunities that provide adequate income, were also important to consider when examining causes of homelessness from a critical theory perspective. Participants in Piat et al.'s (2015) study reported that transitioning from foster care and other institutions contributed to their homeless status. Transitioning from foster care or other institutions were abrupt and did not give participants the skills for successful independence (Piat et al., 2015). The participants also described stigma and discrimination that sustained homelessness and the inability to secure affordable housing (Piat et al., 2015). Piat et al.'s (2015) study participants felt that affordable housing in unsafe areas increased their risk for substance use. Participants put aside urgent healthcare needs in order to find safe housing (Piat et al., 2015).

Lack of housing was often a barrier to palliative care (Cagle, 2009). There was a lack of privacy and space for interventions to occur whether homeless people were sheltered or not (Cagle, 2009). In addition to homeless individuals' own lack of housing, facilities for homeless

people that provided palliative care, such as the support house described in Hakanson et al. (2016) were rare in the U.S. (Song et al., 2007). Beresford (2017) identified five facilities in the U.S. The facilities were described as following the standard model for hospice homes, with the capacity to bring in a Medicare-certified hospice team if necessary (Beresford, 2017). It was unclear if basic palliative care was provided in these facilities, or if they were solely for patients that qualify for hospice. One review of the literature found that palliative care facilities dedicated for the homeless would be more cost efficient than providing care in a hospital setting or a traditional palliative care facility (Sumalinog, Harrington, Dosani, & Hwang, 2017).

Healthcare Access

Homeless people often sought care in acute care settings rather than in primary care settings (Fazel et al., 2014). Studies have looked at the hospital admission rates and readmission rates for homeless people (Dirmyer, 2016; Doran et al., 2013; Russolillo et al., 2016). Doran et al. (2013) found that 30-day readmission rates were 50% among the homeless population compared to a rate of 18% for all Medicaid patients. The study also found that many readmissions occurred within one week of discharge (Doran et al., 2013). Over a 10-year period, Russolillo et al.'s (2016) study identified an average of six inpatient admissions per person. Dirmyer (2016) also reviewed the admission and readmission rates of homeless people over a three-year study period. One-third of homeless patients were readmitted within 30 days and almost half of the homeless patients had multiple admissions per year (Dirmyer, 2016). Doran et al.'s (2013) study found that patients discharged to a specific location, such as with a family member or motel had lower odds of readmission than those patients discharged to the street or a homeless shelter (Doran et al., 2013).

Medication Management

Drug and alcohol use was a common barrier to palliative care for homeless people (Cagle, 2009; Hakanson et al., 2016; MacWilliams et al., 2014; Song et al., 2007). Tobey et al. (2017) found that 90% of the homeless people in their study had substance use disorders. While there was a correlation between homelessness and substance use, poor health outcomes have been reported for the homeless population resulting from healthcare provider bias (McNeil & Guirguis-Younger, 2011; Song et al., 2007). Homeless participants in Song et al. (2007) described experiences where healthcare professionals inadequately treated pain because of preconceived ideas about homeless people and substance use. Healthcare professionals in McNeil and Guirguis-Younger's (2011) study struggled with prescribing opioids to opioid tolerant homeless patients. Opioid tolerant patients required higher doses which led providers to fear the chances of an accidental overdose in an attempt to relieve pain (McNeil & Guirguis-Younger, 2011). Homeless individuals also often lacked a safe place for storage of medications or the inability or unwillingness of shelters to provide a place for safe storage (Cagle, 2009; MacWilliams et al., 2014). People who use drugs or alcohol may be excluded from traditional palliative care facilities due to zero-tolerance policies (McNeil & Guirguis-Younger, 2011). Such policies make it challenging to house patients in a safe place where adequate medications can be administered to relieve symptoms related to chronic illness.

Past Experiences

Overall, homeless people reported poor experiences with healthcare providers, with the deaths of friends and family, and with their own serious illness (McNeil & Guirguis-Younger, 2011; Song et al., 2007; Tobey et al., 2017). A quarter of the homeless participants in Tobey et al.'s (2017) study did not trust any doctors or nurses. Experiences of discrimination (McNeil &

Guirguis-Younger, 2011) and providers' preconceived beliefs about homeless people (Song et al., 2007) contributed to this distrust.

Personal experiences that homeless people had with the death of a family member or close friend also shaped some of their beliefs and attitudes about end of life care (Song et al., 2007). Many had fears of not being remembered, dying alone, or without anyone knowing that they had died (Song et al., 2007; Tobey et al., 2017). Ko et al. (2015) studied how homeless people described a good and a bad death. Dying alone, becoming dependent, prolonging life with life support and experiencing death via an accident or violence constituted a bad death for participants in this study (Ko et al., 2015). Themes of a good death included dying peacefully, absence of suffering, making a spiritual connection, and making amends with significant others (Ko et al., 2015).

The theme, becoming dependent, described in Ko et al. (2015) referred to the loss of independence as a chronic illness progressed to the dying phase. Homeless participants feared losing control of basic functions (Ko et al., 2015). Homeless people also feared becoming a burden to others, especially if the caregiver was someone who was older and frail as well (Ko et al., 2015). One reason that homeless people did not want contact with family as they neared death was they did not want to be a burden on them emotionally or financially (Song et al., 2007).

Literature described homeless individual's concerns with the progression of chronic illness and fears surrounding the dying phase and death (Ko et al., 2015; McNeil & Guirguis-Younger, 2011; Song et al., 2007; Tobey et al., 2017). Basic palliative care provided by those who commonly work with homeless populations can help to ease these concerns by helping

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patients complete advanced directives, creating individualized care plans that support the

homeless patient, and building trusting relationships through non-judgmental care.

Methods

The purpose of this qualitative study was to explore acute care nurses' experiences

providing basic palliative care to homeless patients. Institutional review boards (IRB) at

University of Wisconsin – Milwaukee and the healthcare organization where the study was

conducted approved this study.

Sample and Setting

Nurses were recruited through employee emails, flyers, and word of mouth. Acute care

nurses from three acute care hospitals were recruited to participate in focus group and individual

interviews. For inclusion in this study, nurses needed to work as a registered nurse in an acute

care setting and read, write, and speak English. Nurse managers and nurses working in intensive

care and emergency departments were excluded; however, unknown to the researcher, a nurse

manager participated in a focus group interview that was set up by another manager. Both IRBs

were notified of this breach in study protocol. The researcher felt that the presence of the nurse

manager did not inhibit the freedom of expression from the other nurses in the group and the data

was used in the analysis phase.

Hospital A was in a downtown metropolitan area directly across the street from a

homeless shelter and a newly-opened shelter that has beds specifically for patients discharged

from the hospital who need acute medical care (Catholic Charities of St. Paul and Minneapolis,

2017). The nurses from this hospital had the most experience working with homeless patients

and the data forming the basis of this manuscript are primarily from the narratives of these

nurses. Hospital B and C were a part of the same healthcare organization and were in suburban areas of the metropolitan area.

Data Collection

A semi-structured interview guide (see Appendix B) was used to collect data in this study. A pilot focus group interview was conducted first to refine the interview guide. After data analysis began, data from the pilot group was deemed valuable and included in the final data analysis. Following the pilot focus group interview, six subsequent focus group interviews were led by the researcher. Eight individual interviews were conducted to augment credibility of the focus group interview results and to guarantee saturation. Nurses who participated in the focus group interviews were not eligible to participate in the individual interviews. All interviews followed the same semi-structured interview guide. In addition to the interview data, participants completed a demographic form (see Appendix A) and provided written informed consent. Following each interview, the researcher recorded field notes on the setting and other circumstances occurring during the interviews.

Data Analysis

Interviews were audio-recorded and transcribed by the researcher. Transcripts were reviewed multiple times to ensure accurate identification of themes. Thematic data analysis was employed. Theme and subthemes were organized by the process of indexing and sorting as described in Richie, Lewis, McNaughton Nicholls, and Ormston (2014).

Trustworthiness

At the start of the focus group interviews, participants were asked if they would be willing to volunteer as a member check. From the list of volunteers, two randomly chosen participants reviewed a summary of themes to ensure accurate portrayal of the interviews. Both

participants responded, confirming the accuracy. Dependability was established by consulting with an external qualitative researcher throughout the process of study design and data collection. This external researcher also reviewed raw data and a matrix that depicted the construction of themes and subthemes.

Results

Sample Description

Thirty-four acute care nurses participated in this study. The seven focus groups consisted of 26 acute care nurses; eight nurses participated in individual interviews. Most of the nurses (n=24) worked at hospital A, the hospital located across the street from a homeless shelter (see Table 3). Most nurses identified as female (n=32), White (n=28), and reported 6-15 years of nursing experiences (n=14).

Themes

Four main themes and three subthemes were identified when acute care nurses talked about caring for homeless populations in the context of basic palliative care. *Invisible patients, determining needs, coinciding obstacles,* and *building relationships* emerged as major themes.

Invisible patients. The first theme, *"invisible patients,"* referred to homeless people accessing care in the acute care setting without continuity of care outside the hospital setting. This theme also addressed the comfort level of healthcare professionals working with homeless people. One nurse referred to homeless patients as invisible because they do not access the healthcare system until their condition becomes severe, "These are people, too, that are kind of lost and invisible and we don't see them until we're coding them in the ER from whatever medical issue they actually had." Another nurse supported the views of other nurses in the focus group interview by describing care for homeless patients as follows:

I feel like sometimes we just blow them off because we don't know what else to do, like

their circumstances are so dire that we're just like 'I don't know'. It's kind of sad. You're

right that is the unseen, the invisible population.

Another nurse explained how they do not know what to do with the homeless population and that

doctors especially are not "comfortable working with them."

Nurses often talked about how homeless patients were not in the hospital long enough to

get past their initial reason for seeking care and that when they did seek care they were usually

very sick. One nurse felt that "We are just putting some band aids on…sending them back out

into the wild." Another nurse described having to discharge a homeless person who was actively

hallucinating. The nurse voiced her concerns to the physician who "wouldn't do anything…I felt

awful about it." Similarly, a nurse commented that "We can only do so much here, we see them

for 2, 3, 4 days, maybe a week if we're lucky. And then it's like once we give you your discharge

papers, good luck." One nurse commented on how patients were not "settled down long enough

to respond to a palliative care approach."

