DISSERTATION

HOSPICE CARE: NURSES’ EXPERIENCE AND PERCEPTION OF OLDER ADULT PATIENTS’ EXPERIENCES

Submitted by

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ABSTRACT

HOSPICE CARE: NURSES' EXPERIENCE AND PERCEPTION OF OLDER ADULT PATIENTS' EXPERIENCES

The current study sought to understand the experience of hospice nursing staff with hospice and the differences they perceived in caring for older adult patients who utilize hospice for longer and shorter periods. This study also sought to understand older adult patients' experience of hospice services and if length of hospice stays had an effect on the patients' end-of-life experience, as perceived by hospice nursing staff. Interpretative Phenomenological Analysis (IPA) was used to extract themes and subthemes from 10 interviews conducted with hospice nursing staff. Major themes include nursing staff reporting a positive view of hospice, but also being aware of a perceived stigma against hospice among both older adults and their family members. Another major theme identified was how older adults' perception of hospice changes based on length of use, with longer use leading to more positive views of hospice. Participants discussed aspects that affect length of stay and how longer hospice stays are more positive than shorter. The last two major themes were participants believing more education about hospice is needed and a frustration with the Medicare reimbursement process of hospice. Content analysis was also utilized to extract two noteworthy concepts that did not fit within the guidelines of IPA. These noteworthy concepts were extracted from a comparison of two older adult deaths, one that used hospice for a short period (less than two weeks) and another for a long period (more than four weeks). When comparing these stories, it became evident that longer hospice stays had more aspects of a 'good' death and tended to utilize more services provided by hospice. These themes and noteworthy concepts suggest hospice nursing staff believe longer hospice stays are more positive, hospice nursing staff view hospice more positively than older adult patients, and more education may lead to longer hospice stays.

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INTRODUCTION

Older Adults in the United States

The term "older adult" typically refers to those 65 years of age and older. In 2012 the older adult population was reported to be 44.7 million individuals, which represented 14.1% of the United States population (Administration on Aging [AOA], 2013). More recent estimates find that older adults represent 17% of the population, an increase of almost three percent in two years (U.S. Department of Census, 2014).

The growth of the older population began in the second decade of the 21st century due to the aging of the "baby boom" generation (those born between 1946 and 1964) and increasing life expectancy rates within the United States (Population Reference Bureau, 2015). It is expected that this population growth will continue to rise dramatically, reaching 21.7% of the United States population by the year 2040 (AOA, 2013). The number of individuals older than 85 is expected to triple over this same period of time (U.S. Department of Health and Human Services, 2011). After 2040, the percentage of older adults in the United States is expected to plateau at 20% of the population (U.S. Department of Commerce, 2012) or approximately 80 million (U.S. Department of Census, 2014).

Hospice Services

Because of this aging population, the need for end-of-life care will continue to grow. Those at the end of their lives have many options regarding their care (Field & Cassel, 1997). Palliative treatments, one of these options, aims to improve the quality of life by "forgoing life-sustaining treatments and focusing on relief from pain and distressing symptoms; affirming life; regarding dying as a normal process; integrating psychological and spiritual aspects into care;

offering social support; and offering a support system to help the family cope" (World Health Organization [WHO], 2009, p.1). One form of palliative care is hospice services. The hospice philosophy accepts the approaching death and tries to neither slow nor hasten it, providing services dedicated to helping patients in their last months of life with a focus on compassionate and holistic care without life-prolonging measures (Candy, Holman, Leurent, Davis, & Jones, 2011).

Today's modern hospice movement originated in the 1950s with the first studies focusing on terminal cancer patients in the United Kingdom. These studies reviewed approaches used to assist terminal patients, particularly in regards to pain management near the time of their death (Clark, 2007). The results of the studies were the first scientific attempts to treat and document work with dying individuals. The goal was not to cure, but rather to help them die in a dignified and less painful manner. This approach also acknowledged that more than physical pain must be managed; issues such as emotional, spiritual, and social distresses of the dying were also important (Story & Knight, 2003). Hospice in the UK provided evidence to create such settings across the world, and the first modern hospice was built in the United States in 1974 (Clark, 2007).

Today, modern hospice services are provided by independent hospice organizations, hospital programs, nursing home wards, or other healthcare systems and can be provided in any location deemed appropriate by the recipient. Hospice care is provided by an interdisciplinary healthcare team that can include a doctor, nurse, social worker, counselor, home health aides, clergy, therapists, and volunteers. This health care team will also work in conjunction with the patient's primary care physicians or long-term care nursing facility staff to ensure coordination of care (American Cancer Society [ACS], 2014).

Hospice organizations may differ; however, there are a number of services offered by all hospice providers. One of these fundamental services is pain and symptoms management, allowing patients to be more physically comfortable while dying. Pain management services include improved assessment of pain, increased medication management, quicker delivery of medication, and ability to prescribe higher dosages of medication. An additional component of pain management services is allowing the patient to remain in control whenever possible by allowing them to choose the amount of pain medication they utilize (ACS, 2014).

The emotional and psychosocial needs of the patient are also a hospice focus. Counselors and social workers are provided to help the patients cope with the stress of dying as well as allowing patients to ask questions (National Hospice and Palliative Care Organization [NHPCO], 2015). Spiritual care is also provided based on the differing needs and spirituality of patients, and can therefore varies from person to person (ACS, 2014). Spiritual care is viewed as increasing patient control, as they set the guidelines for their own desired religious services. Special services can also be provided based on the necessity of the patient, for example, speech therapy, physical therapy, massage therapy, and art and music therapy (Association for Frontotemporal Degeneration [AFTD], 2007; NHPCO, 2015).

Hospice also provides assistance with activities of daily living for those who are unable to care for themselves, such as bathing and transportation (AFTD, 2007). Assistance with meal planning, nutrition, and feeding can help patients maintain their independence and health (AFTD, 2007). In addition, durable medical equipment and supplies provided by hospice, such as a hospital bed, allow patients to remain in their home while receiving high-quality care (AFTD, 2007). Another important service is coordination of care. Hospice team members ensure that all members on their team are updated on the patient’s care as well as updating important medical staff outside of hospice (ACS, 2014). In addition, hospice team members are responsible for coordinating care with hospitals, nursing homes, or inpatient centers if the need arises (ACS, 2014).

Hospice provides extensive services for the caregivers and families of hospice patients. Regular family meetings are scheduled to help caregivers remain aware of prognosis, progress, and interventions (ACS, 2014). In these meetings caregivers are also informed about the dying process, an important aspect of hospice services (Kehl, Kirchhoff, Finster, & Cleary, 2008). Additionally, during caregiver meeting, issues that have arisen for the caregiver can be discussed allowing them to receive support. Additional respite care and bereavement services may also be provided (ACS, 2014).

These services are available to those who are facing a life-ending illness or injury (NHPCO, 2015). In the United States, this is determined by a physician's statement that death can be expected within six months, but hospice care can be provided for longer than six months if the condition remains life threatening. If a patient, after beginning to use services, wishes to try a new curative treatment or their prognosis improves, the patient can stop utilizing services. This is considered "graduating hospice" and is typically seen as a positive event, as it means patients are no longer dying or have longer to live than expected. Individuals who "graduate" are able to use services again when they meet the necessary criteria.

Use of Hospice in the United States

Although hospice provides important services for those at the end of their life, the percentage of dying individuals who use hospice is low and services are utilized for less than the available six months. In the United States, less than half (44.6%) of all deaths utilize hospice services (NHPCO, 2012). For those who do take advantage of hospice care, the majority may begin services too close to their death to receive maximum benefit (Anderson, 2014; Christakis, 1998). In 2013, almost 50% of those who did use hospice utilized services for less than 2 weeks and 34.5% used services for only seven days before their death (NHPCO, 2014).

The amount of time a patient uses hospice services before death is known as length of stay or length of use within the hospice literature (NHPCO, 2014). The median number of days of use decreased for all ages of patients from 39 to 28 days between 1994 and 2000. In 2008, the median stay declined to 21 days (Vig, Starks, Taylor, Hopley, & Fryer-Edwards, 2010). The most current median length of hospice use found during this review was less than 20 days (Scheffey et al., 2014), clearly a significant decrease in the median length of stay over the past twenty years.

When looking at older adults and hospice use, the rates are significantly lower than those of younger individuals (Taylor, Ostermann, Van Houtven, Tulsky, & Steinhauser, 2007). For older adults alone, the percentage of use varies by study, but has been shown to be as low as 10% (Christakis & Iwashyna, 2000) and as high as 40% for some diagnoses, such as cancer (NHPCO, 2014). While this percentage varies, it is a startling percentage due to the reported benefits of hospice use and given that in the United States (74%) of deaths are in the older population (Munn, 2012). It has been argued that percentages of hospice use could be unrepresentative due to unexpected deaths in the older population. This argument likely impacts statistics a minimal amount due to the leading causes of death in the older population being chronic, which would not cause an unforeseen death (Eure, 2016).

End-of-Life Concerns

Most individuals nearing the end of their life likely have a number of concerns regarding their death and end-of-life care. Heaven and Maguire (1998) found a strong association between the number of concerns that older adult patients have at the end of their life and the anxiety and depression they suffer. They find that concerns regarding pain are most associated with increased anxiety and concerns regarding disability and how that affects independence and control are most associated with depression (Heaven & Maguire, 1998).

In a further review of the literature, pain is identified as a significant concern in many studies (i.e. Area Agency on Aging [AAA], 2013; Caruso-Herman, 1989; Maguire, Walsh, Jeacock, & Kinston, 1999; Payne, Langley-Evans, & Hillier, 1996; Singer, Martin, & Kelner, 1999; Steinhauser et al., 2000). It is found to be a concern not only for the dying individuals, but also for their families, caregivers, and medical professionals. Both physical and emotional pain are often noted near the end of life, leading to the fear of dying in pain being more feared than death itself (AAA, 2013). As a participant in Singer, Martin, and Kelner's (1999) qualitative study clearly expressed, "I wouldn't want a lot of pain; it's one of the worst ways to go" (p. 165).

Furthermore, in line with the findings of Heaven and Maguire (1998) others find that loss of independence and control is a significant concern for those nearing the end of their life (Caruso-Herman, 1989; Singer, Martin, & Kelner, 1999). A large study of family members of the dying found that loss of independence was one of their biggest concerns for their dying family member (Givens & Mitchell, 2009). For many patients, their level of independence and autonomy are directly related to their perception of dignity (Woo, Maytal, & Stern, 2006) and the loss of independence and increase in disability are associated with increased distress among the dying (Chochinov, Hack, McClement, Harlos, & Kristjanson, 2002).

Benefits of Hospice Services Compared to Non-Hospice

Hospice has many known benefits for patients and their caregivers when compared to non-hospice patients. As already discussed, there is a clear link between the number of concerns a patient has at the end of life and their end-of-life experience (Heaven & Maguire, 1998). Hospice provides assistance with a number of the common concerns at the end of life, which in turn can decrease depressive and anxious symptoms.

Hospice can assist with pain management; one of the most commonly expressed concerns. Patients enrolled with hospice have been shown to have superior pain management and significant symptoms improvement when compared to conventional care (Elsayem et al., 2004; Meier, 2011; Ringdal, Jordhøy, & Kaasa, 2002; Wallston, Burger, Smith, & Baugher, 1988). This suggests that patients who utilize hospice are more likely to have their pain noticed, assessed, and treated.

Nursing homes tend to have difficulty managing the pain symptoms of all their residents when compared to a more personalized setting, due to lack of individualized attention. Nursing home residents using hospice report improved pain management and that appropriate dosages of pain medication were more closely monitored and available (Miller, Mor, Wu, Gozalo, & Lapane, 2002). This suggests that hospice services can help alleviate the major concern of the dying, as well as their families, caregivers, and medical professionals, by helping patients, including nursing home residents, die in a less painful manner.

Independence and control are also important concepts within hospice philosophy; measures are taken to allow patients to live in the most independent manner possible and maintain their individual control (Mesler, 1995). Independence is maintained through allowing the patients to make decisions regarding medication dosages and the choice of services utilized, many of which assist in maintaining independence (i.e. physical therapy). While these aspects can be complicated by factors such as the patient’s cognitive awareness, it is an important aspect of hospice care (Center to Advance Palliative Care, 2008; Mesler, 1995). In addition, patients who use hospice care tend to report a higher satisfaction with involvement in care decisions compared to non-hospice care (Kane, Klein, Bernstein, Rothenberg, & Wales, 1985; Meier, 2011; Ringdal et al., 2002).

Individuals who are enrolled in hospice report a higher quality of life prior to death (Bakitas et al., 2009; Wright et al., 2008) and a higher quality of death when compared to those who are not enrolled (Wallston et al., 1988). Quality of death is typically measured by looking at the last three days of life and determining if they occurred as the patient wished (Wallston et al., 1988), but measures are being developed to create a standard measurement of quality of death (Curtis et al., 2002).

A component of quality of death is the medical measures taken in a patient’s final days. Patients who use hospice have a decrease in painful and aggressive measures used, leading to a more peaceful and higher quality death (Wright et al., 2008). This is particularly important because it is known that patients often do not want aggressive measures used to keep them alive (Field & Cassel, 1997; Heyland et al., 2006; Singer, Martin, & Kelner, 1999). Unfortunately, documented preferences regarding the use of aggressive measures at end of life are often ignored in non-hospice settings (Field & Cassel, 1997). While using hospice services, these aggressive measures are less likely to occur and the patient’s wishes are more likely to be taken into full consideration (Wright et al., 2008).

Those who utilize hospice services also have more frequent social interactions during their end-of-life care (Wallston et al., 1988). Social interactions are important as one nears the end of life, as patients indicate this can help lead to a higher quality of life and decrease stress (Sidney, 1976; Yanos, Rosenfield, & Horwitz, 2001). Additionally, Yen and Kaplan (1999) found, after looking at over one thousand deaths in the older adult population, that individuals living in areas with more social interactions had a lower chance of dying during the eleven-year duration of the study. This supports the need for more social interaction for older adults, particularly at the end of their life, which is provided by hospice.

One of the most surprising benefits may be that the use of hospice can extend a person's life for up to two months longer than those who choose not to utilize hospice (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007; Meier, 2011; Temel et al., 2010). There are a number of theories regarding why enrollment can increase the length of a patient's life. One idea is that hospice patients avoid the risk of overtreatment and overmedication, decreasing the use of aggressive treatments and risk of side effects (Connor et al., 2007). Further, hospice patients typically have more monitoring than others which may simply lead to awareness of issues that can be remedied before becoming fatal (Connor et al., 2007). Finally, as discussed previously, hospice provides services that deal with patients' psychosocial needs. Several studies have suggested that psychosocial support may extend life, which may explain the prolonged life in those who use services (Berkman, Leo-Summers, & Horwitz, 1992; Kroenke, Kubzansky, Schernhammer, Holmes, & Kawachi, 2006; Spiegel, Kraemer, Bloom, & Gottheil, 1989).

As can be seen in this literature review, hospice has a number of benefits for older adult patients utilizing the services instead of conventional care. Moreover, services can be tailored to a specific patient's needs, allowing each individual patient to have the best care and best death possible, leading to fewer concerns as they reach their end of life.