Determining needs. While nurses did not often reflect on basic palliative care for

homeless patients, they were asked in the interviews what they would assess for in respect to

basic palliative care with this population. *"Determining needs"* was the second theme that was

identified from the data with three subthemes: *"essentials," "survival at discharge,"* and *"extra*

effort." A few nurses directly referred to Maslow's Hierarchy of Needs (McLeod, 2017) when

talking about homeless patients' needs. Nurses often discussed homeless patients as concerned

for those basic needs of food and shelter and in turn, nurses focused care in those areas. The

subtheme, *"essentials",* described the idea that nurses expressed about homeless patients being

focused on those lower level of needs. One nurse stated,

When I have those people, I really don't think about advanced directive[s] for them. I think about how I'm going to make them clean because they are dirty, and they are hungry…I think about them being full and clean first.

Another nurse said that "it's not their focus, their focus is on getting food and shelter, it's the hierarchy of needs." One nurse indicated that the focus on food and shelter would come before "any kind of comfort or quality of life." This nurse also commented that homeless patients are worried about the near future and "not an overarching goal." Again, this nurse talked about being "helpful in the moment" even if that means providing a shower or meal; however, she also stated that providing these essential needs could be considered a form of palliative care. These nurses talked about meeting essential needs as necessary before considering how basic palliative care could be appropriate for homeless patients. However, one nurse talked about meeting these basic needs so that patients could focus on their health. She said, "Trying to get them so that they don't have to focus on meeting their basic needs, they could be able to just focus on being comfortable and not worry about that."

The next subtheme, *"survival at discharge",* addressed what was available to homeless patients once they were discharged from the hospital, how nurses could meet their needs, and the lack of support systems. One nurse said it would require *"*trying to really assess like what needs they would need for their living environment, depending on … their medications or oxygen that their gonna have to be bringing around with them." The discussion of resources often included the new homeless facility that has a limited number of medical beds located across the street from hospital A. Nurses, in general, did not know what resources would be available to homeless patients if they were to need palliative care once discharged from the hospital setting. Additionally, many nurses referred to utilizing social workers as a resource. One nurse stated "I

would sure hope that we could lend some support um, how do you manage a situation like that? I'd really rely on [social worker] and [case manager]. They have the resources; I don't even know what's out there…" Most nurses did not know what resources were available; some assumed there was assistance available through Medicaid or hospice. Nurses assumed that hospice staff would be able to find a place for the patient to go. One nurse stated, "There's a lot of things that you can do once we get them onto the hospice because hospice will help find them places."

Other nurses focused on finding out what homeless patients had available to them and what their living situation was, "Is that homeless? Is it couch surfing at someone's house? Is it in a center?" Nurses wanted to know how homeless patients would get their treatments and medication, if someone was able to "help coordinate and connect pieces," where they would keep medications, and if they had a bed to sleep in. One nurse said, "I just think of not…being super sick and not having a warm safe place to just be." Another nurse said that she once had a homeless patient tell her at discharge, "I just need to find a bed and go die." This nurse then stated, "If they don't even have the resources for a bed to sleep in, it's hard to get them the resources for palliative."

Nurses often mentioned that homeless people lack a support system that would otherwise be available to help in palliative care situations. One nurse said, "If they had support systems they may not be homeless." Another nurse talked about a homeless woman who stayed in the hospital for the last couple of months of her life because she had "issues with her support system" which consisted of her boyfriend, who was also living in a homeless shelter. This was the only example given in the interviews of a homeless patient being cared for at the end of life for a terminal diagnosis. Nurses talked about how homeless people tend to "burn bridges" or

"exhaust their resources." For example, nurses believed that homeless people became a burden to family and friends to the point that these support systems were no longer willing to provide assistance. One nurse said she would involve social workers to find shelter for a homeless patient in need of palliative care, while others had experienced social workers who tried to find family support for homeless patients. Nurses felt that the lack of a support system limited the options of where patients could be cared for and by whom.

The last subtheme, *"extra effort"* under the *"determining needs"* theme referred to the complexity of care perceived by nurses when addressing issues described by the next theme, *"coinciding obstacles."* Nurses talked about how assessing for palliative care needs or going beyond providing those basic needs would require *"extra effort"* on their part. As they described it, providing basic palliative care or discharging a homeless patient on palliative care would be complex. One nurse said, "It's gonna be very difficult to even navigate through palliative to hospice you know because they are not with it…their life is kind of scramble…it's going to be a lot of education." Another nurse said, "It's gonna be a lot of effort from my [part] to go beyond that and talk about palliative." Nurses referred to the common experience of homeless patients having drug and alcohol issues. One nurse talked about detaching herself from "those populations depending on, I mean if it's a homeless person or the drug seeker, the alcoholic, you kind of do the best you can for them while they're there." Another nurse talked about helping a patient out of a problematic situation so long as they were not continuing in certain behaviors,

> If you're still digging yourself deeper, I can't spend a lot of energy trying to pull you out
> if you're still digging…and drinking and doing whatever else. I'll do my job and do what
> I can while you're in the hospital, but I focus most of my energy on people that actually
> do want to get better.

Coinciding obstacles. Another theme, *"coinciding obstacles"*, described nurses'

perception of mental illness and substance use in providing basic palliative care for homeless

patients. One nurse claimed, "Ninety-nine percent of the homeless population that I've taken

care of have been dealing with ETOH [alcoholism] or drugs in general." Nurses believed that the

prevalence of substance use among homeless patients would make it difficult to prescribe pain

medication for palliative purposes. One nurse stated,

> I think because we associate a lot of homelessness with drug and alcohol use…if
>
> somebody's needing that for long term, that's going to be an issue because people aren't
>
> going to want to prescribe that in large amounts…they'll think they'll get sold.

Nurses also attributed drug use to patients building a tolerance that would require larger than

normal doses to address pain. One nurse who worked on a unit designated as hospice, talked

about the need to "make sure once the patients are discharged that they are not going to take all

of their medication at once and have an unintentional overdose." This nurse felt that drug use and

mental illness could result in an accidental overdose when a patient was given a medication

regimen for palliative care.

Nurses in one focus group interview talked about how it felt like "banging your head

against a wall" as the nurses try to fix all the homeless patient's problems. Others felt that they

could not expend much energy on patients that engaged in behaviors such as drinking. As this

discussion continued, another nurse spoke up and said, "We can probably all understand too, just

that something like homelessness and poverty and the factors that contribute to it can be pretty

broad and pretty complex." This statement led another nurse to talk about instances in which

nurses' own biases were proven wrong and said, "There's people end up homeless that it's not

because they were doing anything wrong."

Mental illness was also an obstacle that nurses described as common with homeless patients. One nurse commented that "Homeless and mental health goes pretty hand and hand." Nurses in one focus group interview discussed how some mentally ill patients they have cared for were smart, "but it's that mental illness that gets in the way." Also, due to mental illness "They're not part of society in the normal way." These nurses went on to say that they don't care if patients have insurance or if they are homeless. One nurse said, "They still need care."

Relationship building. The last major theme associated with providing basic palliative care to homeless patients was *"relationship building."* Nurses talked about how their lives were very different from the homeless patients they cared for and trust issues created a barrier to considering basic palliative care. Two nurses talked about their past volunteer experiences with homeless people outside of the hospital. One nurse indicated that trust was an issue with the homeless population and a possible barrier to palliative care. Another nurse implied that most nurses come from "White suburban" areas and this created a barrier to understanding the lives of homeless people. One nurse worried about being coercive and impeding patient autonomy when it came to medication compliance. She said, "I have no idea what their lives look like and what has contributed to where they are."

A nurse said that homeless individuals have "had people steal from them…that plays a role in them trusting us." Another nurse talked about how homeless patients do not "want to talk about anything" and are "very distrustful, they don't think anybody is really trying to help them." This nurse also attributed this challenge to creating a barrier to basic palliative care, "You have so much that you have to get over to even begin to form a palliative relationship with these people."

Some nurses reported that nurses' biases against homeless patients affected the care that they provided. "Sometimes you can see there's some people's judgment of them. You know they go in with a preconceived judgment…cause they're homeless, they're gonna be this way or that way." One nurse described a homeless patient's experience of going to three different hospitals, "And you know what they all told her? 'Get out of here, you're using'." This patient was found to have a serious medical issue that was finally addressed at hospital B.

Nevertheless, the nurses emphasized that they did not treat their homeless patients any different from other patients. One nurse stated, "Sometimes we take care of people who live in mansions and sometimes…we don't know the difference."

Discussion

The themes that were identified in this study were interactional and created a cycle of non-existent basic palliative care for homeless patients. Homeless patients were called invisible by nurses in this study because they were not present in the healthcare system until they were seriously ill. Nurses also described a lack of knowledge about how to work with homeless patients, which resulted in a quick fix and discharge. While they were hospitalized, the focus for some nurses was to provide the essential needs that they believed homeless patients lacked, such as food and shelter. Basic palliative care was viewed as a complex type of care for patients, requiring additional effort beyond basic nursing care. Complexities of care were magnified by the higher prevalence of mental health and substance use disorders experienced by homeless people. Homeless people have reported in the literature a distrust of healthcare providers because of stigmatization and discrimination experienced in past encounters (American Nurses Association & Hospice and Palliative Nurses Association, 2014; Bernstein et al., 2015;

Narendorf, 2017). These negative experiences lead them to avoid the healthcare system and therefore, become an invisible patient. This cyclic thematic framework is depicted in Figure 3.

Nurses in this study referred to homeless people as *"invisible patients"*. Some felt this way because patients had not been part of the healthcare system until they were severely ill. Other studies also found that staff believed that homeless patients were more likely to seek treatment later in an illness trajectory (MacWilliams et al., 2014; McNeil & Guirguis-Younger, 2011).

When asked about assessing needs for the homeless population, nurses stressed the importance of fulfilling basic essential needs. Some of the nurses referred to Maslow's Hierarchy of Needs. According to this theory, people are first concerned with basic needs, such as food, air, drink, shelter, warmth, sex, and sleep before moving on to focus on higher level needs, such as relationships and meaningful activity (McLeod, 2017). Nurses used this theory to describe the focus of care they provided and what they believed was the sole concern of the homeless patient. Literature supported the perspective of the nurses in this study. Other studies, such as that of Rae and Rees (2015), found that homeless people reported neglecting their health when they did not have the basic resources, such as shelter, food and money (Narendorf, 2017; Rae & Rees, 2015). Healthcare professionals (McNeil & Guirguis-Younger, 2011) and homeless people (Rae & Rees, 2015) believed that the use of drugs also diminished the priority placed on health needs. However, homeless people in Tobey et al.'s (2017) study expressed daily worries about mortality. Studies also found that homeless people felt a lack of quality relationships within the homeless community but also relied on some relationships for obtaining certain resources (Bower et al., 2017). It would be worth exploring how basic palliative care providers could

deliver basic needs to homeless people while simultaneously enhancing helpful relationships that improved quality of life.

Nurses felt that it would take *"extra effort"* to move beyond meeting a homeless person's basic needs and to think about basic palliative care for homeless patients. Staff experiences in a support house in Hakanson et al.'s (2016) study pointed out the challenges of working with and providing palliative care to homeless people in Sweden. Similar to nurses' comments in this study, Hakanson et al.'s (2016) study participants talked about the challenges of meeting the complex needs of patients who are homeless. Participants in Hakanson et al's study (2016) stressed the need to be more flexible with homeless patients in order to enhance well-being as best as possible. Staff also highlighted the need to create care plans and interventions that were realistic for a homeless person (Hakanson et al., 2016). Standard interventions for common chronic illnesses may be unrealistic for a homeless person. For example, in Hakanson et al.'s (2016) study, it was important to understand that the patients may not keep appointments as expected and that being flexible was essential for continuity of care for patients across disciplines and services.

Healthcare providers may perceive providing basic palliative care as *"extra effort"* due to the complex lives of homeless people. However, nursing is a profession that recognizes that patients have complex health needs. A holistic and complete approach to care is necessary to meet the needs of all patients. This includes equitable care to those that lack basic needs but also require additional effort to address complex problems that extend beyond what is expected with patients that have resources readily available.

Another subtheme, *"survival at discharge,"* referred to the type of living situation that was available and how patients received services or treatment once discharged from the hospital.

Nurses lacked knowledge of the available resources, and often referenced social workers and case managers as appropriate resources for homeless patients. Social workers and case managers serve as useful resources within the healthcare team; however, unlike nurses, they are not available 24 hours a day in most settings. Therefore, it is necessary that nurses become aware of the resources in the communities in which they practice so that they can identify the available resources for homeless patients once they are discharged from the hospital.

It is possible that the ability to allocate resources may create a power imbalance between nurses and homeless patients. Oudshoorn, Ward-Griffin, Forchuk, Berman, and Poland (2013) studied a community clinic for homeless patients using a critical theory perspective. This clinic offered basic necessities for their patients; however, power relations were evident in the allocation of these supplies. None of the nurses in the current study expressed such abuse of power as described in Oudshoorn et al. (2013). Though some nurses felt that bias did affect the care other nurses provided to homeless patients.

Lack of family support was a major theme in the literature (Hakanson et al., 2016; Ko et al., 2015; Krakowsky, Gofine, Brown, Danziger, & Knowles, 2012; Song et al., 2007; Song et al., 2008). There were mixed results in the literature about contacting family when a homeless person was severely ill or dying. Some homeless people expressed a desire to contact family to make amends or reconcile (Ko et al., 2015; Song et al., 2007) and felt that doing so was an important factor in ensuring a good death (Ko et al., 2015). Others feared that family would not be compassionate or did not want contact because of past abandonment by the family members (Song et al., 2007). Some homeless people did not want to be a burden on their family or others (Ko et al., 2015; Song et al., 2007). Nurses in this study did not go in depth about their homeless patients' preference for contacting family besides saying that many of the patients have "burned

bridges" with family and friends. Others referenced utilizing social work to help find family to support the patient. Future research needs to explore the family dynamics of patients experiencing homelessness in order to analyze how this patient population determines preference for initiating contact with family members particularly at end of life to ensure that patient autonomy is upheld and respected.

One challenge homeless patients faced when seeking palliative care outside of the hospital setting was zero-tolerance policies. Facilities with zero-tolerance policies excluded patients who continued to use drugs or alcohol from services. Participants in McNeil and Guirguis-Younger (2011) described substance use as a barrier to specialist palliative care providers because these providers feared liability for possible adverse reactions associated with high doses of opioids. These issues are difficult to overcome, however unless a solution is found, homeless people will continue to be exclude from adequate palliative care. A policy change that would enable homeless people to access palliative care facilities is a move toward a harm reduction approach. McNeil et al. (2012) described the goal of harm reduction programs as meeting the basic needs at end of life and decreasing the hardships of poverty and homelessness for people unable to access traditional services. Beirness, Jesseman, Notarandrea, and Perron's (2008) "narrower definition" of harm reduction includes reducing or minimizing adverse consequences of drug use without requiring the discontinuation of drug use by the individual. Hakanson et al.'s (2016) study of a harm reduction approach explored staff perceptions of providing palliative care in a support house. The homeless people living in the support house had health issues, were known drug or alcohol users, and were not accepted in traditional palliative care, end of life, or general care facilities because of these behaviors (Hakanson et al., 2016). Staff found discussions surrounding palliative care and dying difficult because of the drug use

and mental health issues; however, staff re-defined many aspects of care to meet the needs of patients (Hakanson et al., 2016). Moving away from zero-tolerance policies would make palliative and end of life care more inclusive to people who struggle with addiction and continue to use drugs and alcohol.

Nurses in this study expressed that homeless patients often did not trust healthcare providers, making it difficult to establish a relationship with them. The lack of trust in healthcare professionals was widely discussed in the literature (Cagle, 2009; Hakanson et al., 2016; Huynh et al., 2015; Krakowsky et al., 2012; McNeil & Guirguis-Younger, 2011; Rae & Rees, 2015; Tobey et al., 2017). While some nurses in this study said that they tried to give equal care to all patients, other nurses implied that meeting the needs of homeless patients required extra effort and that they did not want to expend energy on patients who were not willing to help themselves. Stigma, discrimination, and overall negative past experiences with healthcare professionals created a distrust of healthcare professionals among homeless people (Cagle, 2009; McNeil & Guirguis-Younger, 2011; Rae & Rees, 2015). Comments from some of the nurses in this study, suggested that bias could be a barrier to establishing trusting relationships with homeless patients. These biases may be part of the nurses' frame of reference as described by Mezirow (Merriam et al., 2007). From a transformative learning viewpoint, critical reflection of experiences with homeless patients would be an essential starting point for changing one's perspective and point of view (Merriam et al., 2007). Researchers point out that such biases often led to patients' limited use of healthcare services (Oudshoorn, Ward-Griffin, Forchuk, Berman, & Poland, 2013). Hakanson et al. (2016) suggested a gentle and respectful approach to providing palliative care to homeless people that do not trust healthcare professionals. The authors also indicated that overcoming trust issues before starting treatment was important (Hakanson et al.,

2016). Frequently, nurses working in acute care settings have a limited amount of time with patients due to shortened hospital stays. Overcoming deep seated trust issues may be difficult in these settings. Providing care in a non-judgmental way would help enhance trust between healthcare providers and people experiencing homelessness in acute care settings where trust needs to be established quickly.

Limitations

The experiences described in this study only consisted of nurses' perceptions of needs of the homeless people when they access care in an acute care setting. The actual perceptions of the homeless individuals would provide great insight as to their needs, expectations, and experiences in acute care and with basic palliative care. Eighty-two percent of the participants identified as White; this was also a limitation to understanding the experiences of acute care nurses who come from diverse backgrounds.

<div align="center">

Conclusion

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This study sought to explore acute care nurses' experiences of providing basic palliative care to homeless patients. Findings indicate that there is a lack of basic palliative care for homeless people despite statistics that show homeless people are more likely to suffer chronic illness (Bernstein et al., 2015; Cagle, 2009; MacWilliams et al., 2014), have a much shorter life expectancy than the housed population (MacWilliams et al., 2014) and would likely benefit from basic palliative care. Due to higher prevalence of substance use, homeless people are often excluded from traditional facilities designed to care for people in need of palliative or end of life care (Hakanson et al., 2016). A harm reduction approach tied to non-judgmental care may be a starting point for creating a safe, trusting space for homeless people to seek and receive basic palliative care services. When homeless patients access the healthcare system entirely through

the acute care setting and only when seriously ill, it is essential that services are appropriate and adequately meet their needs.

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Chapter 7: Synthesis: Implications for Research, Policy, and Practice

The American Nurses Association (ANA) (2017) recently published a call to action for nurses to lead the transformation of palliative care. This follows on the Institute of Medicine's (IOM) (2014) report on how people die in America that recommended all healthcare providers be competent in basic palliative care. The IOM defined basic palliative care as:

> 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; and nurses, social workers, pharmacists, chaplains, and others who care for this population but are not certified in palliative care (p. 1-6).

Basic palliative care has been described to include the following characteristics: basic pain and symptom management, ability to discuss goals of care, prognosis, advanced care planning, resuscitation, having a familiarity with community resources, understanding various illness trajectories, and assessing social and spiritual needs (American Nurses Association, 2017; Quill & Abernethy, 2013; Weissman & Meier, 2011; Wiencek & Coyne, 2014). The ANA (2017) recognized a lack of clarity between the roles of primary and specialty palliative care. The descriptions offered by the IOM (2014) and others inspired this study to explore acute care nurses' perspectives on how they provide basic palliative care. The aim of this study was to gain in-depth understanding of how acute care nurses engage in basic palliative care in the acute care setting.