There are also benefits for the patients' families and caregivers. Hospice team members keep families up to date on the patient's condition and give an overview of what to expect during the dying process, which has been shown to make the deaths less difficult (Kirkendall, Holland, Keene, & Luna, 2015; Meier, 2011; Waldrop & Rinfrette, 2009). Families of hospice patients have also been shown to have decreased anxiety and greater satisfaction with involvement in care than did families in conventional care (Kane et al., 1985; Ransford & Smith, 1991). Other benefits that have been noted include improved bereavement outcomes, increased satisfaction in end-of-life care, improved family functioning, and lower mortality rates in the surviving family after the loss (Casarett & Quill, 2007; Christakis & Iwashyna, 2003; Miller et al., 2002; Miller, Mor, & Teno, 2003; Teno et al., 2004).

Benefits of Longer Length of Services

As already stated, the amount of time a patient utilizes hospice services before death is known as length of stay or length of use (NHPCO, 2014). While an 'ideal' length of hospice use is not known, a length of stay of at least three months has been suggested as appropriate (Christakis & Iwashyna, 2000; Quill, 2007). Only 11.5% of hospice patients utilize services for three months or longer (NHPCO, 2014). Experts in the field agree that those who enroll should do so earlier, leading to longer stays prior to death (Byock, Forman, & Appleton, 1996; Christakis & Iwashyna, 1998; McGorty & Bornstein, 2003; Miller, Weitzen, & Kinzbrunner, 2003).

"Long" hospice stays provide a number of benefits to patients and caregivers, above the already noted benefits of hospice use alone. The most obvious benefits are the more time a patient and their caregivers have within hospice, the more time they have to benefit from the physical and psychosocial support provided and make use of appropriate services (Christakis & Iwashyna, 2000; Rickerson, Harrold, Kapo, Carroll, & Casarett, 2005). Studies have shown that the longer a patient utilizes hospice, the more services they and their caregivers use (Rickerson et al., 2005). The less time a patient is in hospice, some aspects of care are less likely to occur, such as important end-of-life discussions, establishing end-of-life goals, comfortable dying, and effective grieving (Miller, Kinzbrunner, Pettit, & Williams, 2003; Miller, Weitzen, & Kinzbrunner, 2003; Teno, Weitzen, Fennell, & Mor, 2001).

Pain management is the area that has received the most research attention with respect to length of hospice use. Patients benefit more from pain and symptoms management the longer they utilize services (Christakis & Escarce, 1996; Han et al., 2007; Miller, Mor, & Teno, 2003; Schockett, Teno, Miller, & Stuart, 2005; Wright et al., 2008). Miller, Mor, and Teno (2003) found that nursing home residents that used hospice for over seven days have significantly more access to opioids, even twice a day where necessary, than patients who use hospice for less than seven days due to inadequate time to allow for full implementation of pain management strategies.

Patients who utilize services for longer periods of time also have been shown to have a higher quality of life in the time before their death, as shown by Wright and colleagues (2008). Patients who were in hospice for less than two weeks had the same quality of life score as patients who did not use services at all (Wright et al., 2008). Quality of life continued to increase the longer a patient was in hospice, becoming significantly higher at two months of hospice use (Wright et al., 2008). Quality of death is also impacted by length of use. Patients who use services for two months have a higher quality of death than those who are in hospice for less than one week (Wright et al., 2008).

Continuity can also be an important benefit of a longer hospice stay. In the final days of an illness, having continuity in care can lead to less turbulent end-of-life experiences for patients (Waldrop, 2006). A longer length of stay can allow for hospice team members to have more time to set up needed equipment in a patient’s home or preferred location of death, allowing them to live their last days as they wish without a stressful move (e.g. to a hospital) in the last days of life (Miller et al, 2003). Due to this increased time, patients who utilize hospice for longer amounts of time are more likely to die in their home and less likely to be in an inpatient hospice or hospital bed at their time of death (Miller et al, 2003).

While not often researched directly, it can be assumed that the longer an individual is in hospice the more time hospice personnel have to create working relationships with patients and their families. One observational study demonstrated that the development of empathic relationships between hospice nurses and their patients occurred over time and continued to improve the longer an individual used services (Raudonis, 1995). It has been suggested that fostering a more positive relationship between hospice nurses and the patients will improve patients' physical and emotional well-being (Raudonis, 1993). Another researcher found that social workers who were able to spend more time with their patients were better able to build rapport which led to increased client satisfaction (Resse & Raymer, 2004). While research is sparse, it can be assumed that the relationship between the patient and personnel is impacted by length of use and may impact the care the patient receives.

Caregivers also receive increased benefits when patients are in hospice for longer periods of time. The longer caregivers are connected with hospice and with the professionals involved, the more they benefit from services after the death, including support and bereavement services, and the more prepared they feel for the loss (Han et al., 2007; Wright et al., 2008). Caregivers of patients who utilize hospice for longer periods of time have been shown to have lower chances of being diagnosed with major depressive disorder six months later (Bradley et al., 2004). Likewise, family members and caregivers generally find the deaths of their loved ones less stressful when services are utilized for longer periods of time (Waldrop & Rinfrette, 2009) and have more needs met and reported higher satisfaction levels with the care provided when introduced earlier in a terminal diagnosis (Schockett et al., 2005). Longer hospice stays also lead to better caregiver outcomes in terms of overall quality of life, self-reported health, physical functioning, and mental health after the patient's death as well as less regret experienced (Wright et al., 2008).

Longer use can also save the patients and caregivers a significant amount of money during end-of-life care (Waldrop, 2006). Taylor, Osternmann, Van Houtven, Tulsky and Steinhaser (2007) did an extensive study looking at the costs at the end of life, taking into account hospice use and length of hospice use. It was found that individuals who use hospice from 1.5 to 3.5 months saved the most money, with saving of more than $7,000 for cancer deaths and $3,500 for non-cancer deaths (Taylor et al., 2007). These researchers suggest that increasing all hospice stays, even by as little as seven to 10 days, could save patients and insurers money and dramatically lower end-of-life costs (Taylor et al., 2007).

Why Patients Commonly Have a Short Length of Hospice Use

There are a number of theories regarding why the dying are not in hospice for longer periods. Many of these theories focus on physicians, as they are often the first individuals to disclose that an individual has a life-threatening illness and is eligible to receive hospice services.

One theory why patients do not utilize hospice services for longer periods is physicians' discomfort communicating with their patients regarding end of life and hospice. The assumption is that this lack of communication directly influences the patients' and their caregivers' knowledge regarding available end-of-life care options (Waldrop, 2006). Physicians worry that mentioning hospice will lead patients to believe they are being given up on or that their physician simply wants to save money by utilizing hospice (Brickner, Scannell, Marquet, & Ackerson, 2004; Johnson & Slaninka, 1999).

Previous research has shown that physicians provide information on hospice services for only a quarter of their patients while most caregivers state they wish they had been provided with more information (Casarett, Crowley, & Hirschman, 2004). When physicians do discuss end of life and hospice options, the discussion lasts for an average of five to six minutes, with the physician talking for 66% of the short conversation (Casarett et al., 2004; Hofmann et al., 1997; Tulsky, Fischer, Rose, & Arnold, 1998). This discussion most often occurs when the patient is very close to their time of death (Casarett et al., 2004; Hofmann et al., 1997; Tulsky et al., 1998) even though most caregivers wish they had known about services sooner (Casarett et al., 2004).

Congruent with the research regarding physicians' reluctance to discuss hospice, another common reason patients do not utilize hospice or do not utilize it until late in their diagnosis is a lack of awareness of hospice and the services provided (Szirony, Sopko, Masiulaniec, & Binder, 2011). Without a doctor or another medical staff member mentioning that a disease is terminal or that hospice should be considered, many caregivers and patients are unaware or unwilling to look into end-of-life options themselves (Casarett & Quill, 2007). Many patients learn about the full value of hospice only after they have enrolled, indicating that if this information is more available, services may be utilized more often (Casarett et al., 2004).

Another common reason why hospice may not be utilized at an earlier time is that patients and caregivers tend to be overly optimistic regarding the expectation of treatment (Bruera et al., 2001; Hofmann et al., 1997). This optimism, again, may be due to physicians wanting to keep hope alive, and therefore speaking in optimistic terms to their patients (Schockett et al., 2005). A similar area of research shows that caregivers and patients are often reluctant to think about end-of-life services and will use comorbid issues to delay the conversation. For example, aches and pains may be attributed to arthritis and coughing can be attributed to bronchitis instead of a more serious cancer diagnosis. Symptoms that may signal a serious illness can be written off as a more banal issue due to reluctance to discuss end of life and hospice (Waldrop, 2006).

Individuals may choose not to utilize hospice until late in their illness due to negative misperceptions regarding hospice and its services. It has previously been shown that a common misperception of hospice services is that it is only for the last few hours of life and only for cancer patients (Vig et al., 2010). A study completed by this author and Dr. Tammi Vacha-Haase (2016) found that long-term care nursing staff believe their patients have an exceedingly negative view of hospice services, leading to its underutilization. These negative views include the fear that utilizing hospice means that death will come sooner and the out-of-date view that hospice is a separate facility that they move an individual into in order for them to die alone (Aeling & Vacha-Hasse, 2016).

Another hypothesis for the lack of hospice utilization is that some patients are concerned about logistics. The eligibility requirements are fixed by the Medicare Hospice Benefit and include having six months or less to live and forgoing curative treatment. Often, physicians are not able to correctly estimate length of life and may over-inflate estimates, leading to the patient being unable to qualify for hospice services (Casarett & Quill, 2007). Also, some treatments, such as chemotherapy, can be used as a pain-reducing method but are also considered life-prolonging treatments and therefore make patients unable to use the Medicare benefit (Huskamp, Buntin, Wang, & Newhouse, 2001).

Individuals who live in a nursing home near their time of death are less likely to utilize hospice services (Taylor et al., 2007). Research pertaining to hospice use in nursing homes is sparse (Oliver, Porock, & Zweig, 2005). This difference in use may be due to a number of reasons, including, but not limited to policies making reimbursement difficult within nursing home settings (Zerzan, Sterns, & Hanson 2000). In addition, as in other settings, a lack of information from physicians can make nursing home residents less likely to utilize hospice services (Casarett et al., 2005). It is important to note that this trend has been changing in recent years, with the number of nursing home residents who use hospice services doubled between 1999 and 2006 and was projected to continue to increase (Miller, Lima, Gozal, & Mor, 2010).

Utilizing hospice at the end of life can save a significant amount of money (Taylor et al., 2007). Although this is known in the research, cost can have a huge impact on length of hospice use, as older adults and caregivers do not always fully understand the financial impact of hospice use. Some patients have concerns regarding reimbursement (Casarett & Quill, 2007; Zerzan, Sterns, & Hanson 2000). In addition, patients are not always aware that hospice services are covered through Medicare, Medicaid, and most employee-sponsored health insurance programs (Friedman, Harwood, & Shields, 2004). Even though most people have full insurance coverage for hospice care (Friedman, Harwood, & Shields, 2004), the Medicare Hospice Benefit remains one of Medicare's smallest programs, accounting for less than 1% of Medicare expenditures (Riegel, Moser, Powell, Rector, & Havranek, 2005).

Other factors associated with short hospice stays include having a non-cancer diagnosis, being over the age of 85, being male, having private insurance, and being referred from a hospital (Miller, Weitzen, & Kinzbrunner, 2003). Being an ethnicity other than White/non-

Hispanic has also been shown to lead to less information about hospice services, and therefore less hospice use at the end of life (Johnson, Kuchibhatla, & Tulsky, 2011).

Limitations of Previous Research Regarding Hospice Length of Use

It is clear based on the above information that length of stay within hospice is an important concept for research in order to better understand rates and length of hospice use, especially among the older population. It is a particularly important line of research given the relationship between length of hospice stay and the quality and comprehensiveness of end of life care for older adult patients and their caregivers (Naik & DeHaven, 2001). Although the necessity of this research is clear, many of the previous studies in this area, including most of those presented in this literature review, have a number of limitations.

A significant limitation is the participants involved in most of these studies (Sziroy et al., 2011). Most previous research regarding hospice have utilized family members and caregivers as their participants (e.g. Bradley et al., 2004; Casarett et al., 2004; Field & Cassel, 1997; Kris et al., 2006; Rickerson et al., 2005; Schockett et al., 2005; Schulman-Green et al., 2004; Teno et al., 2012; Waldrop & Rinfrette, 2009). These family members and caregivers are often participating after the death of the patient has occurred (e.g. Casarett et al., 2008; Kirkendall et al., 2015; Teno et al., 2004). While these studies have led to increased knowledge on length of hospice use, asking family members and caregivers may not be the most effective approach to learning about end of life and hospice, due to three concerns.

The first concern is that family members often have significant negative emotionality following the death of the patient (Forbes, Bern-Klug, & Gessert, 2000; Schulman-Green et al., 2004; Wright et al., 2008). This strong negative emotion can affect family members' memory of the last few days of life and this can lead to reporting more negative beliefs around these end of life experiences (Friedman, 1994). Contact and communication with the dying individual is a second area of concern when family members and caregivers are participants of research. Family members may have had limited contact with the dying family member (Port et al., 2001) and often family members have few to no discussions regarding end of life with the dying patient (Schulman-Green et al., 2004) which may further influence the experience. End-of-life preferences among caregivers and the dying patients do not always match (Gardner & Kramer, 2010) suggesting, again, that there is a lack of communication regarding end of life. Third, researchers are typically asking about one specific death that occurred, leading to an overall limited discussion about death in general. Due to these three areas of concern using caregivers and family members as participants is a major limitation of not only studies regarding length of hospice use, but most areas of research related to end of life.

Some researchers utilize other methods. For example, some studies have recruited dying older adult hospice participants (e.g., Szirony et al., 2011). This is a very limited approach due to being both difficult and ethically complicated (Raudonis, 1992). Some studies use data from hospice companies' computer systems or national databases (e.g., Miller, Mor, & Teno, 2003; Miller et al., 2003). While these studies have led to information on hospice usage rates and places of death, databases do not allow for understanding of why patients used hospice for the length they did or their experience of end of life. Additionally, studies of "hospice professionals" have taken place, but they are often nonspecific and combine the data from multiple professions - for example, nurses, doctors, and volunteers together (e.g. Waldrop & Rinfrette, 2009). This has not allowed for an in-depth analysis of one type of hospice professional and their experiences related to the effects of length of hospice use.

An additional limitation is the operational definition of hospice, given that no universal definition exists (Candy et al., 2011). This is particularly important in studies encompassing many nations as hospice services differ between countries (Candy et al., 2011). Even when looking at research done within the the United States, where much of the cited research has taken place, hospice is not often clearly defined within the literature. For example, hospice is sometimes defined as being part of palliative care (e.g. Christakis, 1998; Jennings, Ryndes, D'Onofrio, & Baily, 2003; Meier, 2011; Vig et al., 2010), being the same as palliative care (e.g., Bakitas et al., 2009; Nilsson et al., 2009), and at other times different from palliative care (e.g., Elsayem et al., 2004; Scheffey et al., 2014; Temel et al., 2010).