This qualitative study explored acute care nurses' experiences providing basic palliative care, including their experiences providing basic palliative care specifically to Hmong patients and homeless patients. The results of this study provide relevant information for improvement in research, policy, and practice. This study offers guidance for future research in the area of basic palliative care. Policy implications include educating nurses and approaching populations with a

focus on equitable care. Lastly, practice implications address ways to integrate basic palliative care into general practice using interactive educational strategies. There are plans for dissemination of the study findings in academic journals and at nursing research conferences.

Summary of Results

Palliative care encompasses the entire trajectory of an illness starting at the time of diagnosis of serious chronic illness in patients that experience symptom burden or require care planning. Palliative care can transition to hospice care at end of life as well. Nurses in this study only experienced providing palliative care at end of life in the acute care setting. The IOM (2014) and ANA (2017) emphasized a need for healthcare providers to be competent in providing basic palliative care throughout the illness trajectory.

The data from this study described the overall perceptions of the dimensions of basic palliative care. Acute care nurses described the care they provided to patients and families in the end of the patients' lives. They described aspects related to basic palliative care in the Hmong and homeless populations. Nurses' comments also eluded to factors that could lead to moral distress. One definition of moral distress by Varcoe, Pauly, Webster, and Storch (as cited in Whitehead, Herbertson, Hamric, Epstein, & Fisher, 2015) stated that moral distress was "the experience of being seriously compromised as a moral agent in practicing in accordance with accepted professional values and standards" (p. 118). Some of the factors that lead to moral distress that were relevant to the findings of this study include providing patients with truthful information about care and condition (Lusignani, Gianni, Re, & Buffon, 2017), feeling powerlessness (Hamric, 2012), and lack of knowledge (Hamric, 2012). Nurses in this study described translating information from physicians into language patients and families could understand. These acute care nurses also gave options that were not given to them, by other healthcare providers, surrounding care options. These two factors could lead nurses from this

study to feel that other team members were not truthful or complete in their discussions with patients and families.

The second factor, feeling powerless, was clear when a nurse who felt the discharge of a homeless patient was not safe. The nurse expressed the safety concerns to the physician, yet the physician continued with the orders to discharge. Other examples, particularly with the homeless population, surfaced when nurses felt they could not address all the problems of the patient for various reasons. One nurse stated, "…you kind of do the best you can for them while they're there."

The last factor that could contribute to moral distress that resonated with the data in this study was lack of knowledge. Nurses in this study expressed a lack of knowledge in assisting some families of diverse background in cultural traditions. Nurses that expressed this also said that the lack of knowledge about culture made them feel less connected with patients and families. Overall, nurses practice of basic palliative care in the acute care setting was described as end of life care. This in and of itself described a lack of knowledge of the differences between palliative and hospice care, which some nurses openly asked during the interviews.

Moral distress was not a factor that was measured or discussed during data collection; however, factors that have been identified in the literature were present in the discussions nurses had in the focus group and individual interviews. The results of this study identified important areas where acute care nurses support patients and families in illness; however, there is room for further research to determine how the provision of basic palliative care earlier in the illness trajectory can be operationalized and to use knowledge about moral distress to prevent this phenomenon from affecting acute care nurses providing basic palliative care. Figure 4 depicts interactions among all themes within this study. Table 6 presents a summary of all themes.

Helping families navigate progressive illness

Chapter four described findings related to acute care nurses' experiences providing basic palliative care in the acute care setting. The two themes and three subthemes showed how acute care nurses provide basic palliative care to patients and families at end of life. Family was a key aspect included in nurses' descriptions of the care they provided. Therefore, the construction of themes includes the word 'families' with a purposeful meaning that included the patient and their family as the unit of care. The first theme identified in the data was *'helping families navigate progressive illness'*. Acute care nurses described experiences in which they educated families about different types of care, helped families with decision-making, and role modeled how to engage with the patient in the end stages of their life.

Nurses often reinforced what other healthcare providers had told families. For example, nurses discussed translating physicians' medical jargon into terms the patients and families could understand. They also continued education that specialist palliative care providers started during consultations with families, throughout the rest of their hospital stay. Many nurses discussed their role in helping families make difficult decisions that could lead to guilt. One nurse helped family members think about what the patient's wishes were and explained to the family that their role was to carry out those wishes. Nurses also stated that family members may not know how to interact with their loved one once the dying process began. In these cases, nurses were there to role model by continuing to talk to the patient and teach family members how to participate in cares for the patient, such as massaging the patient's hands.

The second theme that was identified was *'empowering families'*. This theme had three subthemes: *'giving options', 'being present',* and *'advocating'. 'Giving options'* and *'being present'* addressed care for the patients and their families while *'advocating'* pertained strictly to

the nurse and patient's relationship. *'Giving options'* was described by the nurses as helping families see all of their options, some of which may not have been given by other members of the healthcare team. Nurses felt that they were empowering families by giving them knowledge about treatment options or what to expect as a patient's condition progressed. *'Giving options'* was how nurses reaffirmed for patients and families that decisions about care was theirs to make and informing them that there was no wrong choice.

'Being present' was the second subtheme of *'empowering families'*. Nurses in this study described *'being present'* as providing space for families to either open up and talk about their situation or to just sit in silence. *'Being present'* allowed patients to share their feelings about their situations or concerns they had about future treatments, such as fears about an upcoming surgery. *'Being present'* for families included sitting with families as they anticipated a patient's death. Nurses' presence encouraged families to share stories about the patient.

The last subtheme of *'empowering families'* was *'advocating'*. This subtheme was discussed by nurses as a role they provided only to patients. Nurses talked about how they advocated for patients with other healthcare professionals and family members. Nurses described supporting the patient in their decisions when it contradicted with family's wishes. *'Advocating'* was important to nurses when physicians were seen as pressuring patients into certain treatment regimens that conflicted with the patients' wishes. Nurses in this study described *'advocating'* as a difficult role and at times, they felt that they were stepping over a line when confronting physicians.

Findings from chapter four, which include the themes and subthemes described above, will be submitted for consideration for publication in The Journal of Family Nursing. The Journal of Family Nursing has an audience devoted to family nursing. This journal focuses on a

myriad of topics related to family nursing including families experiencing chronic illness and family care across the life span. The intentional inclusion of families as the unit of care in palliative care as reported in this chapter makes this chapter a good fit for this particular journal. Through dissemination of the findings from this study, researchers and practitioners will have access to this much needed information as nursing moves toward integrating basic palliative care into standard practice.

Nurses' perceptions of basic palliative care in the Hmong population

Chapter five explored nurses' perceptions of providing basic palliative care to culturally diverse patients. During the interviews, the question posed to the participants was "For our culturally diverse patients, how do you assess for palliative care needs?" The hospitals where the nurses in this study worked met the healthcare needs of a large Hmong population. Therefore, it was not surprising that many nurses focused their discussions on their experiences caring for Hmong patients. There were three major themes identified in this portion of the study; *'assisting tradition'*, *'understanding culture'* and *'language barriers'*.

'Assisting tradition' spoke to how nurses assisted in rituals or traditions as a patient was nearing death. This theme had two subthemes, *'family focused'* and *'closure'*. The *'family focused'* subtheme described the family involvement witnessed when caring for Hmong patients. Nurses described large numbers of family members who visited Hmong patients in the hospital, sometimes as many as 40 or 50 people. The nurses in this study viewed the Hmong culture, in general, as very family oriented. Nurses sometimes felt that because of strong family involvement with Hmong patients, these families declined palliative care services. Many nurses in this study described Hmong families as wanting to take their family member home to care for

the patient themselves. When patients were kept in the hospital as they neared death, nurses assisted families in traditions, such as helping dress the patient in a "death robe."

The second subtheme, *'closure',* referred to nurses' beliefs about the Hmong culture and how helping with tradition aided families in finding closure in the death of a loved one. Nurses also discussed the beliefs about the Hmong culture and how bad things could befall the family if certain rituals were not performed. For example, nurses learned that in the Hmong culture if a person did not die with specific rituals being performed, the family would experience a haunted fate. This served as motivation for assisting families in the rituals. Nurses also believed that if they did not assist in the traditions and rituals, people from the Hmong community would not trust healthcare professionals in the future.

'Understanding culture' was the second major theme for this part of the study. *'Understanding culture'* had two subthemes, *'uncertainty'* and *'learning more'*. The subtheme, *'uncertainty',* described how some nurses felt when they were unfamiliar with patients' cultures. Nurses seemed to take a step back when caring for patients in such situations and instead of assisting with the traditions, they let the families adhere to traditions alone. One nurse felt that she was unable to connect to the patient and family because of the uncertainty that she felt. Despite, caring for a sizeable Hmong population, many nurses commented on not knowing about the Hmong culture.

When patients made healthcare decisions based on their cultural beliefs, nurses who did not understand these decisions sought out more information. These actions by the nurses described the second subtheme, *'learning more'*. The nurses who sought more information either asked the families directly how they could provide care that included traditions, or they searched the literature to gain a better understanding.

The last major theme, *'language barriers'*, had two subthemes; *'means to communicate'*, and *'incomplete understanding'*. Nurses in this study were overwhelmingly dissatisfied with the resources they had for language interpretation for patients who were not proficient in English. Nurses preferred using in-person interpreters rather than a communication device for interpretation. Though nurses preferred in-person interpreters, it was difficult for them to access this service without advanced planning. Some nurses found other ways to communicate with patients and their families. Nurses suggested the use of translation applications on their phones to communicate with families rather than the organization's interpreter services. Another nurse described how she drew pictures to illustrate a disease process to Hmong patients and families with limited English proficiency.

The subtheme, *'incomplete understanding'* was perhaps the most enlightening subtheme related to *'language barriers'*. *'Incomplete understanding'*, described the belief that despite appropriate interpreter services, there was some kind of disconnect between languages that resulted in the patients and families having a fragmented understanding of what the nurse was attempting to communicate. Some nurses attributed this phenomenon to a lack of medical terms in the different Hmong dialects.

Findings focused on palliative care with the Hmong population as delineated above, will be submitted as a manuscript to the Journal of Transcultural Nursing. The findings from this chapter were presented in October 2017 at the Transcultural Nursing Society Annual Conference. The Journal of Transcultural Nursing is the official publication of the Transcultural Nursing Society. This journal is "dedicated to the advancement of culturally competent and culturally congruent health care" (Sage Publishing, 2018). Death and dying, symptom management, and care of the older adult are among a long list of interests to this journal.

Researchers, educators, nurses, and practitioners are the audience for this journal and therefore, it is a good fit for disseminating the findings presented in chapter five of this study.

Homelessness and basic palliative care

The final manuscript that reports on findings from this study described the experiences acute care nurses had with basic palliative care and homeless patients. Nurses in this study had not had the opportunity to reflect on the care they provided to homeless patients. Based on the interviews, four themes were identified describing the experiences acute care nurses had working with and caring for homeless patients in the hospital setting. The first theme, *'invisible patients',* revealed how nurses perceived the interactions between homeless patients and the healthcare system. Nurses felt that homeless patients accessed the emergency departments and hospitals when their conditions were severe. Nurses also talked about the short length of stays in the hospital that were not adequate to address the multiple and complex issues faced by this population. Nurses described the treatment of homeless patients as putting a band aid on the problem and sending them back out to the streets. One nurse felt that healthcare professionals, did not know how to care for homeless patients.

The second major theme, *'determining needs',* had three subthemes. The first subtheme, *'essentials',* discussed nurses' references to Maslow's Hierarchy of Needs when caring for homeless patients. Nurses believed that homeless patients were mainly concerned with food, shelter, and hygiene while in the hospital and so they focused on meeting those very basic essential needs. Nurses in this study often did not consider addressing whether a homeless patient had or wanted an advanced directive because they were focused on helping to meet their basic needs. Nurses generally believed that homeless patients did not think about long term

goals. Still, a few nurses considered that if nursing could meet those basic needs for homeless patients, it would allow the patients to focus on comfort and well-being.

The second subtheme was *'survival after discharge'*. *'Survival after discharge'* spoke to what was available to homeless patients, such as support systems and possible areas of shelter once discharged from the hospital. One crucial finding was that nurses were unsure what resources were available to homeless patients. Many nurses relied on social workers and case managers to address these concerns. Other nurses thought it would be important to find out what being homeless meant for the patient, such as where the patient was staying – in a shelter, on the street, or on a friend's couch. Many nurses believed that homeless people lacked the support of family and friends and felt that many had probably "burned bridges" with those potential support systems.

'Extra effort' was the last subtheme in *'determining needs'*. Nurses expressed how approaching palliative care needs with homeless patients would require *'extra effort'* on their part. The nurses felt that homeless patients were quite complex, and it would require great energy to broach the topic of palliative care with such patients. Nurses also described many homeless patients as having substance use issues or mental illness, which added to the challenges of approaching palliative care with them. One nurse stated that if a patient continued to use substances, they were not going to spend the same amount of energy on that patient as on one who wanted to get better.

The third major theme, *'coinciding obstacles'* identified in this portion of the study described nurses' experience with substance use and mental illness within the homeless population. Nurses felt that the majority of homeless patients have some type of substance use or mental illness. While some nurses talked about these issues as challenging and a barrier to care,

other nurses felt that homelessness was a complex issue that required nurses to consider the broader context and refrain from introducing biases into their care. From a palliative care perspective, nurses pondered how substance use could be a barrier for adequate prescribing of medications, especially pain medications. There was speculation about fears of selling prescription medications or accidentally overdosing.

Lastly, *'relationship building'* was a theme in this manuscript. Nurses talked about the distrust homeless people have of others as a result of living on the streets or in shelters. Nurses found that it was difficult to build relationships with homeless patients based on this distrust and short hospital stays. Nurses also felt that they did not understand what it meant to be homeless. One nurse commented that most nurses in this study came from a suburban background which made it difficult to understand what a homeless person's life was like.

This portion of the study results described acute care nurses' experiences with providing basic palliative care to homeless patients. This manuscript will be submitted to the Journal of Health Care for the Poor and Underserved. This journal focuses on medically underserved communities in areas of health care access, quality, costs, legislation, regulations, health promotion, and disease prevention (John Hopkins University Press, 2016). The findings in chapter six reinforces the idea that the homeless population is not only underserved but also rarely have access to basic palliative care services. There is very little research that addresses the lack of basic or specialist palliative care services for homeless people and this study starts to fill that gap by exploring the experiences of acute care nurses on this topic. A portion of these findings were also presented as a poster at the Transcultural Nursing Society Annual Conference in October 2017.

Implications of Study

The findings presented in this study, through three manuscripts, fills a major gap in the literature. Basic palliative care defined by the IOM (2014) identified non-specialists as providers and was recommended as a standard knowledge set for all healthcare professionals. All of the nurses in this study met the criteria for providing basic palliative care; however, none of them had ever heard the term. This study starts to fill the gap in the literature about how nurses provide basic palliative care. In this study, basic palliative care was described in practice as caring for patients and families at end of life.

In addition, there was a dearth of literature on the provision of basic palliative care to homeless and culturally diverse patients. This study also uncovered a lack of basic palliative care for homeless patients. Many nurses had not previously reflected on basic palliative care needs for homeless patients and did not know what, if any, resources were available. Through nurses' experiences, this study described basic palliative care for Hmong patients, such as assisting with traditions as a patient was dying. However, some nurses were uncertain on how to care for Hmong patients. This study thus adds to the limited research on how basic palliative care can be provided to homeless and Hmong patients.

The combination of the three manuscripts that forms the basis of this dissertation study contribute to the limited knowledge on how basic palliative care is practiced by acute care nurses in the hospital setting. Deficiencies in care for homeless and culturally diverse populations was noted as well as the implementation of basic palliative care only at end of life. This study's findings contribute to the body of knowledge and supports the need for future research, policy, and practice changes, which are outlined in greater detail in chapters four, five and six.

Implications for Research

This study not only helps to fill the gap in the literature related to basic palliative care but also has implications for future research. The findings of this study indicate that palliative care provided by general practitioners is limited to end of life care and rarely extends to homeless and culturally diverse patients. Future research exploring the expected palliative care needs among homeless and culturally diverse populations is an important contribution to the limited body of literature. Research should focus on making basic palliative care available to and equitable for all patients. It is important to recognize that some patients will need the "extra effort" nurses described with homeless patients in this study. For equitable care to occur, intervention research is needed to help nurses overcome the barriers that exist when providing care to populations with multiple and complex health and social needs.

Future research also needs to focus on moving basic palliative care upstream in the illness trajectory. Palliative care is necessary from the time of diagnosis, not just at end of life. Patients with chronic illness must have healthcare providers who recognize their palliative care needs much earlier in the illness process to improve symptom management, quality of life, and define patient and family goals of care. Intervention studies that seek to introduce basic palliative care as standard practice need to be conducted to build evidence for its essential role in practice.

Implications for Policy

The findings of this study described basic palliative in the acute care setting through the experiences of nurses working with patients, families, and homeless and culturally diverse patients. There are implications from this study that affect policy. Nurses first need the education to be competent in basic palliative care. This can be accomplished through healthcare organizations providing financial support to attend programs such as End of Life Nursing Education Consortium (ELNEC) (American Association of Colleges of Nursing, 2018a).

ELNEC has various train-the-trainer programs that focus on teaching attendees the main aspects of palliative and end of life care. This program is offered at different locations throughout the year and has a variety of specialty courses, such as pediatric and critical care (American Association of Colleges of Nursing, 2018a). One recently developed course includes online modules for undergraduate nursing students (ELNEC, n.d.). These programs would be beneficial for healthcare organizations and schools of nursing in supporting their employees and students to attend in order to advance the knowledge and skills necessary to practice basic palliative care.

Homeless people often do not have access to traditional palliative care services outside the hospital setting due to lack of housing or substance use prohibitions. One policy change that could improve access to palliative care services is to adopt harm reduction programs. Harm reduction programs allow for the provision of care to patients while accepting that some of these patients may have problems with substance use (Beirness, Jesseman, Notarandrea, & Perron, 2008). Adopting harm reduction policies in providing care to homeless people may improve health outcomes for this population and enhance the establishment of trusting relationships with healthcare providers which is currently of concern as demonstrated in this study.

Policy changes in the way nurses provide basic palliative care to culturally diverse populations require a culturally safe approach to care. Nurses in this study expressed uncertainty when caring for patients from a different background than their own. A cultural safety framework requires the recognition of the unequal power existent in between professionals such as nurses operating within the healthcare system and the patients who they serve. To provide culturally safe patient care, nurses need to avoid disempowering patients and work towards shared power (Richardson, Yarwood, & Richardson, 2017). One way to reach this goal is

through self-reflection on the part of the nurses of their beliefs, values, and biases and how this impacts their relationship with patients (Richardson et al., 2017).

Increasing diversity in the nursing profession is an ongoing goal of multiple organizations (Williams et al., 2014). The majority of nurses in this study self-described themselves to be White, which closely resembles the national makeup of the nursing profession. This, however, does not reflect the patient demographics that nurses care for (Phillips & Malone, 2014). Phillips and Malone (2014) indicated that increasing the diversity of nursing faculty would likely contribute to reducing health disparities through research with minority groups. These authors also highlighted the importance of diverse faculty serving as role models to future nurses. One way that schools of nursing can increase the diversity in the future of nursing is to adopt the American Association of Colleges of Nursing's Holistic Admission Review (2018b). This admission process considers broader requirements beyond grades and test scores alone (American Association of Colleges of Nursing, 2018b). The process considers students' potential contribution to the learning environment, importance of balance between experiences, attributes, and academics, and the goals of diversity within the schools (Urban University for Health, 2016).

Each of the policy changes discussed can help towards improving basic palliative care through education, inclusion of homeless patients, and expanding the culturally safe care that is provided by acute care nurses.