Research regarding length of use often compares a long hospice stay to a short hospice stay. Similar to the previous limitation, the operational definition of a long and short hospice stay varies across research study. A short hospice stay has been quantified from as little as three days (e.g. Bradley et al., 2004; Kris et al., 2006) to as long as two weeks (e.g. Waldrop & Rinfrette, 2009; Waldrop, 2006). Often, there is no rationale for why that time point was chosen provided in the literature (e.g. Bradley et al., 2004; Kris et al., 2006; Waldrop & Rinfrette, 2009; Waldrop, 2006). Some studies are unclear on their definition of a short stay (e.g., Miller et al., 2003) while others use family members perception of short use (e.g., Schockett et al., 2005). Researchers typically define a long hospice stay as anything over their qualifier for a short hospice stay. For example, Bradley et al. (2004) call a short hospice stay anything less than three days and a long hospice stay anything over three days. This is a significant limitation as researchers may be comparing patients who utilize hospice for very similar amounts of time, for example, three days versus four days. A comparison of three days to a longer length of stay, such as two weeks, may be more appropriate, as it would allow for a greater and more meaningful comparison.

Previous studies comparing length of hospice stay often do not limit the age of the dying individual discussed or studied. Most often, ages of those who use hospice are not provided (e.g. Bradley et al., 2004; Casarett et al., 2006; Johnson et al., 2011; Miller et al., 2003; Schockett et al., 2005). Age of hospice recipient is important to note because patients of varying ages have different wants and needs as death approaches. Differences have been found in hospice agencies who typically care for children as compared to older adults (Lindley, Mark, & Lee, 2009). Additionally, the emotional states of the caregivers, who are most often being interviewed, may drastically differ depending on the age of the individual dying and utilizing hospice.

Another limitation is simply a lack of research (Schockett et al., 2005). Although there is a substantial amount of research on end of life, there is limited research on end of life and hospice, particularly in regards to qualitatively understanding the experience of long hospice use compared to short hospice use. Based on the previous review, and the importance of length of hospice stay, this is a major limitation in hospice research.

Aside from these limitations, previous research regarding length of hospice use often focus on the financial component of hospice (Miller et al., 2003; Taylor et al., 2007). While this is an important aspect of hospice services, the focus on finances leads to the common misconception that hospice is only recommended as only a cost-saving technique (e.g. Brickner et al., 2004; McGorty & Bornstein, 2003). This may contribute to a number of the common negative beliefs held by patients.

Other studies regarding length of hospice stay are often comparisons of records to determine if differences across patients affect use (e.g. Johnson et al., 2011) as well as articles simply providing information (e.g. Carlson, Morrison, & Bradley, 2008). While these studies have led to an increase in relevant and up-to-date information, studies that provide an in-depth qualitative analysis with participants other than caregivers and family members are scant.

Current Study

The current study sought to understand the perspectives of specific hospice professionals, hospice nursing staff, on length of hospice stay. It explored the differences they experience in caring for older adult patients who utilize hospice for a long period as compared to similar patients who utilize hospice for a short period of time. It also investigated their understanding of why older adults use hospice services for differing periods. More specifically, this study sought to understand if length of hospice use had an effect on patients' end-of-life experiences as well as the hospice nurses' experience. Previous research regarding length of hospice use has not examined the perspective of hospice nurses.

Interviewing hospice nurses prevents a number of the previously mentioned limitations in this line of research. First, hospice nurses have routine interactions with their older adult patients, often for multiple weeks before their death (Bowers, Lauring, & Jacobson, 2001; Eika, Espnes, & Hvalvik, 2014; Pepper, Kane, & Teteberg, 1976; Radosevich et al., 1990; Robertson & Cummings, 1991). Second, hospice nurses have numerous end-of-life experiences to draw on (Robertson & Cummings, 1991). Third, nurses typically experience the deaths less emotionally than the families of patients (Ablett & Jones, 2007). Multiple previous researchers in the field have suggested that understanding hospice nurses' experience with hospice is an important area for growth in this line of research due to the information they hold regarding end-of-life experiences (Casarett et al., 2004; Taylor et al., 2007; Waldrop, 2006). Due to these factors, interviewing hospice nurses was novel, led to a rich discussion of length of hospice stay, and eliminated the major limitations of previous research.

For the purpose of this study, hospice use was clearly defined as extra palliative services provided by an independent hospice provider at the end of a patient’s life. A short hospice stay was considered any length of hospice use under two weeks. This operational definition of a short length of hospice use was created based on the research findings that half of hospice patients utilize services for less than two weeks. Using this definition leads to a larger base of patients on the long and short continuum. In addition, two weeks seems to be an important time period for hospice based on the number of patients who begin using services at that time. Two weeks was also an appropriate time period due to the studies showing that those who receive services for less than two weeks have a similar quality of life to those who do not use hospice, suggesting distinct and meaningful differences would be found based on length of use (Wright et al., 2008). Moreover, two weeks has been used as a qualifier in the previous research (e.g. Aldridge, Canavan, Cherlin, & Bradley, 2015; Waldrop & Rinfrette, 2009; Waldrop, 2006). Taken together, this information suggests that this was an appropriate cut off point for a short hospice stay.

A long hospice stay was defined as any use longer than four weeks. In previous research a long stay was typically considered anything over the researchers’ qualifier for a short stay. This researcher chose a longer period of use, four weeks, to further distinguish the experiences of the hospice nurses. This provided more meaningful data regarding the difference between a long and short stay, as participants are not comparing, for example, a patient who used hospice for two weeks and a patient who used hospice for fifteen days. These clear definitions of short and long hospice use assists in eliminating a previously discussed limitation.

The participants were asked to discuss only deaths that occurred in the older population, defined as individuals over the age of 65. This assisted in preventing another limitation found in previous literature, as often there is no specification of age of the patient using hospice. This led to more useful data on older adults, the population that experiences the most deaths. Also, due to the lack of older adults utilizing hospice services, this is a particularly important age group to study, as many more older adult patients could be using hospice services and receiving the aforementioned benefits.

Research Questions

The overarching goal of the current study was to understand hospice nursing staffs' experiences with hospice and with older adults who utilize hospice services for a short period of time and a longer period of time. In addition, determining if differing lengths of hospice use impacted the nurses' understanding of end-of-life care was reviewed. Because nurses have worked with many different patients and often establish a connection with patients due to routine care, it was especially important to investigate nurses' perspective on why older adults utilize hospice services for differing periods and if these differing lengths of use have an impact on older adults' end-of-life experience.

METHODS

Phenomenological Research

Phenomenological research "describes the common meaning of a concept for several individuals of their lived experience" (Creswell, 2013, p.76) and seeks to explain these individuals' experience in a universal way. In the present study, the concept was hospice nurses' experience of end-of-life care for patients who utilize hospice for a short and a long period. In particular, based on their experiences, how the experience of end-of-life care changed depending on length of hospice use. This study used interpretative phenomenological analysis (IPA) to identify themes and meanings across interviews with hospice nurses. Although IPA is a relatively new research method, it has become one of the most popular methods of analysis for qualitative research, particularly in the field of psychology (Smith & Osborn, 2008).

Establishing trustworthiness

Standards of trustworthiness have been created to determine the credibility and rigor of qualitative research without imposing quantitatively traditional terms, such as validity and reliability (Morrow, 2005). In this study, trustworthiness was developed and maintained through the following strategies:

Peer Debriefing is the use of an external check during the research process. The "peer debriefer" acts as a "devil's advocate, an individual who keeps the researcher honest, [and] asks hard questions about methods, meaning, and interpretations" (Creswell, 2013, p.251). Peer debriefing assists in reducing some bias on the part of the primary researcher as another individual is reviewing her thoughts and processes. In the current study peer debriefing occurred with a research assistant who has a bachelor's degree in psychology. In addition to discussions regarding bias, this research assistant reviewed the primary researcher's coding and analysis at multiple times to act as an external check, as described in the analysis section.

Member Checking involves the researcher returning to the participant for their view on a finding or interpretation (Creswell, 2013). After verbatim transcription of the interviews, transcripts were sent back to participants who consented during the interview process, with the request that they review their transcript and revise anything they wished. Seven participants consented to the member check and were sent their transcript by e-mail, with four interviewees returning comments. The four interviews returned contained no major changes to the transcripts; two participants asked that the "ums" be removed, one participant asked that the researcher remove an identifying fact, and the fourth participant reported no changes were necessary.

A **Researcher's Journal** was kept to help the researcher both acknowledge and show their awareness of any biases that were present during the research (Morrow, 2005). This journal was used throughout the research process. During the data collection process, it was used to document notes, reactions, ideas, and experiences of interviewing hospice nurses. The journal also contained an ongoing record of the personal feelings and reactions of the primary researcher. These personal notes were later used to allow the researcher to remain aware of biases and to determine if these may have affected any aspect of the research project. During analysis, this journal was utilized to organize themes and coding. While this journal was not used as data, it was reviewed and shared with the previously mentioned research assistant to assist in reducing bias.

Thick Description is the use of rich and detailed descriptions of the participants for the purpose of determining if the findings are transferable to other situations and to other individuals (Morrow, 2005). For the current study, self-reported demographic information was obtained using a short verbal self-report demographic survey that had been used in previous research with nursing staff (Appendix B). Verbatim transcription was used in the analysis to confirm that the true content and meaning in the interview are present. Quotes presented in the results section are direct quotes, except for the removal of filler words (i.e., “um,” “eh”) and removal of any possibly identifying information.

In phenomenological research, researchers are encouraged to become aware of how their biases, personal identities, and experience can affect their work. This process is termed “being reflexive.” It is impossible to completely remove bias from the research process, especially in research involving interviews, as in this study with hospice nursing staff. Bias can affect every part of the research design, analysis, and written summary; however, understanding these biases is more important than attempting the impossible task of removing them (Smith, Flowers, & Larkin, 2009; Willig, 2001). When a researcher consciously acknowledges who they are and their previous life experiences, the researcher is better able to explore these biases and the intersecting relationship between herself and the research (King & Horrocks, 2010).

The primary researcher is self-identified as a White, heterosexual female, 25 years of age. She is using the current study to complete her dissertation in counseling psychology with an emphasis in geriatric end-of-life care. The primary researcher has had experiences in senior centers, long-term care facilities, as an in-home personal care assistant for an older individual with a life-threatening illness, and as a therapist for older adults. Her experience in senior centers and long-term care facilities was as a recreation intern, totaling two years. In this position, she often spent time doing “one-on-ones,” during which she had individualized conversations with residents regarding end of life and hospice, amongst many other topics. Her experience as an in-home personal care assistant was a six-month placement where she interacted daily with an older woman who was nearing the end of her life and who was choosing not to utilize hospice. The primary researcher is currently Assistant Director of the Aging Clinic of the Rockies providing services to older adults and their caregivers. The primary researcher identified two preconceived expectations: (1) hospice has many benefits for older adults who choose to utilize it and (2) many older adults who do utilize hospice choose to do so too close to their death to receive maximum benefits.

Purposive Sampling

In IPA, small sample sizes are the norm (Brocki & Wearden, 2006). Having too large of a sample size can take away from the meaning of each individual experience, which is a main tenet of qualitative research (Bowen, 2008). Participants are selected with a specific research question in mind and are chosen based on their ability to give a full description of the phenomenon in question (Brocki & Wearden, 2006). As is common in qualitative research, purposive sampling was utilized in this study (Glaser & Strauss, 1976; Patton, 2002; Schulman-Green et al., 2004) and based on the previous discussion, hospice nurses were the purposively selected population to avoid limitations found in previous research.

When using an IPA framework, data saturation - the idea that a researcher reviews previous interview transcripts for a theme found in a new transcript and continues interviewing until no new themes arise - is not a desirable goal, and thus was not attempted in the present study (Brooks, King, & Wearden, 2011; Hale, Treharne, & Kitas, 2008). Smith, the creator of IPA, found data saturation to be a problematic concept (Smith, 1991). Moreover, Brocki and Wearden (2006) stated that this process could “theoretically continue ad infinitum” (p. 22). Due to this cyclic nature, Smith reported that data saturation is commonly not utilized in IPA (Smith & Osborn, 2007). Based on Smith’s reasoning, data saturation was not used in the current research. A number of other studies utilizing IPA followed this same reasoning and did not include data saturation as part of their analysis (e.g., Brooks, King, & Wearden, 2014; Bulley, Donaghy, Howden, Salisbury, Whiteford, & Mackay, 2009; Chan, Lopez, & Chung, 2010; Finfgeld-Connett, 2014; Mason, Porcellato, Van Der Woude, & Goosey-Tolfrey, 2010).

During the proposal stage of this study, it was determined that eight participants would be interviewed. Eight was viewed as the appropriate sample size for qualitative research as well as being within the 'large' range for a typical IPA analysis (Brocki & Wearden, 2006; Smith, 2011). After the primary researcher interviewed the eight participants it was determined that six of the participants were Registered Nurses (RNs) and two were Certified Nursing Assistants (CNAs). Additionally, six of the eight participants were from the same workplace. After a discussion with a qualitative research expert, two additional CNAs were interviewed to allow for a more meaningful comparison between RNs and CNAs concerning their endorsement of different themes and subthemes. In addition, these two extra participants were chosen from a different workplace. Due to the flexibility of IPA, this small addition of participants is not considered a concern, as it remains within the 'large' range that Smith (2011) deemed appropriate, as he suggests a large sample size for IPA is commonly between eight and 10 participants.

Participant Selection

Hospice nurses were recruited by posting flyers and attending staff meetings within hospice organizations (Appendix C). All participants met the following criteria: (1) currently employed as a Certified Nursing Assistant (CNA) or Registered Nurse (RN) for a hospice organization; (2) work in hospice services, with direct patient contact, for one year or longer; (3) work with hospice patients older than 65 years of age; (4) provided services for one older adult patient who utilized hospice for less than two weeks and one older adult patient who utilized hospice for more than four weeks; and (5) over the age of 18. Exclusion criteria included: (1) previously been a participant in research with the primary researcher and (2) currently working as a nurse for a different type of setting. One participant was excluded due to currently being a social worker, rather than a nurse, within a hospice organization.

Nine of the 10 participants self-identified their gender identity as female, with the participant with the pseudo-name Steve being the only male participant. Eight of the 10 self-identified their ethnic heritage as White/non-Hispanic/European American. Bernie and Adelyn reported their ethnic heritage was multiracial. As can be seen in table one, participants' ages range from 31 to 70 years of age. Two levels of the nursing staff are represented, although there are more RNs than CNAs. The participant sample had more individuals who worked in their current position for one to five years as well as more participants who worked in hospice, total, for six or more years. A range of higher education levels was present. The 10 participants, at the time of their interviews, worked within three different hospice organizations in Northern Colorado, as seen in table one. All three organizations are independent, not-for-profit hospice organizations.

Table 1.
Demographic Information of Participants

Participant Pseudo-Name	Age Range	Job Title	Level of Education	Current Organization	Time Worked in Current Organization	Total Time worked in Hospice
Elizabeth	41-50	RN	Associate's Degree	Organization 1	1-5 Years	6-10 Years
Elise	61-70	RN	Bachelor's Degree	Organization 2	1-5 Years	21-25 Years
Bernie	31-40	CNA	Some College	Organization 1	1-5 Years	11-15 Years
Melanie	41-50	CNA	Associate's Degree	Organization 3	11-15 Years	11-15 Years
Kirsten	31-40	RN	Bachelor's Degree	Organization 3	1-5 Years	11-15 Years
Rachel	41-50	RN	Some Graduate School	Organization 3	1-5 Years	6-10 Years
Steve	61-70	RN	Some College	Organization 3	6-10 Years	6-10 Years
Adelyn	41-50	RN	Bachelor's Degree	Organization 3	1-5 Years	1-5 Years
Crystal	51-60	CNA	Some College	Organization 3	11-15 Years	11-15 Years
Molly	31-40	CNA	Some College	Organization 2	1-5 Years	1-5 Years

Data Collection

The 10 participants were interviewed by the primary researcher. One in-depth, semi-structured interview was done with each participant. These interviews were audio recorded and transcribed by a senior-level research assistant. The audio recordings and transcripts were kept in a locked file on a locked computer and will be destroyed appropriately to retain confidentiality. The interviews occurred in a private area of the participant's workplace, researcher's office, or similar private location.