Implications for Practice

Acute care nurses had not heard of the term 'basic palliative care' before participating in this study. Education that enables nurses to integrate basic palliative care into nursing practice should include recognizing patients with palliative care needs and distinguishing the need for specialist or basic palliative care. Additionally, nurses need educational experiences that allow

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them to practice having conversations with patients and families about the differences between palliative care and hospice care. Classes that offer interactive role-playing could increase nurses' comfort level when having these discussions. Lastly, in order to integrate basic palliative care into nursing practice, nurses need to be knowledgeable of the available resources so that they can share this information with patients and their families. Nurses in this study expressed their concerns about the large workloads they already have. Finding ways to incorporate the work they already do into palliative care assessments would help to decrease the burden of adding more to nurses' workloads.

Conclusion

This study helps to fill the gap in the literature on basic palliative care through exploring acute care nurses' experiences and perceptions of basic palliative care in the acute care setting, including how basic palliative care can be provided to homeless and culturally diverse patients. The findings of this study are presented in this dissertation as manuscripts that will be disseminated in targeted scholarly journals. Through dissemination of these findings, nurses can work toward the goal of expanding knowledge and skills in basic palliative care to ultimately improve the quality of care that chronically ill patients and their families experience in the acute care setting.

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Appendix A

Demographic Data Collection Form

1.   Total years of experience as a registered nurse _____

2.   Circle the college degrees in nursing that you have:

        Associate   Bachelor's   Master's   Doctorate

3.   What facility do you work the majority of your hours at?

        St. Joseph's Hospital   St. John's Hospital   Woodwinds Health Campus

4.   How many hours do you work in a 2 week period?_____

5.   What unit do you work the majority of your hours on?_____

        ☐   Is there a nursing specialty on this unit?_____

        ☐   Are you in the float pool? Yes   No   If yes, which one?_____

6.   Have you had any education in palliative care? Yes No

        ☐   If yes, where did you get this education?_____

        ☐   Did your employer encourage you to get this education?   Yes   No

        ☐   Did your employer reimburse you for this education?   Yes   No

7.   Have you had personal experiences with palliative care?   Yes   No

        ☐   If yes, briefly describe experience:_____

        _____

        _____

8.   Age
        ☐   Under 21
        ☐   21-29
        ☐   30-38
        ☐   39-47
        ☐   48-56
        ☐   56-64
        ☐   65 and older

9. Gender that you most identify with_____

10. Do you identify with a specific religion or spiritual group?

   ☐   Yes. (Please specify)_____

   ☐   No

11. What race or origin do you identify with? Select all that apply and print the specific race

   and/or origin.

   ☐   White – For example, German, Irish, English, Italian, Polish, French, etc.
   _____

   ☐   Hispanic, Latino, or Spanish origin – For example, Mexican or Mexican
   American, Puerto Rican, Cuban, Dominican, Salvadoran, Columbian, etc.
   _____

   ☐   Black or African American – For example, African American, Jamaican, Haitian,
   Nigerian, Ethiopian, Ghanaian, etc.
   _____

   ☐   Asian – For example, Chinese, Filipino, Asian Indian, Vietnamese, Korean,
   Japanese, etc.
   _____

   ☐   American Indian or Alaska Native – For example, Navajo Nation, Blackfeet
   Tribe, Muscogee (Creek) Nation, Mayan, Doyon, Native Village of Barrow Inupiat
   Traditional Government, etc.
   _____

   ☐   Native Hawaiian or Other Pacific Islander – For example, Native Hawaiian,
   Samoan, Guamanian or Chamorro, Tongan, Fijian, Marshallese, etc.
   _____

   ☐   Other race or origin
   _____

   ☐   I choose not to identify race and/or origin.

If clarification is needed on any of these questions, can I contact you through email?

   ☐   Yes Email:_____

   ☐   No

Appendix B

Semi-Structured Interview Guide

1. (Describe purpose of study). Tell me how you define or describe palliative care.

2. How do you define basic palliative care?

3. (Introduce WHO & IOM definitions. WHO definition: Specifically highlight applicability of PC early in illness trajectory and that this aspect is what I'd like to talk about today. IOM definition: introduce basic PC definition, identifying that those described in the definition are all of us.)

4. Thinking about the patients you care for day to day, tell me about how these definitions of palliative care can be applied to your patients and your nursing practice. (Summarize key aspects of palliative care they may have mentioned in their examples)

5. Tell me about other aspects of palliative care that you feel comfortable including in your nursing practice?

6. What areas do you feel you'd like more education on in order to integrate a palliative approach into your practice? (Summarize education needs discussed)

7. How would you prefer to receive more education on these topics?

8. At our hospitals, we care for a variety of different people. Tell me how you assess culturally diverse patients' needs.

   a. How would you assess their possible palliative care needs?

9. Tell me about some experiences you've had caring for seriously ill, culturally diverse patients that had palliative care or you feel would have benefited from palliative care

based on the WHO definition that allows for palliative care throughout the course of the illness.

(Summarize any stated challenges and needs specific to this population)

10. We also care for homeless patients. Tell me how you assess the needs of this population.

     a.   How would you assess them for possible palliative care needs?

11. Tell me about some experiences you've had caring for seriously ill, homeless patients that had palliative care or that you feel would have benefited from palliative care based on the WHO definition that allows for palliative care throughout the course of the illness. (Summarize any stated challenges and needs specific to this population)

12. If you were going to integrate a palliative approach to your practice, what barriers might you expect in your area/location of work?

13. Tell me about facilitators you currently have that would help you integrate basic palliative care into your practice.

14. Is there anything you could think of that might make integrating basic palliative care into your practice easier?

     (Summarize)

15. To start wrapping up, are there any thoughts, comments or questions you'd like to address that we haven't discussed today?

Figure 1: Actions of nurses providing basic palliative care in the acute care setting.
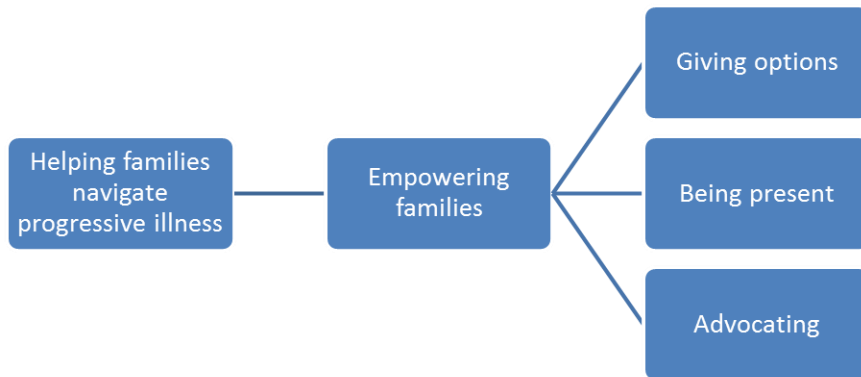
Figure 2: Interactions among themes and subthemes toward culturally safe nursing care or incomplete care.
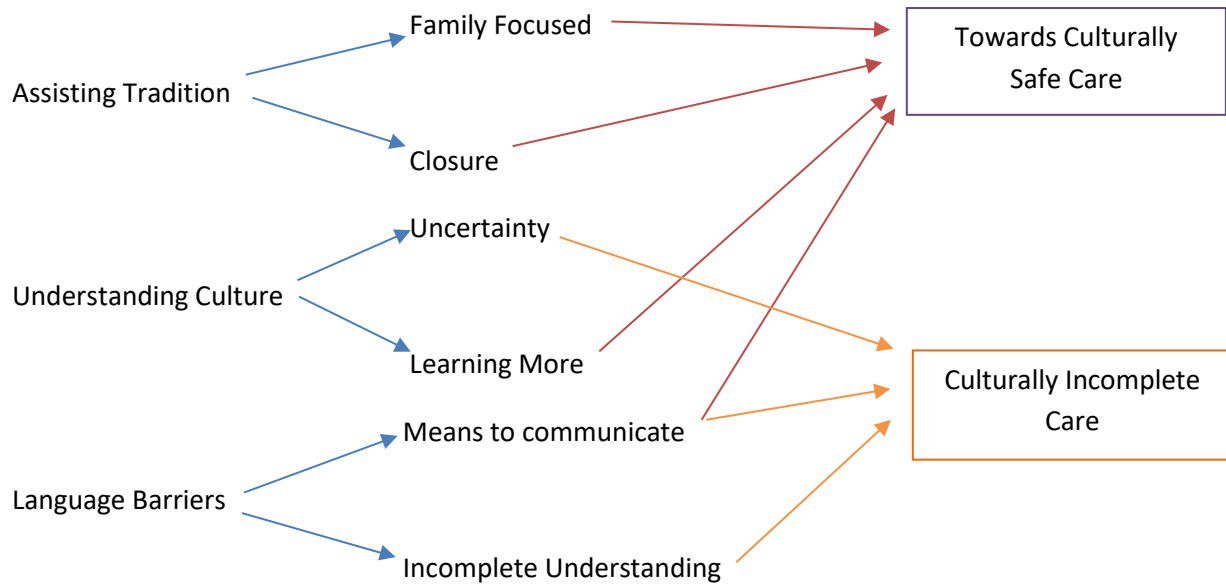
Figure 3: Interconnections of themes related to basic palliative care with homeless patients.