Participants were first informed about the study and reminded they were able to leave or end the interview for any reason and at any time. They were assured of their confidentiality and informed of their rights as a research participant. To further ensure confidentiality, participant names were not utilized after the recording began. The participants began by answering questions of a verbal demographic survey (Appendix A), which was not audio recorded, to ensure confidentiality. This demographic survey was created based on previous surveys used with long-term care nurses and lasted approximately five minutes.

The interviewer then had a general list of open-ended questions (Appendix B); emphatic reflections, probes, and follow up questions were used as deemed appropriate to facilitate discussion. Participants who wished to say more on the topic were given the opportunity (Brocki & Wearden, 2006). The interview length range, not including the demographic portion, was 40 to 65 minutes.

The questions and probes (Appendix B) used in the interviews were created based on a review of the literature and discussions with experts who have extensive experience in hospice settings and qualitative research design. The questions were created to develop an understanding of the nurses' experience with patients who utilized hospice for less than two weeks or more than four weeks. More specific questions, including items such as the differences seen between these patients and their end-of-life experience, were formulated to elicit more detail about end-of-life experiences and the meanings created by them. When asking about previous patients, only patients who had already died were discussed, to allow for a fuller understanding of their end-of-life experience. Allowing the participants to add more unstructured information led to a richer discussion of their main concerns, experiences, and the meaning they have found during their work with older adults in hospice. The Colorado State University Institutional Review Board approved all procedures.

DATA ANALYSIS

Interpretative Phenomenological Analysis

IPA was utilized to extract themes and meaning from all interviews (Smith, Jarman, & Osborn, 1999; Smith, 2011). IPA is not a rigid method, but there are guidelines with the primary aim being to describe an experience and its meaning across multiple people, in this case end of life and length of hospice use, as experienced by hospice nurses (Eatough & Smith, 2008). NVivo version 10 qualitative software was used to assist in the data analysis.

Although flexible, IPA guidelines are provided to assist in data analysis of the chosen experience; this study utilized the IPA guidelines provided by Smith, Jarman, and Osborn (1999). According to their guidelines, there are five stages to the analysis; a sixth stage was added by the primary researcher after extensively learning about IPA and utilizing this method in a previous study. Due to the flexibility of IPA, adding stage six is a welcome addition to continue to stay aware of bias (Eatough & Smith, 2008). These methods are the same as those utilized in Aeling and Vacha-Hasse (2016).

Stage One. A senior-level research assistant transcribed all audio recordings verbatim. All transcripts were compared to the original recording by the primary researcher, resulting in each transcript being initially reviewed by two individuals. The primary researcher then read the transcript twice to become familiar with the content and subjective interpretation before any formal analysis began.

Stage Two. After the initial familiarity readings, transcripts were read line-by-line while the primary researcher made note of anything significant, in that it pertained to the experience of end of life or hospice use. After those notes were completed, the transcript was read again line-by-line, and emerging themes that reflected a broader level of meaning were noted. Each transcript was coded in this manner, with each statement and theme having equal importance; no hierarchy of meaning was created yet.

Stage Three. After all transcripts were coded, the transcripts were compared to each other and these notes were organized into clusters of similar statements and themes from all transcripts.

Stage Four. The primary researcher then determined if these themes could be reduced into categories that are more inclusive and if there were “master themes” that encapsulated multiple subthemes found while coding. Themes that were mentioned in more transcripts were considered “stronger” themes.

Stage Five. To be sure meaning formation was representative of the participants’ experience; the primary researcher continually evaluated and reevaluated the meaning and theme formulations based on the original transcripts. The themes that did not fit after reevaluation were dropped. After completing the aggregated formulation of meaning, thematic deduction, and organization, themes were then referred back to the original transcripts for validation and refinement. A senior level research assistant also reviewed all forming themes at this point to ensure that quotes chosen fit within the themes presented. Based on the criteria set forth by Smith (2011), the primary researcher considered a code a theme or subtheme if it is present in four or more interviews.

Stage Six. To ensure credibility and reduce bias, each transcript was read an additional two times after the previous five stages are completed. Each transcript was read one additional time to ensure that the inclusive categories and master themes created in stage four and five fit within all interviews and were coded correctly. After primary write-up begins, each transcript was read one last time specifically searching for codes or sections that negate the forming themes to ensure that the codes are truly present in the interviews and not the effect of bias.

During these stages, the primary researcher continuously peer debriefed with the research assistant, as previously discussed. In stage five, the research assistant was asked to review all codes to ensure meaning within a code was homogeneous and to reduce bias. Additionally, after analysis was completed, this research assistant read the forming results section to ensure her interpretation matched that of the primary researcher. In the following results and discussion, the term ‘participating nurses’ is an inclusive term used to describe the entire participant pool, including both the RNs and the CNAs.

Content Analysis

During the process of coding, it became apparent that elements of the data presented information did not fit within the IPA framework. IPA, as already discussed, focuses on the meaning of a shared experience. A small subset of data regarding a specific patient’s death did not fit within this framework, but still presented important information and allowed for a direct comparison between a short- and long-use hospice death. Due to this data not fitting within the IPA model, content analysis was performed for this subset of data. Content analysis was performed using the guidelines provided by Hsieh and Shannon (2005). This subset of data will be known as a ‘noteworthy concept’ in the following results and discussion sections.

Stage One. Verbatim transcription occurred as described in stage one of the IPA process. Data analysis began by the primary researcher reading the subset of data twice to become immersed in the meaning and content.

Stage Two. Data were then read word-by-word by the primary researcher to create codes that captured key ideas, thoughts, and concepts. In this case codes that pertained to how the death occurred, services utilized, and length of stay.

Stage Three. The primary researcher created labels for codes that were reflective of more than one key idea, thought, or concept.

Stage Four. The codes and labels were then organized and sorted into broader meaningful categories. The codes within each category were counted and compared to determine which has more support based on the present subset of data.

For all data, regardless of coding method, matrix coding in NVivo was utilized to determine if the type of nursing position had an effect on the themes and subthemes presented. This was the same process utilized in Aeling and Vacha-Haase (2016). Due to the unequal and small numbers of each nursing position within the participant pool (six RNs, four CNAs) the researcher used percentage of each nursing position that endorsed a certain theme, out of total participants in that same nursing position, for comparison. For example, if three RNs endorsed a subtheme the percentage was 50%. If four CNAs endorsed a subtheme that would be 100% of the individuals in that position. This was done for every theme and subtheme. If there were 42 percentage points or more between the percentage of RNs and CNAs who endorsed a theme or subtheme, this was considered a difference based on nursing position. This cut off was created based on a review of the differences between all the subthemes for each nursing position; at 42 percentage points the differences appeared to be practically significant. There are differences of this size noted in five subthemes. These are indicated in the following results and discussed further in the conclusion.

FINDINGS

Seven major themes emerged with each major theme having a number of subthemes (Table 2). The first major theme to emerge was how positively the participating nurses view hospice, finding it beneficial for patients and their families. The second major theme was that participants were aware of a stigma surrounding hospice care, particularly among older adults and their family members. Although this stigma was clear, many of the participating nurses believe it had begun to and will continue to decrease. The third major theme that emerged, which was based on the participants' experiences and perceptions, was that patients viewed hospice differently depending on their length of use. Patients were more likely to view hospice negatively before utilizing services and more likely to view hospice positively after receiving services for a longer period. The fourth major theme discussed aspects that impact the length of use. The fifth major theme revealed participating nurses' frustration with Medicare. Sixth, the participants explained that in their experience, longer hospice stays are more positive than shorter. The last major theme that was noted was that more education is needed regarding hospice services.

In addition to the seven major themes identified above, two additional noteworthy concepts emerged. Participants were asked to share a specific story of one patient who died after using hospice for less than two weeks and one patient who died after using hospice for more than four weeks. Differences arose in two major areas. First was whether the death was a 'good' or 'bad' death with the second being actual services utilized during end of life. When compared to the length of hospice use, these concepts became an important point of comparison. This data will be discussed and presented in figure 1 and figure 2.

Table 2.
Common Themes and Subthemes in Participants' Experiences of Hospice Services and their Interpretations of Older Adult Patients' Experiences. Frequency of these Themes and Subthemes in Number of Participants Endorsing it.

Themes/Subthemes	**# of Participants**
Hospice Nurses View Hospice Positively	*10*
Physical Comfort and Medication	8
Emotional Comfort and Support	7
Family Support and Services	7
Quality of Life	6
Holistic Care	5
Attention and Presence	5
Team Approach	5
Choices and Independence	4
Home Death	4
Spiritual Support	4
Appropriate Length of Hospice Use	See text
Hospice Nurses Noted a Stigma Against Hospice	*9*
Older Adults' Stigma	8
Family Members' Stigma	6
Stigma Will Decrease	5
Older Adults' Perspective is Impacted by Length of Use	-
Older Adults' Negative Perspective	8
Dying Immediately	7
Actively Going to Kill Them	6
Giving Up	5
Older Adults' Positive Perceptions	10
Comfort	7
Good and Personalized Care	5
Relationships	5
Aspects that Impact Length of Use	-
Lack of Knowledge	9
Inability to Predict Death	7
Denial	6
Late Referrals	6
Facility	-
Longer due to Being in a Facility	6
Shorter due to Being in a Facility	4
Long Hospice Stays are More Positive than Short	*10*
More Positive Relationship with Nurse	10
Personalized Care	8
Less Likely to be a Crisis Situation	8
More Services Utilized	6
More Conversations about End-of-life Preferences	6
More Emotional Support	5
More Family Support	5
Better Pain Management	4
Education	*10*

More Education Needed	9
Can “Graduate” Hospice	6
Not Just about Death	4
Frustration with Medicare	*7*
Additional Noteworthy Concepts: Analysis of Specific Stories	
Length of Stay compared to Aspects of a ‘Good’ and ‘Bad’ Death	See Figure 1
Length of Stay compared to Services Utilized	See Figure 2

Hospice Nurses View Hospice Positively

All 10 participants stated that, based on their experience, hospice is a very positive service. No participants mentioned a negative impression of hospice when discussing their own perceptions. For these participating nurses, hospice meant ten positive aspects: physical comfort, emotional comfort, family support, quality of life, holistic care, positive relationships, providing an entire ream, independence, allowing for a home death, and spiritual support.

Physical Comfort and Medication. Eight out of 10 participants expressed that physical comfort and medication are important aspects of hospice services. As Elizabeth stated, “[hospice] means helping with pain and symptom management… pain is something we do every day and so I think we’re better at it than [non-hospice care].” Elise shared,

> I just feel like people don’t need to suffer during the dying process… [hospice can provide] the higher level of care for pain control. … [Long term care] facilities can see that we [hospice] can come in on a daily basis, monitor pain, and call the pharmacy consult and tell them how [the patient is] doing.

Additionally, Molly said hospice is able to “get them the right comfort medications, get them the right products in their house that they need to make those last transition weeks work better.” Adelyn mentioned that physical pain is important to understand, but that hospice can also assist patients with other symptoms, such as shortness of breath.

The physical comfort portion of hospice was an important subtheme for these participating nurses. As Elizabeth clearly stated, “people don’t need to [physically] suffer during the dying process." Keeping patients free of pain, and therefore alleviating one of the previously discussed fears of the dying, was an extremely important aspect of hospice services to these participating nurses. Physical comfort and medication was a subtheme that had a difference based on nursing position. More RNs (100%) endorsed the subtheme than CNAs (50%).

Emotional Comfort and Support. Seven of the 10 participants discussed emotional support and comfort for the dying individual as a primary definition of hospice. While this subtheme has some overlap with later subthemes, all seven participants explicitly endorsed the importance of providing support to the patients' emotional needs.

As Adelyn stated, "making days the best they can be [includes] not just physical comfort, but emotional." This emotional comfort was described in varying ways. Molly explained that she provides comfort by providing education: "this is stuff they've never encountered before… they don't know why their bodies are changing and I like to be able to explain that to them… [then they] can be a little more emotionally comfortable with what to expect." Adelyn explained that hospice means, to her, "emotional support, you know, did they have regrets? Do they have loose ends? Do they have issues going on with family members? Things they still want to do?" Participants stated that they, as nurses, are often the ones to provide this emotional support, but only up to a point. Steve explained this concept well: "we [nurses] do the psychosocial and emotional aspect of it [hospice], but we have our boundaries. When it gets past a certain point we turn that over to our social workers or our chaplains."

Family Support and Services. Seven out of 10 participants expressed that, to them, a main purpose and meaning of hospice was to provide support to the family of the dying individuals. As Elise stated "[hospice] impacts their families and loved ones, whatever family is defined as for them… as hospice we treat the patient and the family." Bernie explained how family support can come in many forms including relieving family members of some duties, explaining what is happening, helping them with their fears, having open conversations, and reassuring them. Rachel added that this family support extends even to families that are not directly involved in caregiving: “[families] get the reassurance that someone is checking on their loved ones and they’re able to live a more, a semi-normal, life.” For family members who are involved in care, Molly disclosed that she “go[es] in and help the families learn how to take care of their loved one at home and give them the confidence to do that so they can honor the wishes of their loved ones.”

Quality of Life. Six of the 10 participants stated that hospice meant adding quality of life to the remaining days of life. As Adelyn clearly stated, “to me it [hospice] means improving people’s quality of life for however long they have left… just making those last days, months, weeks - even years sometimes - the best they can be.” When asked what hospice meant to her, Kirsten clearly expressed that “[hospice] means choosing to put your quality of life first.” Quality of life is a subtheme where a difference was noted based on nursing position, with more RNs (83%) endorsing it than CNAs (25%).

Holistic Care. Five participating individuals brought up the idea of hospice meaning holistic care. As Steve explained, “hospice is about as close to a holistic nursing model as you can find.” When asked to elaborate he explained this meant care that included physical comfort, emotional comfort, spiritual comfort, and services for the family members. Elizabeth shared that to her hospice meant “caring for the whole person… caring [for them] on every level.” She also identified physical, spiritual, and emotional aspects as all included in this holistic idea.

Attention and Presence. Five of the 10 participants talked about their presence in the dying individual’s life and the added attention they provide. As Bernie stated, hospice means "being with people… they [patients] just want someone to be there." Kirsten discussed how her "presence in their lives at the end… it can make a difference… physically and emotionally being there for them." Crystal stated:

> I wish everyone could have the extra attention… and that can mean so many things, taking them for a walk, just hand holding, just the extra attention. I find that at skilled nursing and assisted living they sometimes don't get that extra little attention, which I think is a really good [part of hospice].

Team Approach. Five of the 10 participants discussed the importance of the team approach provided by hospice. Participating nurses discussed the importance of the pharmacy consults, nurse practitioners, social workers, chaplains, volunteers, and doctors all provided by hospice. Kirsten argued that: "one of the greatest things about hospice care is an interdisciplinary team." Steve added,

> [patients] are able to utilize everyone here in the organization. It's all a good team and collaboration. If I think they need a social worker I'll say "Hey, how about letting me have a social worker give you a call?" and then I'll leave a note for the social worker. When I think they need to visit with the chaplain, same thing. Works really well that way.

Choices and Independence. Four of the 10 participating nurses discussed how hospice services provide patients with more choices and independence regarding their end-of-life care. As Elise said, "[patients] can go in and out of the program. They can use another hospice within the certification periods, if they choose to change hospices. I love options. I love giving people choices." Kirsten explained that hospice "puts our patients and families at the center of their care telling us what they want… patients or whoever you're talking to are saying exactly what they want, and what they want is hospice." Adelyn discussed how hospice provides patients with choices and allows them to have the final say regarding their end-of-life care. As was discussed in the introduction, loss of independence is a major fear of the dying, suggesting that based on these nurses' perceptions, hospice helps to ease this fear.

Home Death. Four of the 10 participants explained that hospice meant ensuring patients are able to die at home. Elizabeth put it clearly. When asked what hospice means, she stated "making sure they die at home." Kirsten explained that the major meaning of hospice is ensuring that patients "can live longer at home more comfortably." Crystal added that the patients' home may sometimes be at a nursing home. She explained:

> I used to think "why don't they move them out of here [their nursing home]?" … The pictures they have, the feeling they get there, the same caregivers coming in, that is their family. That is why they don't move them out of there, that is their home.

She went on to describe that hospice helped maintain the patient within their home, regardless of what "home" meant to that patient.

Spiritual Support. Four of the 10 participants explicitly stated that the spiritual aspects of hospice were important. Steve stated that he "connects with [patients] in a spiritual way" which allowed him to provide better care. Crystal explained that she connects with patients on a spiritual level no matter their faith. She explained how she tries to:

> have their [religious] material around. I'll just read it to them, whatever their faith is. I support their faith… If it's important to proselytize people, I'll let them proselytize me. What I'm saying is whatever it is, I'll read it to them, because that is their faith and it is important to them.

Appropriate Length of Hospice Use. When asked what the perfect length of hospice use would be, six participants stated it should be used for six months, two stated that more than six months would be preferable, and the remaining three said three months. Of note, CNAs had a tendency to suggest higher lengths of time while RNs more often suggested the current allotted amount of time for services, six months.

Hospice Nurses Noted a Stigma Against Hospice

Nine out of 10 participants noted that they have encountered stigma against hospice services. While this stigma was noted across a number of individuals in the public, older adults and their family members were most often mentioned regarding this stigma. The stigmas present will be discussed later in these results while discussing older adults' negative perceptions of hospice services. It was also believed by five participants that in time this stigma will decrease.

Older Adults' Stigma. Eight out of 10 participants discussed how they believe older adults have a stigma against hospice. Elizabeth put it clearly: "unfortunately, I feel there is a stigma attached with hospice [to my older adult patients] … you have to debunk some of those stigmas attached to hospice." Elise stated: "a lot of older people were exposed to that [stigma] or they see the impressions on TV. That it is the H-word." Bernie explained, "a lot of patients… would say no because they heard the word hospice." Different aspects of this stigma will be discussed below, when discussing older adults' negative perceptions of hospice services.

Family Member Stigma. Six of the 10 participants endorsed the idea that family members of their older adults' patients have a stigma against hospice. Often this stigma is related to protecting their dying family member. For example, Elise explained that families may say "don't bring up hospice, just use a different word." Adelyn reported that she had:

> met family members, maybe adult children or grandchildren, that say "don't tell Grandma because if she hears the H-word, she might just give up." Or [families will say] "she [grandma] will think we're giving up on her." I have met a few older adults who might feel the same way, but for the most part it's the family.

Rachel simply noted, "there is a stigma in the general population and around family members."

Stigma Will Decrease. Five participants discussed that they believed the stigma related to hospice would decrease with time. Elizabeth stated, "the baby boomers, they're hopefully a lot more educated… [hospice] is a bigger focus, there is more access to information… they are going to be more informed." She went on to explain how she has seen a decrease in the stigma over the past five years and hopes it will "keep on that continuum." Bernie explained that the more individuals who use hospice, the more positive things will be said about services, which will lead to more individuals choosing to utilize it. Kirsten shared:

> when you approach it with "we have a birth plan and we have a death plan" and all the stuff in between, you have time to decide it, and decide what we are going to do. So the stigma for me is what I like about my job, we're changing it and it's getting better… we have stronger voices now… we're talking about it.

Older Adults' Perspective is Impacted by Length of Use

When nurses were asked what they believe hospice means to their older adult patients, both negative and positive aspects were mentioned. It was made clear by the participants that these perceptions change depending on the older adults' length of use. Before an individual begins utilizing services, their perspective was more negative, according to the participating hospice nurses. After an individual has been on hospice for a longer period of time the meaning of hospice became more positive.

Older Adults' Negative Perspective

Eight participants discussed older adults' negative perspective of hospice. These topics were often discussed after talking about the stigma around hospice, as mentioned previously. The negative perspectives discussed were older adults' belief that if they utilize hospice they would die immediately, the belief that hospice will administer something that will actively kill them, and that hospice means giving up. Based on the participating nurses' experiences, these negative views were reportedly more common before someone was on hospice services or shortly after beginning use.

Dying Immediately. Seven out of 10 participating nurses expressed that, based on their experience, older adults often believe if they used hospice services they were going to die immediately. As Elizabeth stated, older adults "really do think [hospice] is for: I'm dying today." Melanie explained that she believes older adults think that hospice means "this is the end… there is a lot of misconception I think out there regarding what hospice means." Molly expressed that, to older adults, hospice means a "death sentence." Adelyn felt older adults believe "that [hospice] is the very end, the minute you sign up it means you're dying tomorrow."

Actively Going to Kill Patients. Similar to the idea of dying immediately, six participants discussed how older adults believe hospice is going to administer a medication that will actively kill them. Elise explained how older adults believe hospice will "come in and administer something so that it's over at that point." Bernie added that older adults think, "they come in, get morphine, and die. In one day." Melanie reported a similar experience that older adults fear that "we do our thing and the next thing you know the person [is] done… that we go in and kill people." Adelyn stated older adults believe "[hospice is] going to give somebody a hundred milligrams of morphine and that's going to be the end." She explained how she has had patients sign up for hospice with this assumption, "they think we are going to overdose them, like it's assisted suicide."

Giving up. Five of the 10 participants stated that to their older adult patients' hospice means giving up on life. Kirsten reported, that to older adults' hospice means "giving up. One hundred percent giving up." Steve explained: "hospice is the last resort… they [older adults] feel like it is giving up… they don't want to give up." Adelyn added "it is the giving up part" that is the biggest stigma that older adults have regarding hospice services.

Older Adults' Positive Perceptions

All ten participants mentioned that hospice has a positive impact on the dying older adults. These positive perceptions included hospice providing comfort, providing good and personalized care, and positive relationships. When a patient had been using services for a longer period, these positive aspects were more common.

Comfort. Seven of the 10 participants discussed how, based on their perceptions, hospice meant comfort to their older adult patients. As Bernie described, when asked about a certain death:

> the whole time the family would be in the room he would kind of say "ehh" "ehh" [sic, retching noises] … to me it was discontent… I made the family leave the room while I was taking care of him… gave him a few minutes of peace and comfort… you could just kind of feel that "ahhhh" [indicating relaxation].

Kirsten and Steve both mention that hospice simply means "comfort" to their older adult patients.

A concept noted by four participating nurses was that in addition to helping with comfort, hospice allows patients to become comfortable enough to die, both emotionally and physically. As Elise stated, "[hospice] makes all the difference, [patients can] start to move toward actively dying. I don't think some could before [hospice] because they were not comfortable enough to let go." Molly explained: "[When they are in pain] their body is still fighting. There is no way it's going to let go." She explained how hospice "ultimately helps [patients] relax enough so they can let go."

Good and Personalized Care. Five of the 10 participants discussed how hospice means good and personalized care to older adults. Bernie explained that to her older adult patients, hospice means getting care "the way they want." Rachel discussed how many of her patients have dementia, but even they know they are "getting good care." She stated her dementia patients will smile at her and she knows that "on some level" they know they are being well cared for. Molly expressed, when asked what hospice means to older adults, "a lot of them view it as just good end-of-life care."

Relationships. Five of the 10 participants discussed how hospice meant new and positive relationships to the older adult patients in their care. As Bernie explained, when asked what hospice means to older adults, “they [older adults] don’t get visits, especially if they are in a nursing home… they love to have someone just sit with them and hold their hand and talk to them. That’s it.” She goes on to explain that within hospice she can provide this, along with other team members. Rachel recounted:

> many times, because I work in a lot of nursing homes, I see a problem with isolation, loss of independence, loss of the ability to do things for themselves, loss of their home… [loss of] everything they’ve known… [Hospice] means a lot more to people in their elderly years who are living in skilled nursing facilities… They are very open to visits. They love to have us come and talk to them and just be with them.

Rachel went on to explain that these new and positive relationships are invaluable because hospice allows the older adults to “feel like they are being seen, and they are not just an old lady sitting in a nursing home. They get to have that personal attention and express themselves in ways that they wouldn’t have an opportunity to.”

Aspects that Impact Length of Use

In each interview, aspects that impact older adults’ length of stay were explored. Participants discussed aspects that lead to a shorter length of use including lack of knowledge, physicians’ inability to predict death, patients’ or their families being in denial, and late referrals. A fifth aspect, being in a long-term care facility, divided participants. Some argued that being in a facility led to shorter stays in hospice, while others found that being in a facility resulted in longer hospice stays.

Lack of Knowledge. Nine participants discussed how less information has led to shorter hospice stays. As Kirsten stated, individuals may have a short hospice stay because, “they may not be aware [of hospice] because no one wants to talk about hospice.” Rachel added that someone may have a short hospice stay because they “did not even have any education on hospice… maybe no one talked to them about hospice, maybe no one mentioned it.” Steve shared that older adults tend to have short hospice stays because “they don’t understand the purpose of hospice.” He explained “if they [older adults] fully understood what hospice does and why we’re here, then they would be on hospice longer.”

Inability to Predict Death. Seven participants discussed the inability to correctly predict death as an aspect that impacts length of use, and can lead to shorter hospice stays. Kirsten explained:

> some patients along the way have heart disease and we know that heart disease can take someone very quickly. Even if we think “they are breathing fine, their blood pressure is good, their heart rate is great,” they could have a heart attack and not wake up in the morning. Or something [else] that can contribute to a shorter length of stay that you would not expect, but it does happen.

She went on to explain how sometimes “it was no one’s fault that they used hospice for less than two weeks.” Rachel added, “sometimes people decline very quickly… there could be a sudden change in somebody’s condition and that would necessitate a shorter stay in hospice.”

Denial. Six participants felt that older adults’ and their families’ emotions may impact hospice length of use. Participants stated that older adults tend to have a shorter hospice stay because they or their family members are in denial about the upcoming death. When asked why older adults use hospice for a short time, Elise stated, “maybe they are in denial mode where they are not going to die, they are just unwilling to think that they may need help.” Melanie discussed how length of stay is:

> up to the individual who’s receiving the information. Some people completely shut down when you try to discuss death. It depends on what level of denial they are in… my experience has shown that it is not so much the patient, but the family being in denial.

Steve explained, “some people are in denial until they get pretty close to the end… Sometimes the family is in denial just like the patient – it can be either way.” When asked why older adults use services for such a short time, Adelyn stated, “they may be struggling with coming to [terms with] the end of their lives, and they are not accepting, or their family [is not accepting].” Melanie described a typical case in which the caregivers are still in denial and unwilling to let their loved one die:

> I’ve seen people whose children are grasping at every last straw. They’ve got a feeding tube down mom’s throat, 50 million liters of oxygen pumping in them, forcing physical therapy, IVs, and they just don’t want to hear the truth. And I think the only one who suffers then is the patient.

Late Referrals. Six participants mentioned that older adults tend to have shorter hospice stays because their doctors refer late. When asked why older adults use hospice for a short time, Elise stated, “it’s simply a problem of late referrals… then we’re called at the last minute… late referrals are really a struggle.” Kirsten added that physicians wait until “they’re laying a few breaths away from death, [then they] call hospice.” Steve shared, “doctors… they want to hold onto that patient for as long as they can. They’re reluctant to give them up… that’s the primary reason [for short stays].” This was a subtheme with a difference present based on nursing position, with more RNs (100%) endorsing it when compared to CNAs (0%).

Long-Term Care Facility. The fifth subtheme, being in a facility, was discussed in contradictory ways. Some participants felt that older adults used hospice for a shorter time due to being in a long-term care facility, while others felt that being in such a facility results in a longer stay.

Six participants felt that being in a facility caused older adults to be in hospice for longer. As Elizabeth stated, “I think that patients that are in facilities have a better chance of getting on hospice because they generally have people around them that are knowledgeable, so they can get care sooner.” Elise shared: “we’re getting a lot of referrals from the facilities because they can see the benefit of the care we provide if we can get in sooner.” Crystal shared that older adults get into hospice early because “assisted living facilities are smart enough to see the decline.”

Four participants discussed the opposite, and contradictory, idea that older adults used hospice for a shorter time because they were in a facility. When asked why older adults use hospice for a short time, Bernie simply stated, “nursing homes… nursing homes don’t like to refer to us because it takes money away from [them].” Crystal felt that nursing homes sometimes wait to refer to hospice because “sometimes [we] get in their way… because we kind of come in and take over.”

Long Hospice Stays Are More Positive than Short Stays

All ten participants stated that having an older adult utilize hospice for more than four weeks allows for a more positive experience than an older adult who is in hospice for less than two weeks. The participants reported that a longer stay allowed for a more positive relationship, death being less of a crisis, utilization of more services, more conversations about end of life, more emotional support, providing more family support, and providing better pain and symptoms’ management. A statement by Elizabeth sums up many of these concepts in one sentence: “with the longer stay patients you can be proactive but with the shorter ones, you have to be reactive.”

More Positive Relationship with Nurse. All ten participants noted that when an older adult used hospice for longer periods of time the patient was better able to create a positive and trusting relationship with the nurse themselves. As Elise stated, when asked what differs when a patient utilizes hospice for a short time, “you just don’t get the rapport. Especially if they’re less than two weeks.” Kirsten stated: “it’s really hard to build that relationships when [the hospice stay] is so short.” Molly mentioned that when a patient is on hospice for longer periods it “makes them more comfortable with you, and you’re more comfortable with them.” Adelyn shared that the biggest difference she noticed between a long stay and a short stay is “that they know you.”

This was often discussed in regards to the trust created in the relationship. Rachel expressed that having a patient for more than four weeks, allows her to “build good rapport and allow them to trust me as their nurse… So that’s a huge thing.” Steve shared:

> when we have longer relationships with those patients there are several things that happen. You build up a relationship with a lot of trust between the patient and the nurse… so when you’re working with them to try and making things more comfortable then that trust plays a big role… that relationship means a lot. Those that you have for a shorter period of time you’re just hoping you got it right… it’s better for the patient and the amount of trust that they are able to build with hospice, it makes the whole process so much easier.

Kirsten added, when an individual uses services for a short time, “they’re not able, and neither are their family, their facility, or their physician, able to trust the [hospice] team.”