- Delayed treatment
- Lack of knowledge for caring for homeless population
- Quick fixes

- Basic needs- food, shelter
- Lack of or unknown resources/support
- Extra effort - complexities of care provision

Invisible Patients

Determining Needs

Building Relationships

Coinciding Obstacles

- Lack of trust
- Judgment, stigma

- Mental Health Issues
- Drug and Alcohol Use
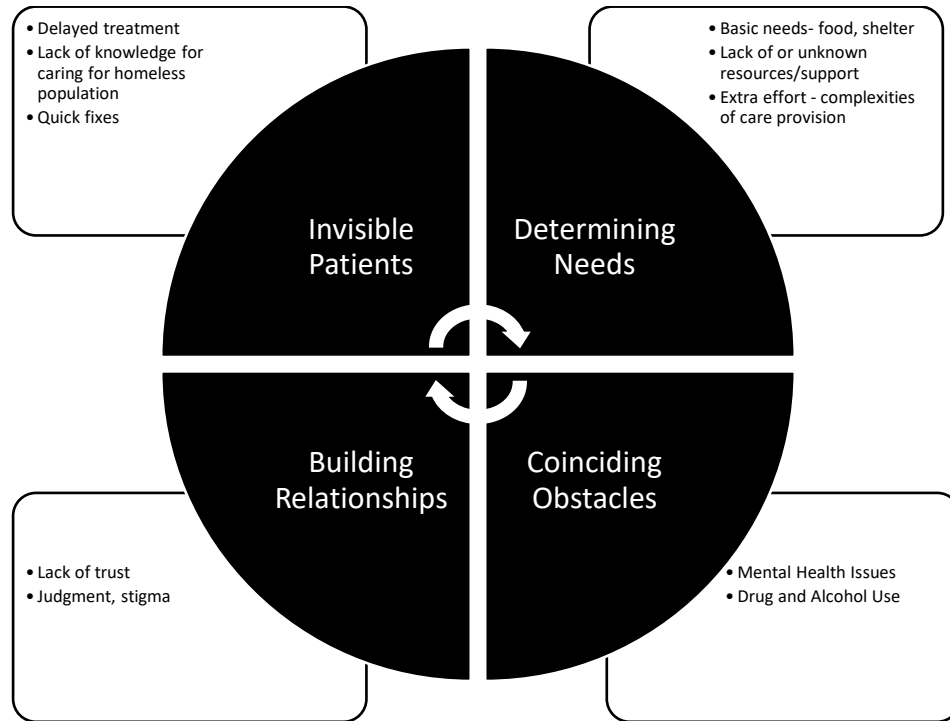
Figure 4: Basic palliative care in the acute care setting.
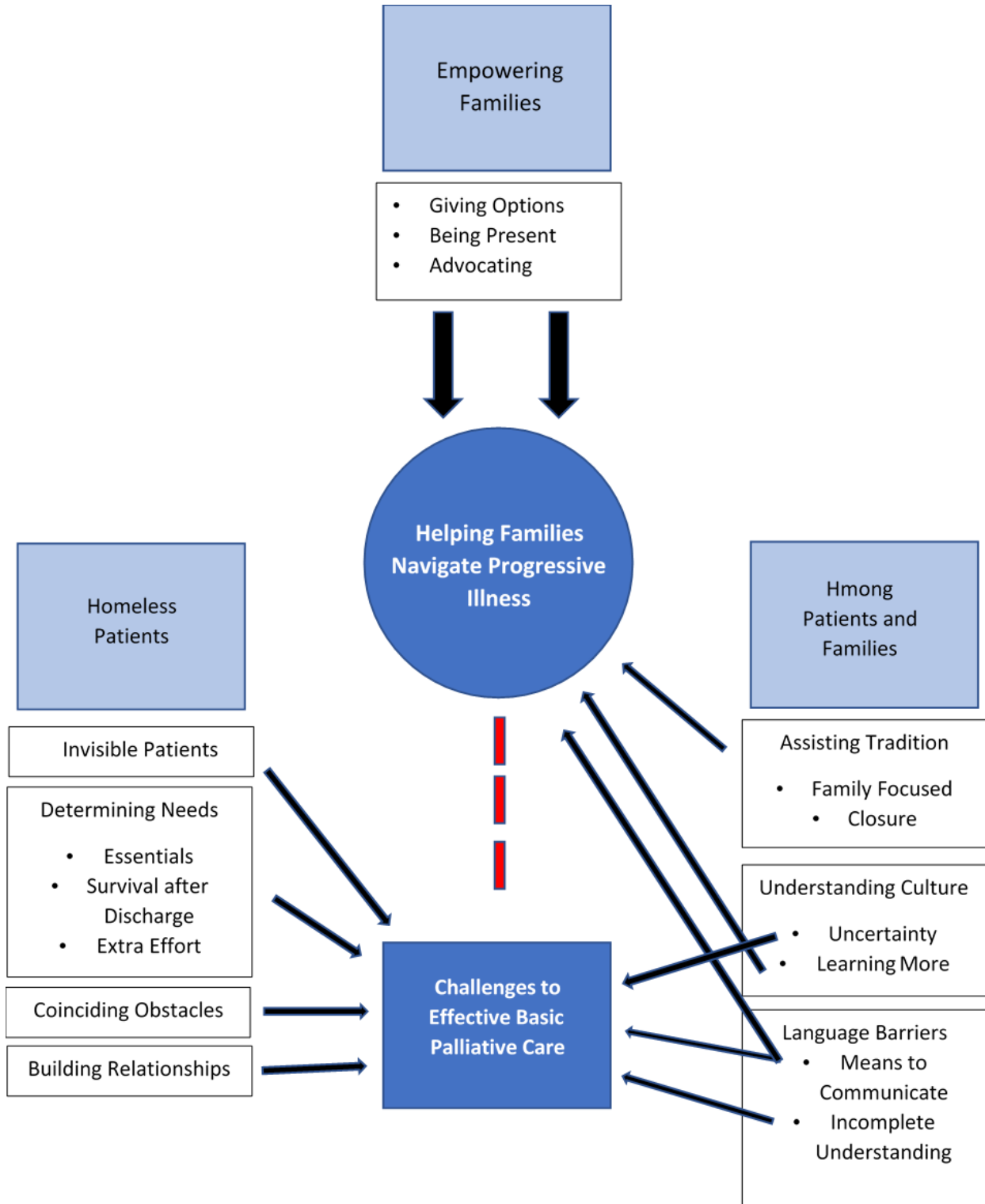
Table 1

Patient Population Demographics of Hospitals Included in Study

Race/ethnicity	Hospital A (N=271,498)	Hospital B (N=392,858)	Hospital C (N=213,055)
American Indian	0.7%	0.4%	0.3%
Asian	4.2%	8.1%	2.8%
Black	8.6%	4.8%	5.1%
White	75.3%	77.6%	84.0%
Multi-racial	0.4%	0.5%	0.7%
Hispanic/Latino	1.4%	1.2%	1.5%
Other	1.1%	0.8%	0.8%
Unknown/missing	8.7%	6.6%	4.8%
Nativity, Language			
Foreign-born	6.9%	8.6%	5.5%
Born in United States	86.6%	88.2%	90.3%
Nativity unknown/missing	6.5%	3.2%	4.2%
Primary Language			
English	95.0%	92.6%	95.9%
Primary language other than English	5.0%	1.4%	2.9%
Unknown/missing	0.0%	6.0%	1.2%

Table 2

Top Ten Diagnoses of Patients Admitted to Hospitals Included in Study

	Hospital A (N=271,498)	Hospital B (N=392,858)	Hospital C (N=213,055)
Cancer	9,957	48,876	13,256
	(3.7%)	(12.4%)	(6.2%)
Heart Disease	31,560	13,930	10,691
	(11.6%)	(3.5%)	(5.0%)
Unintentional injury	9,892	20,734	15,232
	(3.6%)	(5.3%)	(7.1%)
Cerebrovascular disease - Stroke	13,109	6,004	2,530
	(4.8%)	(1.5%)	(1.2%)
Chronic pulmonary disease	12,503	15,185	9,676
	(4.6%)	(3.9%)	(4.5%)
Diabetes	19,875	27,430	12,509
	(7.3%)	(7.0%)	(5.9%)
Renal disease (Nephritis)	9,472	12,335	6,509
	(3.5%)	(3.1%)	(3.1%)
Pneumonia/ influenza	4,009	7,672	4,260
	(1.5%)	(2.0%)	(2.0%)
Self-inflicted injury	324	195	131
	(0.1%)	(<0.1%)	(0.1%)
Cirrhosis	3,094	5,104	2,927
	(1.1%)	(1.3%)	(1.4%)

Table 3

Participant Characteristics

Gender	N
Female	**32**
Male	2
Age	**N**
Under 21	0
21-29	3
30-38	**8**
39-47	**11**
48-56	7
56-64	5
65 and older	0
Years of Nursing Experience	**N**
Less than 1 year	2
1-5 years	10
6-15 years	**14**
16-25 years	5
26-35 years	1
35+ years	2
Race/Origin	**N**

White	**28**
Hispanic, Latino, Spanish origin	0
Black or African American (1-Togo; 1-Jamaca; 2-Nigeria)	4
Asian (1-Japanese; 1-Hmong)	2
American Indian or Alaska Native	0
Native Hawaiian or Other Pacific Islander	0
Other	0
Choose not to identify	0
Highest Degree in Nursing	**N**
Diploma	**1**
Associates	**12**
Bachelor's	**15**
Master's	6
Doctorate	0
Religious	**N**
Yes	**23**
-Catholic	7
-Christian	8
-Lutheran	4
-Methodist	1
-Pentecostal	1

-Spiritual	1
-Unitarian	1
No	11
Hospital majority of hours worked	**N**
Hospital A	**24**
Hospital B	5
Hospital C	5
Unit Specialty	**N**
Oncology/Hospice	6
Ortho/Med-Surg	**16**
Neurology	1
Float Pool	6
Cardiac-Telemetry	5
Education in Palliative Care	**N**
Yes	**15**
-On the job	*4*
-Formal class	***10***
-Employer Encouraged	*11*
-Employer Reimbursed	*8*
No	**17**
Personal Experience with Palliative Care	**N**

Yes	**24**
-Caring for Patients	*16*
-Caring for Family Members	7

Table 4

Patient Languages at the Participating Hospitals

Language	Hospitals		
	Hospital A (N=271,498)	Hospital B (N=392,858)	Hospital C (N=213,055)
English	256,893	363,815	204,307
Hmong	5,169	14,998	1,009
Karen	1,814	3,706	32
Spanish	1,298	1,555	819
Burmese	138	426	3
Nepali	362	158	0
Vietnamese	514	627	330
Kirghiz	4	26	0
Somali	370	362	1,377
Amharic	280	142	79
Sign language	153	425	819
Oromo	120	72	37
Wolof	306	22	37
Arabic	85	165	115
Russian	1,073	158	64
Lao	32	56	4

Table 5

Themes, Subthemes, and Exemplar Quotes

Theme	Subtheme	Exemplar Quote
Assisting Tradition	*Family focused*	"it was nice, it seemed like a really nice melding of what we think of as palliative care and also what the family and the patient would want for her travel for her journey at the end."
	Closure	"They have very, very strong rituals and beliefs and if we don't do them and then that family is going to be haunted or their spirits can't rest and so then somebody else in the family is going to become afflicted."
Understanding Culture	*Uncertainty*	"I wish I had known more about that before I stepped into the room because it was just- felt like I couldn't really connect because I didn't know."
	Learning more	"he felt that if he were to be opened up or to go under surgical procedure, demons or evil spirits would enter him and he would be otherwise um destined for hell essentially… I thought that so strange… I did come across one study that in fact said that very same thing."
Language Barriers	*Means to Communicate*	"Things can be misinterpreted… Because you can't hear right, it's better to have an actual person" "I know what's helped me kind of get the piece of even like what their diagnosis is in other cultures is especially Hmong I draw pictures."
	Incomplete understanding	"it's like there' something that it's so culturally different that it's really hard to get the idea across…it doesn't come across in a way that they can sort of formulate into their culture at first."