This concept of a positive relationship with the nurse was also discussed in regards to how well the nurse knows the patient. Melanie, one of the participating CNAs, shared that the longer an older adult is on hospice the better able she is to:

> bond with that patient, especially on the level of a CNA, because we do such intimate care with these people… you get this level of intimacy… with an early referral you have the ability to celebrate that person’s life with them because you have the ability to share the stories you hear, to hear those stories, and to hear about their life.

Molly stated,

> the ones that come in and are quick, two weeks or less, it’s over really before it began. You don’t understand all the dynamics that are going on in that household or with that patient because you didn’t get a chance to know them. If you see them two times a week for an hour each time, that’s only four hours spent with that person. But if you see them two times a week for four to six months you get to know them on a deeper personal level.

Rachel also shared how this more positive relationship created by longer hospice stays allows her to be a better nurse:

> I feel like if I have a patient for more than four weeks, I get to know them on a more personal level… it gives me a sense of satisfaction to really sit down with them for an hour and listen to them. I get to hear what they have to say. I think for me I'm a better nurse if I have the time to learn about my patients and be with them… the longer I know them the more human connection that is there. And it works both ways, they feel it too, they feel more connected to me and I feel more connected to them.

Personalized Care. Eight of the 10 participants noted a similar concept to relationship, but related it to the individual in hospice receiving more personalized care when they use services for longer. Melanie explained:

> I think the biggest difference [in care between a short and long stay] is if I know someone is stable or just a gradual decline, you don't feel as rushed. You can walk in and get to know them and you can take your time with them and get to know what they like and what kind of care they want. When someone is actively dying and you want in, you're having to juggle a lot of balls.

Rachel added, "I feel like if I have a patient for more than four weeks… I get to know their preference and what they love." And Crystal explained that when an individual is on hospice for longer she knows what type of music to play or what type of prayer to say to make them feel at peace. Molly shared:

> when you have somebody who is on hospice for a long time, you get to know the individual, what they like and what they don't like as opposed to when it is kind of "fly by night" and a real quick thing. You don't get to know their ins and outs…. big picture, when you can take your time, get to know the person, you can make the care more personal… you learn how the person likes their pillows on the bed and stuff like that.

Less Likely to be a Crisis Situation. Eight out of ten participants stated that when an individual utilizes services for a longer period prior to their death, the death is less likely to be a "crisis situation." Melanie said:

> when they use hospice for just a short time, it seems like they get to that point where it's crisis mode and we have to go and intervene to get that person stabilized or comfortable… I would say probably 95% of the time when we get in short length of stay cases, it's crisis mode… you got all this chaos going on.

When asked what difference can be seen between a short and long hospice stay, Rachel answered, “it’s difficult to come in [and provide care] when someone is in their last few hours or days and provide good care. It is a crisis, and hospice should not just be for crisis.” Molly stated:

> it’s kind of a whirlwind when it's less than two weeks; there is a lot of information crammed in a short period of time and changes are happening very quickly in those last two weeks…it’s a lot of people in a very short period of time and it’s overwhelming to the families and the it's overwhelming to the patients definitely… it’s kind of a whirlwind.

Adelyn added that this crisis impacts the patient:

> when you’re there and it's the last week you can walk into a crisis and they don’t know you and it’s hard for them, the whole idea of hospice is new. … it’s just a lot more complicated. When you have been with them for a while it’s an easier road to walk.

More Services Utilized. Six of the ten participating individuals discussed that the longer an older adult uses hospice, the more services they are able to take advantage of. Elise shared that the longer someone uses the hospice the more of a chance she has to:

> try to get my team members to be allowed if they have not been, trying to be creative on how to get the team members in… because we have so many services to be offered… we just have got to be in there and have more time to spend making a difference and offering [services].

When Kirsten was asked what the biggest difference was that she noticed when someone utilized hospice for a short time, she shared:

> the difference would be I don’t feel like they get the full experience… if they use if for longer they’re getting the full experience whereas if they’re using it for a short time the experience is shoved and forced in… they don’t get the full team.

Rachel shared that when someone uses hospice for a short time:

> they don’t get any support from the social workers or the chaplain, they didn’t get the CNA visits, they didn’t get any other kinds of therapy that we have, like music therapy, or volunteer support… [Their family goes] to our bereavement department and then bereavement does not know anything about [the family] because they were not in services long enough.

More Conversations About End of Life Preferences. Six of the 10 participants discussed how when an individual is on hospice for a long period, they are more likely to have time for conversations regarding how the patient wants their death to occur. Elizabeth shared:

> the last two weeks, maybe they are not coherent anymore, you don't really get a chance to really know what their wishes are for the end of life… you have not had time to have those conversations: "who do I want to have in the room," "Do I want to have pain medication?" "Do I like music?" "Do I want to die by myself?"

Kirsten added how these conversations are more likely if the stay has been longer and how these can help the family of the dying individual:

> You're able to have conversations with the patient… you come into their life in a period where it's okay to talk about things and we're not forced to talk about it, so it comes more naturally. You're able to have these conversations with families around, too, so when this happens [family members] are hearing their mother say she does not want a catheter or she does not want to be medicated to the point of being not lucid, even with some pain. You can talk about these scenarios and then there is nothing left to be decided.

This subtheme of having more time to have conversations regarding end of life wishes varied dependent on the nursing position with more RNs (83%) endorsing the subtheme than CNAs (25%).

More Emotional Support. Five out of 10 participants stated that they believed when an individual utilized hospice for longer periods, they experienced more emotional support prior to their death. Steve stated, when a patient is on hospice for less than two weeks, "it's not a long enough period of time for your patient to become emotionally secure… understanding the person helps you provide better emotional support… it all goes back to the same thing, the ability to connect with them emotionally." When asked what the major difference is that she sees between a patient who uses hospice for a short time compared to a long time, Adelyn answered:

> [long hospice] generally has more emotional support… sometimes they just call you and all you have to do it talk them down, no one even needs any medication. They're just

> worried about something and you just need to reassure them… that comes with having worked with them for a while.

More Family Support. Five out of 10 participating nurses stated that the longer a patient is in hospice, the more their family benefits from family support and family services. As Elizabeth stated, when a patient is on hospice for more than four weeks:

> I think it changes that I can be a better support for to the family. I've gotten to know them, they trust me, they know I'm going to do the right thing. When you come in for less than two weeks, they [the family] don't know you. The first week they're meeting ten different people.

Melanie shared that when a patient is on hospice longer, "I become more in tune with the family. You learn about them." In regards to services, Melanie also shared that when a patient uses hospice for a short time, "grief support is lacking [for the family], they don't get the support that they would have gotten had they been in hospice for several months." Steve simply stated: longer hospice stays are "better for the family."

Better Pain Management. Four participants discussed how they feel they are able to provide better symptoms and pain management when an older adult is in hospice for longer periods. As Rachel shared:

> symptoms management can be a huge thing. Sometimes it is difficult to just meet someone and then deal with the symptoms they may be experiencing… [when someone uses hospice for longer] I get to know them and see patterns in their pain and in their symptoms so I can help manage it better.

Steve shared that he simply "need[s] time to get it right… someone who has been on a couple of days, it's like you're using your best judgment as to what is going to work to keep them comfortable." He elaborated saying:

> everybody is different. A drug that may work for one patient may not work for another. [When someone is on longer] you have time to learn what drug you need to use to keep them comfortable for their particular disease and then how to titrate that drug to the level to make them comfortable… a short-term patient, you don't have that time, it's more hit and miss with the short-term patient than it is with the long-term patients.

Education

More Education is Needed. Nine of the 10 participants explained that there is a need for more general public education regarding hospice. Melanie shared, “I wish people had more information. Hospice is not always the end. It’s just supplemental care in case it is your end.” Molly explained:

> I think it [hospice] needs a more public view. Just talk about it in your high schools. Talk about it in colleges. Talk about it in support groups for people who may have a certain kind of illness. Just get it out there, [instead of] just talking about it when you need it.

Crystal explained, “I always think everything is education… [education is needed] for everyone in America… we need to have these conversations with everybody.”

The need for better physician education regarding hospice was also noted. As Elizabeth reported, “I feel like there is a lot of education needed, for America, on what hospice is… I would love for more for education to be given, even to physicians!” Kirsten explained:

> I think hospice is definitely underutilized because people not wanting to have these delicate conversations, and we don’t take the time to do it… We need to educate our physicians to be comfortable having that conversation. And if they’re not having that conversation, giving [patients] the resources to refer the patients to the correct people to talk to.

Can Graduate Hospice. Six of the 10 participants specifically discussed older adults’ need to know they can graduate from hospice. Melanie simply stated, “I need to remind people that you can graduate from hospice.” Molly shared:

> [patients] don’t realize that people graduate off of hospice… there are a lot of people that graduate off of our services… because we are in there giving that extra care, we actually make it to when they don’t need services any longer.

Rachel emphasized how she tells many patients that hospice can lead to them actually feeling better, to the point where they no longer need services.

Not Just About Death. Four out of the 10 participants discussed that older adults need to be informed that hospice is not just about death. When asked what she wished older adults knew about hospice, Bernie stated, “that their life can be extended. How they can have such a better quality of life… letting people know everywhere that it’s not about dying.” Molly added:

> the education piece needs to go on a more public level, to get them to understand that just because you sign up for hospice does not mean it is the end of your life. Just because you sign up for hospice does not mean you are going to die tomorrow.

This subtheme of more education regarding hospice’s other services differed by nursing positions with more CNAs (75%) endorsing this theme than RNs (16%).

Frustration with Medicare

Medicare and insurance was discussed in all 10 interviews. An interesting dichotomy arose in this discussion. When discussing a specific case, each participant was asked if Medicare or insurance had an impact on the patients’ length of stay. For the long stay death, six participants reported that Medicare had no impact on the patients stay and two more reported Medicare had a positive impact. For the short stay death, five reported that Medicare had no impact and one reported having a positive impact. Indicating that regardless of length of stay, most participants stated that Medicare or insurance had no impact on the patients’ stay

However, although participants reported that Medicare had positive or no impact on the specific story of hospice use when asked directly, seven out of 10 participants mentioned general frustration with Medicare. Many participants reported that Medicare prevents them from providing the amount of care their patients deserve. Bernie stated that her biggest frustration with Medicare is “it will only allow us to go certain times a week. When you go in more, you have to justify it… it’s frustrating because I can’t go when I want…I know they need it more.” Rachel shared: “we have patients that are isolated in their home, needing at least once a week visits, and we may have to get out [stop hospice] because they are not dying fast enough. It is a tough situation."

Participants also discussed how Medicare prevents older adults from getting into hospice earlier. Melanie shared:

> getting us [hospice] in earlier is getting harder and harder. Medicare does not help anymore. When you look at our Medicare law the only way you are guaranteed care is if you are 106 years old. Give me a break… The Medicare part is very frustrating. Especially when you have little Tilly who is 98 years old and never been sick a day in her life, and all of a sudden she just gets sick and you've got no supporting diagnosis… it makes it really hard to get in there and it is not fair to the people at all… people are suffering… it's infuriating and Medicare sucks.

Rachel stated: "the whole financial part of hospice, I don't like it. Because it [finances] seems to be the driver, the driving force. What I see is that we have to prove that someone is dying in order to get Medicare reimbursement." Adelyn shared, due to Medicare, she needs to "manage acute symptoms" and then remove patients from hospice if "they are not going to be dying the next day."

This frustration was often discussed in regards to changes in the criteria for receiving the hospice benefit. As Elise shared "the government has gotten pretty strict with using the dementia [diagnosis], we used to be able to use failure to thrive, now it's different." Melanie also stated:

> I have a certain level of frustration because of the criteria changes that was huge because we had to discharge so many people who were benefitting and they were all older because we lost the ability to use adult failure to thrive and declining clinical condition… it's more frustrating to get people the care they need, especially early on.

Although this frustration was apparent, participants expressed that they are aware of Medicare fraud and how this has impacted the rules. As Melanie shared, "there is a lot of fraud out there, too, so it's hard. They [Medicare] had gone from one extreme to the other… there has got to be a happy middle, but the government won't figure that out." Rachel shared, "Medicare fraud does happen… I understand the regulations… but when things are so money-driven… the human aspect gets lost."

Additional Noteworthy Concept: Analysis of Specific Stories Shared

Participants were asked to describe the specific death of one older adult who used hospice for less than two weeks and one older adult who utilized hospice for more than four weeks. Nine participants shared a story of each length of stay. One participant was uncomfortable sharing specific stories because their self-care technique was not remembering the names and faces of the patients that have died. This subset of data was coded using content analysis, as previously described.

Length of Stay Compared to Aspects of a 'Good' and 'Bad' Death. These stories were coded for aspects commonly included in a 'good' death or a 'bad' death as determined by reviewing the stories told as well as reviewing previous literature (Masson, 2002; Singer, Martin, & Kelner, 1999; Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tulsky, 2000) according to the content analysis guidelines provided by Heish and Shannon (2005). A number of aspects of a 'good' death were mentioned, including the patient being clean, having their symptoms controlled, in stable condition, able to say goodbye to love ones, and the patient being ready to die. Other 'good' aspects mentioned were: death occurred as the patient wished, death occurred at home, family present and reassured during dying process, nurse having time to provide personalized care, no unnecessary medical interventions to prolong life, and a positive relationship with nurse. The 'bad' death aspects included the patient having difficult symptoms, a drawn-out death, being unaccepting of or unprepared for death, uneducated about the dying process, giving up, and the patient living in an unsafe situation. Other 'bad' aspects included the family not being nearby or the family being burdened, struggling, exceedingly worried, and grieving. Also included as ‘bad’ were: no spiritual support, no relationship with nurse, and unnecessary medical interventions. The stories often had positive and negative codes and clusters, due to the complexity of the dying process. These stories were also coded for short (less than two weeks) or long (more than four weeks) hospice use, based on the length of time the patient being discussed utilized services.

When reviewing the coded ‘good’ and ‘bad’ deaths compared to length of hospice use, a pattern emerged. Due to the small number of participants, a statistical analysis was not conducted; however, the clear pattern and its values are presented in figure 1.

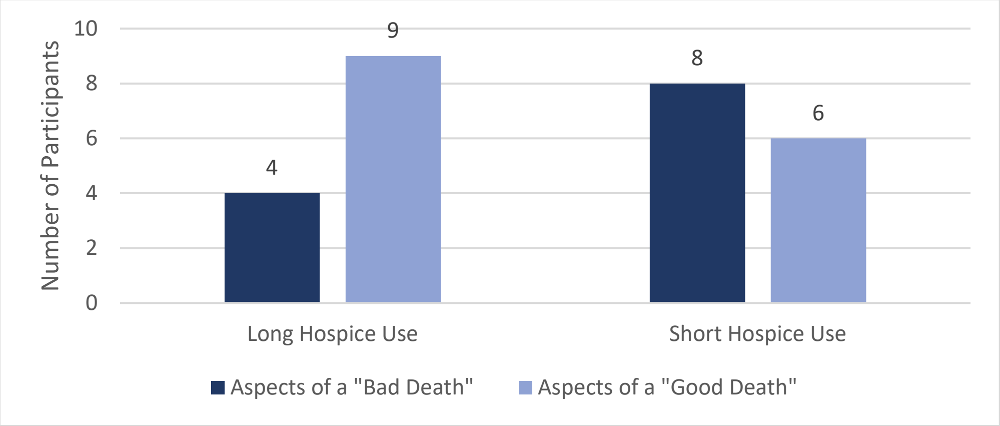

Figure 1.
Comparison of ‘Good’ and ‘Bad’ death in regards to whether hospice was utilized for a long or short period of time.

When looking at the aspects of a ‘bad’ death, many more participants stated that the short-use death contained more aspects of a ‘bad’ death compared to the death utilizing hospice for more than four weeks (eight and four participants respectively). When reviewing the aspects of a ‘good’ death, the pattern is less stark, but still clear. More participants stated that more aspects of a ‘good’ death were present when hospice was utilized for a long period compared to the older adult who used hospice for a short time prior to death (nine and six participants respectively).

Length of Stay Compared to Services Utilized. Using content analysis, these stories were also coded for hospice services that the patient or their families utilized during the end-of-life experience, according to the content analysis guidelines provided by Heish and Shannon (2005). The services discussed within these stories were: bereavement services, educating nursing home staff, family services, feeding assistance, allowing for a home death, providing medication and symptoms management, nursing visits, staying out of the hospital, keeping the patient comfortable, providing peace, personalized care, providing choices, increasing quality of life, showers, spiritual support, supplies, utilizing multiple team members, and emotional support. Services that are included in figure two are the services that more than four participants stated were used for the short stay stories and the long stay specific patient stories. This information shows clearly what the nurses expressed in an earlier section: the longer an individual is on hospice, the more services they utilize.

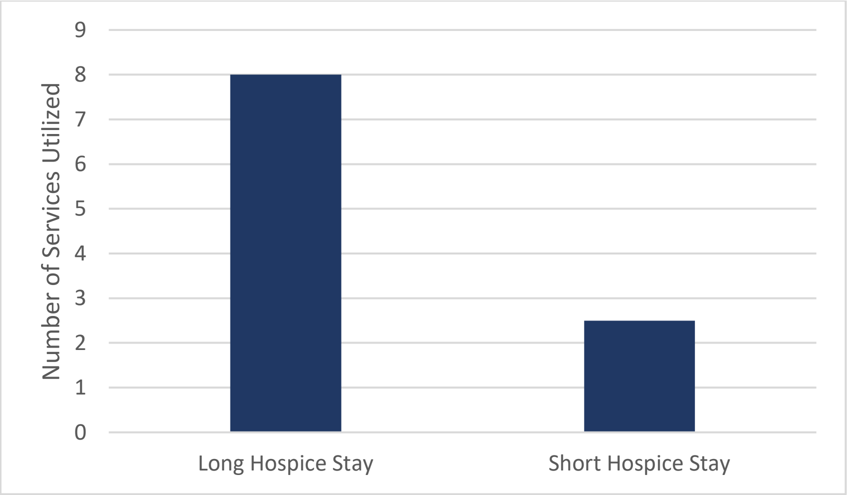

Figure 2.
Services Discussed by more than Four Participants for the long stay and the short stay story.

DISCUSSION

Research Focus

The overarching research focus of this study was to understand the experience and perceptions of hospice nursing staff in working with older adults who utilize hospice services for varying lengths of time. In addition, reviewing if differing lengths of hospice use impacted the nurses' experience of end-of-life care. Results indicated that hospice nursing staff believe hospice to be beneficial and positive regardless of length of use, although participants reported that they could provide a more positive end-of-life experience if a patient made use of hospice for a longer period of time.

The limited prior research on hospice nurses suggests that while they find their job to be stressful, they also find their work to be fulfilling and provides an opportunity to serve a grander purpose (Ablett & Jones, 2006; Evans & Hallet, 2006; Foxall, Zimmerman, Standley, & Captain, 1990; Payne, 2001). These studies indicate that hospice nurses tend to view hospice as positive and fulfilling a need for the dying population. The present study further supports these previous studies and expands on the knowledge provided by hospice nursing staff.

Regardless of the positive meaning of hospice for the participating nursing staff, the present findings suggest that participants perceived that older adults experienced hospice services more negatively, especially prior to utilizing these services. For many older adults utilizing hospice services meant immediate death and giving up on life. Participants also discussed that after an older adult had utilize hospice for a while, their perception of hospice became more positive. After they became familiar with the hospice team, hospice often meant comfort, personalized care, and new positive relationships. Based on the participants' discussion, it was clear that length of hospice use was viewed as having an impact on the perceptions of hospice to their older adult patients.

Although little research was found in the literature review that involved interviewing dying patients on end-of-life topics and no research was found involving patients' phenomenological experiences of hospice services, previous studies have determined what patients are looking for in a 'good' death. The qualities of a 'good' death are similar to what hospice services provide according to the results presented in this study, including pain management, a sense of control, and assistance for family (Masson, 2002; Singer, Martin, & Kelner, 1999; Steinhauser, Christakis, Clipp, McNeilly, McIntyre, & Tulsky, 2000). Thus these results may suggest that hospice usage can help provide a 'good' death.

The present study also focused on trying to understand the differences that nurses perceived between deaths of individuals with differing lengths of hospice use, and whether these differing usage levels had an impact on the older adults' end-of-life experience. Results of the comparisons between death stories suggest that aspects of a 'good' death were more likely and aspects of a 'bad' death were less likely to occur when hospice was utilized for more than four weeks. The comparison of specific death stories also found that in the case of longer hospice use, more services were utilized. This suggests that length of hospice use changed the participants' perceptions and likely impacted the actual end-of-life experience of these older adults.

Lastly, the present study sought to investigate participants' perspective on why older adults utilize hospice services for differing periods. As previously discussed, a number of theories have been proposed regarding why dying patients are not utilizing hospice for longer periods. Prior theories focused mostly on physicians and their discomfort discussing hospice services (e.g., Casarett, Van Ness, O'Leary, & Fried, 2006; Schockett et al., 2005; Waldrop, 2006.) The present study discusses aspects that focused more on patients and families. One aspect that participants discussed was if patients have less knowledge about hospice they are likely to use it for a shorter period. Previous research has supported this finding that older individuals are lacking information regarding hospice services (Mor, Hendershot & Cryan, 1989; Vig, et al., 2010) and are less likely to utilize services due to this (Casarett, et al., 2005). While the present study offers a new perspective on why patients do not utilize hospice for a longer period, these findings relate to the previously mentioned physician-centered theories. Due to physicians' discomfort discussing hospice services, older adults are not being provided the knowledge that could possibly prompt a longer hospice stay.

An aspect found in this study not discussed in previous literature was how emotions can affect the length of hospice use. The present study found that, based on the participating nurses perceptions, patients' and their family members' emotional circumstances and level of denial have an impact on length of hospice use. As previous research has largely focused on physicians, this emotional aspect has been missed in prior literature. Schockett et al (2005) explored how physician discuss diagnoses in positive terms with their patients and how this positive discussion impacts patients and their family members. Positive discussion may support denial if present and may prevent patients and families from facing the severity of their illness. Although there is a connection between these previous theories, such as positive terms used by physician, and the current findings regarding the impact emotions have on length of use and the importance of denial are concepts that have not been reported in prior research. The present results may be the first direct analysis of this idea.

As discussed in the introduction, individuals who are in a nursing home at the time of their death are less likely to utilize hospice services (Taylor et al., 2007). The present results had contradictory information regarding this hypothesis with some participants noting that being in a facility made it more likely that patients will have a longer hospice stay versus others who reported that being in a facility increases the likelihood of a shorter hospice stay. These differences could simply be due to personal experience and workplace differences. It is also possible that current participants had differing views because of the changing trends in nursing home resident hospice use (Miller, Lima, Gozal, & Mor, 2010), and further research in this area is recommended.

End-of-Life Concerns

Prior research indicates two major concerns of the dying: dying in pain and loss of independence. Participants in the present study discussed both of these concerns. They noted that a main purpose of hospice was the physical comfort of their hospice patients and utilizing hospice services for more than four weeks increased the likelihood for better pain management. They also discussed how hospice provides choices for patients and thereby increases their independence. This suggests that the CNAs and RNs that participated in this study believe hospice can help prevent two major fears of the dying. As previously discussed, Heaven and Maguire (1998) found a strong association between these concerns and depression and anxiety during the end-of-life process. This may suggest that if hospice can alleviate these concerns, the mental health of dying individuals may improve.

Benefits of Hospice

Previous research lists a number of benefits of utilizing hospice services. The present study found that hospice nurses report many of the same benefits as discussed in the introduction: pain management, independence, quality of life, less aggressive medical interventions, social interactions, and extending the life of the dying individual. Similarly, and as discussed in the introduction, utilizing services for a longer period had additional benefits for the patient and their family. Present results found that hospice nurses see many of the same benefits when patients use services for a longer period: more services used, better pain management, improved quality of life, continuity of care, and more family support. These nurses' perspectives provide further significant support for the findings of previous research, given that the previous studies are based on caregivers or family members' views.

The idea of having a more positive relationship with the hospice personnel has not been directly researched prior to the present study. Participants in the present study discussed how the length of stay in hospice impacted their relationship with the patient. This was discussed in regards to the patient getting to know the nurse and also the nurse becoming better acquainted with the patient. A more positive relationship between nurse and patient led to more personalized care. The results of this study provide research-based evidence that supports the ideas presented by Raudonis (1995), that the nursing relationship and patients' wellbeing are correlated.

Differences in Subtheme Endorsement Based on Nursing Position

Differences based on nursing position were noted in five subthemes in the present study. More RNs endorsed the following subthemes when compared to CNAs: hospice meant physical comfort; hospice provided a better quality of life; if hospice is used longer, more conversations regarding end-of-life wishes are possible; and late hospice referrals leading to shorter hospice use among older adults. There are a number of possible reasons for these subthemes differences. RNs are more involved in the medication aspect of services; due to certifications needed to dispense medication, this may explain why these individuals discussed the physical comfort of patients more often than CNAs. This physical comfort is likely highly correlated with quality of life, which may explain that subtheme being more endorsed by RNs. CNAs may not have the opportunity to see the immediate quality-of-life change, as they are not administering the medication. Similarly, RNs may have endorsed the subtheme of more end-of-life conversations more than CNAs because these conversations often pertain to medication and the balance between pain and lucidity. Regarding the referral subtheme, RNs are more likely to be involved in discussions with hospice administration. When an older adult begins hospice services, an RN is typically the first individual to visit the patient. Based on this, RNs may simply have more knowledge and discussions regarding an individual's referral.

One subcode had more CNA endorsement than RN endorsement: teaching people that hospice is about more than just death. This difference may have been due to CNAs typically spending more time in face-to-face contact with the patients compared to RNs. For example, CNAs are more likely to do baths or help get individuals out of bed, which are longer face-to-face activities than RNs may have. Those with longer and more face-to face-contact may have simply been more likely to discuss fears regarding hospice and how the patient fears hospice means they will die sooner, leading them to want more education on this topic. These personal care activities are often more personal and intimate, which may lead the patient to feeling more open with the CNA.

PRACTICAL IMPLICATIONS

Education Needed

Although hospice is end-of-life care, the use of hospice does not necessarily mean death will occur in the next few days. Based on the results of the present study, these hospice nurses' interpretation of older adults' experiences was that these patients at first believed that using hospice services meant one is going to die immediately. This suggests that older adults' knowledge regarding the use of hospice services must be increased and specifically knowledge that services can be used for many months during end of life and that utilization of services can actually extend one's life.

The overall lack of information about hospice services for older adults has been cited in previous research. In general, slightly over half of older individuals (53%) are unfamiliar with hospice (Mor, Hendershot & Cryan, 1989). Vig and colleagues (2010) found that older adults and their families often have misconceptions of hospice. They found that these older adults are often unaware of who a "hospice-appropriate patient" is; for example, they believe that a hospice patient needs to be currently and actively dying, be a cancer patient, must be someone without any family to support them, or needs to move to a hospice facility (Vig et al., 2010). Aeling and Vacha-Haase (2016) also found that long-term care nurses believe their nursing home residents do not have adequate knowledge on hospice services, and the knowledge they do have is often outdated.

The lack of knowledge about hospice is further supported by previous research that found physicians fail to discuss hospice with 43% of hospice-appropriate patients (Snyder, Hazelett, Allen, & Radwany, 2012). Additionally, when interventions by physicians are made, they tend to be brief and in close proximity to the patient's death (Anderson, 2014; Snyder, Hazelett, Allen, & Radwany, 2012). This suggests, as do the present results, that older adults lack of knowledge of hospice services. Previous research and the present study support the theory that lack of knowledge is likely one of the major reasons why older adults utilize hospice for short periods.

Suggested Intervention

The results of this study suggest that if older adults knew more about hospice, especially that hospice can be used for months before death occurs and that the use of hospice will not actively cause death, they may utilize these services for longer period. This idea was supported by participants' experiences that patient knowledge influences length of hospice use. These results suggest that creating an informative intervention explaining hospice services to older adults may increase the length of hospice stay.

Participants suggested that such an intervention should take place well before someone qualifies for hospice services. One participant suggested teaching about hospice in high school and college. Providing this information earlier will allow individuals to understand what hospice is and provide knowledge of the necessary use criteria, rather than relying on information provided by their physician. Similar findings were reported in interviews of long-term care nurses in Aeling and Vacha Haase (2016).

While little research regarding extending length of use exists, previous research has found that teaching individuals about hospice services increases hospice use in general. Previous research has indicated that individuals who participate in outpatient services that routinely discuss hospice care (Scheffey et al., 2014), and individuals who create end-of-life care plans in advance are more likely to use hospice services near the end of their lives (Brinkson-

Stoppelenburg, Rietjens, & Van Der Heide, 2014). These previous studies suggest that more information makes an individual more likely to utilize services and this idea may extend to individuals using hospice for longer periods.

Within an informative intervention, emphasizing that hospice is for the end-of-life period, meaning up to six months, and not only for one's immediate death will be an important distinction to make for older adult patients. Stressing the benefits of hospice may also help older adults feel more comfortable using hospice services. Research has identified multiple benefits of hospice services, as already discussed, which could be included in this informative intervention. One of the most important benefits to emphasize may be that the use of hospice can extend a person's life for up to two months longer than those who choose not to use it (Meier, 2011; Temel et al., 2010). The benefit of longer life may help dispel the idea that hospice is "only for the very end" or that hospice will administer something to kill patients.

Overall, if an informative intervention is created based on general knowledge of hospice services and benefits of hospice services for patients as well as their families, then this researcher believes that older adults will be more likely to utilize hospice services and for longer periods. This informative intervention could be presented to both older adults and their families.

Providing this information to physicians would also be an important implication. It was suggested by participants that physicians need to be better informed, which may lead to earlier referrals and more comfort discussing hospice services with patients. Although including primary care physicians in hospice interventions has been shown to be effective in increasing hospice use (Casarett et al., 2005), nurses have far more contact with dying individuals and their families (Dickenson, 2000), and they are more often the facilitators and coordinators between older adults, families, and physicians regarding end-of-life plans (Cramer, McCorkle, Cherlin, Johnson, & Bradley, 2003). Additionally, when hospital nurses have more information on hospice services, they view it more positively, and are more likely to suggest it to those under their care (Cramer, McCorkle, Cherlin, Johnson, and Bradley, 2003). The results of the current study, along with previous literature suggest that it is important to include nurses in the hospice intervention along with primary care physicians and other appropriate medical staff.