Table 6

Summary of All Themes

Theme	Subtheme	Description
Chapter 4: Helping Families Navigate		
Helping families navigate progressive illness		Nurses described patient care situations that involved educating, guiding, and role modeling how families and patients interact in mainly end of life situations. Included in this theme was sharing with families how to care and participate in a dying person's last days and translating what physicians told the patient and/or family.
Empowering families	*Giving options*	Nurses felt that it was their role to offer families all the options, including palliative or hospice care. Nurses felt that by doing this they were giving some control back to the patient and family.
	Being present	Being present allowed patients to open up to nurses, or just to sit and have a shared quiet moment. In end of life situation, being present involved listening to families share stories about their loved one.
	Advocating	Nurses separated patients from family and felt they served as advocate for the patient. Nurses described their role as being on the side of the patient and helping others, family and physicians, understand the patient's wishes. Nurses felt this was an important nursing role but one that was often hard and uncomfortable.
Chapter 5: Nurses' Perception of Basic Palliative Care in the Hmong Population		
Assisting tradition	*Family-focused*	Nurses described a strong family presence, specifically among Hmong patients and families. Nurses found this as a positive aspect but also as a barrier to implementing palliative care with these patients. The families took care of their loved ones and cared for them. Some nurses felt overwhelmed by the large number of family members that visited a hospitalized patient. Nurses also talked about how they could assist with traditions by helping families dress patients in their "traveling" or "death" robes in end of life situations. Nurses felt that by assisting in traditions or rituals when a patient was at end of life, they were helping to ensure closure for the families.
	Closure	Nurses felt that by assisting families with traditions, they were helping the families find closure. The nurses described beliefs about what could happen to families if

		these traditions were not allowed to take place in the hospital. Many believed that families could experience negative consequences, such as haunting of the remaining family or bad luck befalling the surviving family members if rituals were not performed. The nurses also commented that by assisting with traditions, they were building a trusting relationship with the patient's community as a whole.
Understanding culture	*Uncertainty*	Some nurses expressed an uncertainty or unfamiliarity with various cultures that were different than their own and how this impacted the care they provided. Some took a step back and "let them do their thing" while another felt she could not connect with the patient and family because of this.
	Learning more	Some of the nurses that cared for cultures different from their own sought out to learn more through research or discussed what was to be expected with family members.
Language barriers	*Means to Communicate*	Nurses identified a lack of resources available when caring for a patient and/or family that did not speak English. Nurses felt the optimal situation was to have an interpreter present versus relying on communication devices that were unreliable (voceras). Nurses also noted that languages that did not have equivalent medical terms caused miscommunication. Some nurses described ways to get around the language barrier. One nurse described drawing pictures as a way to explain to patients and families what was going on. Others discussed the use of various phone applications for translation.
	Incomplete understanding	Nurses felt that there wasn't always a complete understanding despite the use of technology and interpreters to explain what was to happen next. This concept was hard to explain but the nurses felt that sometimes it took much longer to find the way to explain something so that it translated into something that made sense.
Chapter 6: Homelessness and Basic Palliative Care		
Invisible Patients		Invisible patients described how nurses perceived the interactions between homeless patients and the healthcare system. Nurses felt that homeless patients accessed the emergency departments and hospitals

		when their conditions were severe. Nurses described the treatment of homeless patients as putting a band aid on the problem and sending them back out to the streets.
Determining needs	*Essentials*	Nurses referred to Maslow's hierarchy of needs when describing homeless inpatient needs in the hospital. Nurses talked about getting them fed, clean, and better from the current ailment. Because nurses feel that these are the needs that the patient wants, they don't consider discussing palliative care or advanced directives. Many nurses believed that homeless patients were concerned only with the direct problem in front of them and not future needs or goals.
	Survival at Discharge	*'Survival at discharge'* refers to the availability of services to homeless people and how they meet their needs outside of the hospital. Nurses did not know what resources would be available for a homeless patient in need of palliative care. Many referred to social workers and case managers for this type of resource. Others felt it would be important to inquire more about their social and family situation to determine what resources could be utilized would they need help. Lack of a support system was also a resource that homeless people lacked regarding basic palliative care.
	Extra Effort	The complexity of discharging a homeless patient with palliative care or initiating palliative care seemed to require an *'extra effort'* on the part of the nurse. One nurse stated that it would be very difficult because homeless patients' lives are "kind of a scramble." Nurses felt they could only do so much for homeless patients, especially those with substance use issues. One nurse said that they would expend most of their energy on patients that wanted to improve themselves and their health but would not expend much energy on those that the nurse perceived as continuing non-improvement behaviors.
Coinciding obstacles		This theme refers to comments nurses made regarding homeless patients and their relationship with mental health and substance and alcohol use. Data available supports these comments; the top diagnoses for homeless patients' admissions are mental illness. Nurses cited these conditions as making it more difficult to address palliative care needs or in providing general care. Not all nurses referred to this negatively

		but as a way of describing the situation. Some felt frustrated and that nurses can't fix all their problems.
Relationship building		Nurses recognized that their lives are very different than the homeless patients they care for. They noted that homeless patients have trust issues, and this could be a barrier to basic palliative care. Some nurses talked about their colleagues allowing judgment to affect the care they provided to homeless patients and this affects how the patient responds.

CURRICULUM VITAE

Tammy Neiman

Place of birth: Kenosha, WI

Education

      B.S., University of Wisconsin-Milwaukee, May 2003

      M.S., Minnesota State University, Mankato, May 2012

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Professional Membership

      Midwest Nursing Research Society, July 2013-present

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      International Family Nursing Association, 2012-present

      Minnesota Nurses' Association, September 2008-present

Teaching Experience

      Minnesota State University Mankato, Mankato, MN

         Assistant Professor, 2017-present

      St. Olaf College, Northfield, MN

         Instructor, Fall 2015

      St. Catherine University, St. Paul, MN

         Assistant Professor, 2012-2015

Research Experience

      Using Critical and Transformative Theory to Describe Basic Palliative Care in the Acute Care Setting, Dissertation Study, 2017-2018

Under the supervision of Dr. Lucy Mkandawire-Valhmu

Worldview Project, Graduate Student, 2016

Research Lead: Dr. Lucy Mkandawire-Valhmu

Palliative Care in Malawi, Graduate Student, 2016

Research Lead: Dr. Lucy Mkandawire-Valhmu

Team Communication in Palliative and End of Life Care, Graduate Student, 2014-2015

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Awards

Jonas Nurse Leaders Program Scholarship, 2014-2016

Chancellor's Award, August 2013-August 2015

Publications

Kovach, C., Taneli, Y., **Neiman, T.,** Dyer, E., Hesse, C., Arzaga, A., & Kelber, S. (2017). Evaluation of an Ultraviolet Room Disinfection Protocol to Decrease Nursing Home Microbial Burden, Infection and Hospitalization Rates. *BMC Infectious Disease, 17,* 186-193.

Wittenberg, E., Ferrell, B., Goldsmith, J., Buller, H. & **Neiman, T.** (2016). Communication About Goals of Care. *Journal of the Advanced Practitioner in Oncology, 7* (2), 146-154.

Neiman, T. & Kovach, C. (2016). Research needs and challenges regarding palliation for people in long term care settings. *Research in Gerontological Nursing, 9* (1), 2-5.

Wittenberg, E., Goldsmith, J., & **Neiman, T**. (2015). Nurse Perceived Communication Challenges and Roles on Interprofessional Care Teams. *Journal of Hospice and Palliative Nursing, 17* (3), 257-262.

Ferrell, B., Wittenberg-Lyles, E., & **Neiman, T**. (2015). A historical perspective in palliative care communication in *Textbook of Palliative Care Communication.* New York, NY: Oxford University Press USA.

Presentations

Neiman, T. (2018). "Confidence in Basic Palliative Care: Needing Language." Midwest Nursing Research Society 42rd Annual Conference. Poster.

Neiman, T. (2017). "Understanding Basic Palliative Care: Homeless and Culturally Diverse Populations." Transcultural Nursing Society 43rd Annual Conference. Poster.

Neiman, T. (2015). "Jonas Leadership Project: Roles of a Nurse Leader." 2015 Jonas Scholars Leadership Conference. Roundtable discussion.

Neiman, T. (2013). "A Community Health Art Project: The use of art as reflection on student experiences." Sigma Theta Tau, Biennial Convention. Poster.

Sieve, L., Neiman, T., & Eggenberger, S. (2013). "A Pilot Project Grounded in Family Nursing; Designing a Simulation in Behavioral Health Nursing." 11th International Family Nursing Conference. Podium.

Neiman, T. (2012). "Nursing Students' Attitude Toward End-of-Life Care." Mu Lambda Research Forum. Podium.