THEORITICAL IMPLICATIONS

Contact Hypothesis

Contact hypothesis is a well-known theory that postulates that increased intergroup contact leads to more positive feelings about a different group of people (Everett, 2013). This theory is most often used in regards to discrimination, suggesting that the more time two differing groups of people spend together, the better they will get along (Singal, 2017). An important component of this theory is that the positive feelings regarding another group of people increase if the two groups have similar goals (Allport, 1954).

While this theory has not previously been utilized to describe relationships between hospice nurses and hospice patients, it has been utilized in regards to other medical relationships such as nurses' attitudes toward patients with mental illness (Callaghan, Shan, Yu, Ching, & Kwan, 1997), those with a learning disability (Slevin & Sines, 1996), and patients diagnosed with HIV (Uys et al., 2009). Results of these studies suggest that the more time a nurse spends with an individual with a mental illness, learning disability, or someone who is HIV positive, the more positive the nurse feels about that individual and the group as a whole (Callaghan, Shan, Yu, Ching, & Kwan, 1997; Slevin & Sines, 1996; Uys et al., 2009).

The present study found that nurses feel they have better relationships with patients who are on hospice for longer than 4 weeks, compared to patient who are on hospice for less than 2 weeks. Additionally, the participating nurses reported that the longer an individual is in hospice, the more time they have to talk about end of life plans and goals. The contact hypothesis maybe one explanation for these results, given that nurses are identifying more positive relationship with the patients with whom they have more contact.

Ambiguity Effect

The ambiguity effect proposed that individuals with insufficient information regarding a new situation are less likely to change from their current situation to a new and ambiguous one (Baron & Fris, 1994). Through this effect, older individuals may not use hospice services because, a) they are familiar and comfortable with the situation they are in and, b) the ambiguity and unfamiliarity with hospice services prevents them from using additional services when appropriate.

Previous research has found that individuals who do not use hospice lack basic knowledge regarding hospice and may have misconceptions regarding hospice (Aeling & Vacha-Haase, 2016; Mor, Hendershot & Cryan, 1989; Vig et al., 2010). The current study found supports these past results. Many older adults are unaware of hospice services, and when informed maybe more likely to use the services provided.

STRENGTHS AND LIMITATIONS

The study focused on hospice nursing staff, rather than family members or caregivers. The study also formulated clear operational definitions of hospice, short hospice stays, and long hospice stays. Additionally, the age of the dying individual was limited to over the age of 65. These aspects address some of the limitations of previous research discussed in the introduction.

An additional strength is that the themes and subthemes were found across the three different hospice organizations the participants were chosen from. In addition, except for five subthemes, similar ideas were found across nursing position. This indicates that these ideas and themes were not specific to one organization or nursing position.

One limitation of the present research is that eight participants were of one self-identified ethnic group, nine participants were of one self-identified gender, and all were living in Northern Colorado. Although this indicates that these results are likely transferable to other individuals from a similar background and geographic location, it does not allow for analysis of individuals of more diverse backgrounds. It also prevents a comparison between diverse groups of participants.

An additional limitation was that the themes regarding how an older adult patient feels or thinks about hospice was filtered through nurses' perceptions. Although these nurses likely have a deep understanding of their patients' views, as expressed in the introduction, no older adults were interviewed. It is possible that there was incongruence between the nurses' perceptions and the older adults' actual experiences.

Lastly, it is important to discuss how throughout the present study it is clear that the participating nurses feel they had a more positive relationship when an individual was on hospice for a longer period. Research regarding the nursing relationship is limited and the present results are the first direct attempt to understand this concept. It is possible, though, that the nurses' relationship causes 'rose-colored glasses.' For example, it is possible that the nurses remember long-stay deaths as being more positive due to the strength of their relationship. Conversely, they may remember short-stay deaths as more neutral or less positive due to the lack of relationship. The nurses' may be doing so unconsciously, as it is known that memory can be impacted by a number of factors, including emotion, mood, amount of time present with a stimulus, and level of attention to the stimulus (D'Argembeau, Comblain, & Van Der Linden, 2002; Erk, et al, 2003; Gray, Braver, & Raichle, 2002; Lewis & Critchley, 2003). While there is no way to discern this with the current results, it is an important limitation.

FUTURE DIRECTIONS

More research on hospice, particularly differences based on length of use, should be a focus of future research. Studies should be created to reduce the limitations identified in the introduction: not using family members as participants, having clear operational definitions of hospice and length of use, and limiting the age of the dying individual discussed. Future studies should include large qualitative assessments of hospice nurses' beliefs and knowledge which would allow for more generalizability.

Although this study has clear results of older adults having varied perceptions of hospice, this information is gathered from the nursing participants' experiences, rather than the actual experience of terminally ill older adults. It is important to gain an accurate understanding of older adults' view of hospice by asking them directly. It would be beneficial to do such studies in a longitudinal design, allowing researchers to see older adults' changing perception from prior to hospice use, through less than two weeks of use, and after more than four weeks of use. These studies could be done in both a qualitative and quantitative design to ensure generalizability, while also truly understanding a small number of participants' experiences.

Two themes in the present study generated conflicting views and could benefit from further research. First, participants expressed extreme frustration with Medicare while stating that within a specific case, Medicare had no impact on an individual's hospice use. Second, the impact of long term care facilities on length of hospice use differed. The reason for this discrepancy in perceptions of length of stay and implications of Medicare should be further studied to allow clarity not provided by the present study.

Additional research on the previously suggested educational intervention for older adults will also be of benefit. Researchers should determine if such an intervention truly would affect the length of hospice use by older adults. Also, it is important to determine if different interventions lead to different outcomes, such as providing information to individuals before they are diagnosed with a life-shortening illness rather than after such a diagnosis.

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APPENDIX A: DEMOGRAPHIC SURVEY

Thank you for your willingness to be part of this study
In order to participate in this study, you must meet the following criteria:

- You must be currently working on the nursing staff (i.e. CNA, RN, LPN) within a hospice organization
- You must have worked in hospice, with direct resident contact, for one year or more
- You must have experienced the death of an older adult patient who utilized hospice for less than two weeks and the death of an older adult patient who utilized hospice for more than four weeks
- You must be 18 years of age or older.

1. **Gender Identity:** ____
2. **Age:** ____
3. **Ethnic Heritage**: ____
4. **Religious Affiliation:** ____
5. **Job Title:** ____
6. **What type of organization do you currently work for**: ____________________
7. **Highest level of education:** ____
8. **How long have you been working in Hospice?** ___________________________
9. **How long have you been working in your current position?** ______________

May I contact you later in the research process to do a member check? To do this, I will e-mail you a copy of the typed transcription of today's interview for you to review. You can let me know if there is any incorrect information in the transcript, leading to more accurate results.

If yes - Please write your e-mail here:

____

If no - continue to next question

After the research process in complete, would you like a copy of the typed results for your own personal knowledge?

If yes - please provide your e-mail here:

____

If no - continue with interview

APPENDIX B: INTERVIEW PROTOCOL

Hello! Thank you for participating in my study. As a reminder, if you wish to end this interview at any time for any reason you have the right to do so. Also, this interview is being recorded, and the recording will be held on a locked computer and will be deleted in an appropriate manner after the completion of this study. Do you have any questions before we begin?

This interview will have two parts. For the first part of this interview, I am going to ask you questions regarding your general experience of hospice, specifically when working with older adults over the age of 65. For reference, a short hospice stay is considered anything <u>less than two weeks</u> and a long hospice stay is considered anything <u>over four weeks.</u>

1. What does hospice care mean to you?

    Tell me more about what hospice means to you

    Could you explain the meaning a little more?
2. What, do you think, hospice means to your older adult patients?

    Tell me more about what hospice means to your patients

    Could you explain the meaning a little more?
3. What is your experience with why older adults might choose to utilize hospice?

    Explain more about why patients choose to use hospice

    What do you mean when you say….
4. What is your experience with why some older adult patients utilize hospice, but for a short period of time? As a reminder, a short stay is considered under two weeks.

    Explain a little more about why

    Tell me more about why patients have short hospice stays
5. What, if any, differences in care have you noticed when an older adult utilizes hospice for less than two weeks?

    What other differences have you noticed?

    Tell me more about the differences when hospice is used for a short time

6. What is your experience with why some older adult patients utilize hospice for longer periods of time? As a reminder, a long stay is anything over four weeks.
   - Explain a little more about why
   - What do you mean when you say…
7. What, if any, differences in care have you noticed when an older adult utilizes hospice for more than four weeks?
   - What other differences have you noticed?
   - Could you share a few more differences?
8. How does a patients' length of use change what hospice means to you, as a nurse?
   - Explain a little more about how the meaning changed for you
   - What do you mean?
9. How does a patients' length of use change what hospice means to the older adult patient?
   - Explain a little more about how the meaning changed for your patients
   - Tell me more
10. Based on your experience, what do you believe an appropriate length of hospice use is?
    - Why did you choose that length?
11. What else would you wish to say regarding hospice services or length of stay within hospice?

Now, I am going to switch focus and ask you to think about two older adult patients whom have died that you knew well near the end of their life. One older adult who used hospice services for less than two weeks and another who utilized hospice for more than four weeks. Please take a moment to think of these two patients.

1. First, let's talk about the older adult patient that you knew fairly well whom you worked with who utilized hospice for less than two weeks.
   a. What do you recall about this individual?
   b. Tell me about his/her death
   c. What was the setting in which this patient received hospice care?
   d. What stood out most about his/her end of life experience for you?

    e. What did hospice mean to this individual?
    f. How did hospice play a role in his/her end of life care? (Possible Probes)

        If hospice did not play a role/played a limited role:

            Why do you believe hospice did not play/played a limited a role?

            What could hospice have done differently to play a more significant role?

    g. What, do you believe, led this individual to utilize hospice for less than 2 weeks?
    h. Do you believe this patient could have benefited from using hospice for a different period of time?
    i. Why did you choose this person? (Possible probes)

            What made him or her come to mind when I asked you to select one resident?

2. Now, think about the older adult patient that you knew fairly well whom you worked with who utilized hospice for more than four weeks.
    a. What do you recall about him/her?
    b. Tell me about his/her death
    c. What was the setting in which this patient received hospice care?
    d. What stood out most about his/her end of life experience for you?
    e. What did hospice mean to this individual?
    f. How did hospice play a role in his/her end of life care? (Possible Probes)

        If hospice did not play a role/played a limited role:

            Why do you believe hospice did not play/played a limited a role?

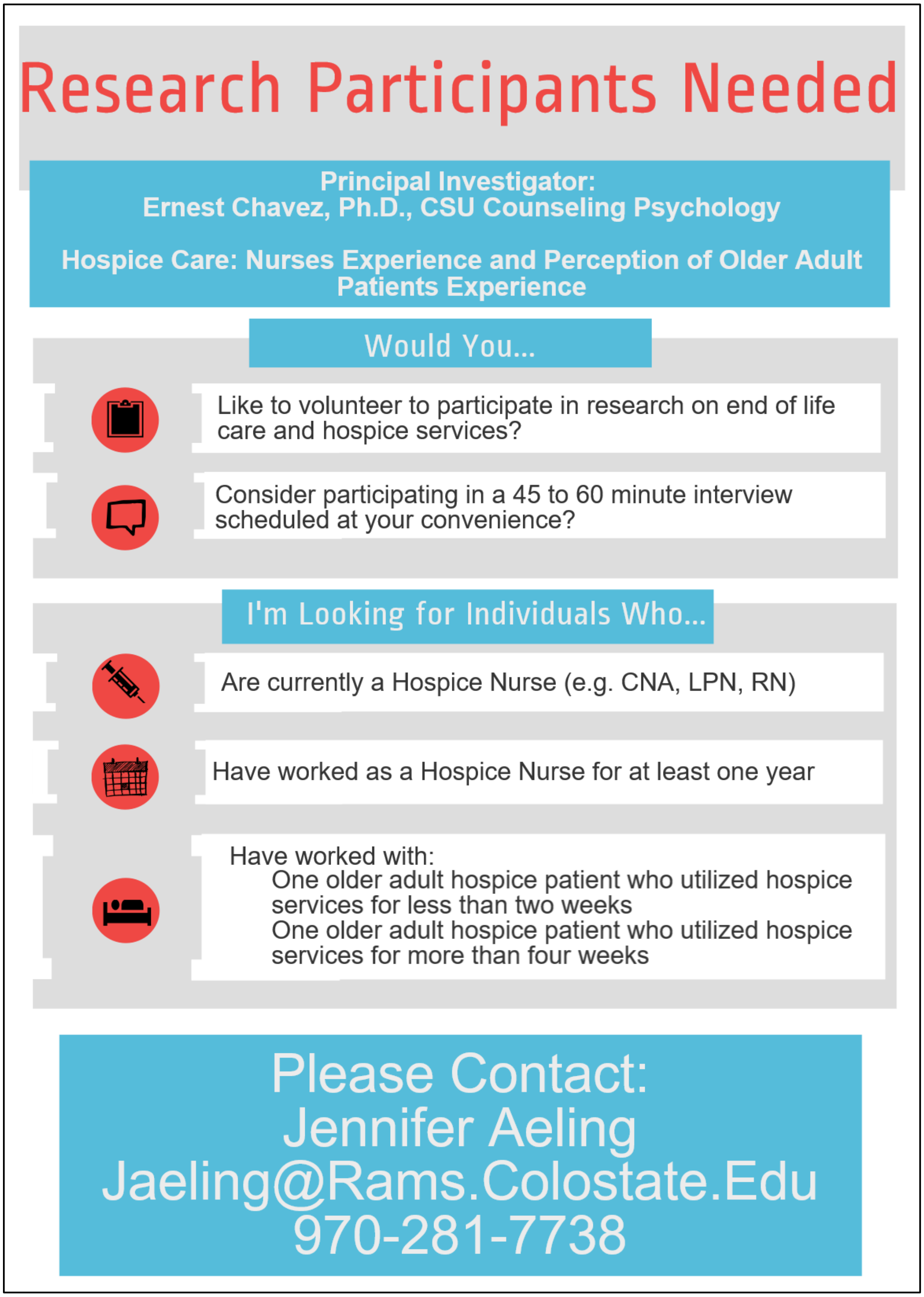
            What could hospice have done differently to play a more significant role?

    g. What, do you believe, led this individual to utilize hospice for more than 4 weeks?
    h. Do you believe this patient could have benefited from using hospice for a different period of time?
    i. Why did you choose this person? (Possible probes)

            What made his/her come to mind when I asked you to select a resident?

3. What differences did you experience or notice between this person's death and the first individual you told me about? (Possible Probes)
    - If differences are mentioned:
        - What do you think about the possibility that the length of the hospice use may have been the reason for those differences?
    - If uncertain or do not have an answer:
        - Research suggests that those who utilize hospice for differing periods of time have different benefits, did you notice that in these two instances?
4. What else would be important to mentions about these patients?

APPENDIX C: RECRUITMENT FLYER



Research Participants Needed

Principal Investigator:
Ernest Chavez, Ph.D., CSU Counseling Psychology

Hospice Care: Nurses Experience and Perception of Older Adult Patients Experience

Would You...

- Like to volunteer to participate in research on end of life care and hospice services?
- Consider participating in a 45 to 60 minute interview scheduled at your convenience?

I'm Looking for Individuals Who...

- Are currently a Hospice Nurse (e.g. CNA, LPN, RN)
- Have worked as a Hospice Nurse for at least one year
- Have worked with:
  - One older adult hospice patient who utilized hospice services for less than two weeks
  - One older adult hospice patient who utilized hospice services for more than four weeks

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