THESIS

HOSPICE SERVICES AS EXPERIENCED BY LONG TERM CARE NUSRING STAFF AND

THEIR PERCEPTION OF RESIDENT EXPERIENCES

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ABSTRACT

HOSPICE SERVICES AS EXPERIENCED BY LONG TERM CARE NUSRING STAFF AND

THEIR PERCEPTION OF RESIDENT EXPERIENCES

The current study utilized qualitative methods to understand long term care (LTC) nursing staff's experience with hospice services and their perceptions of how their residents have experienced hospice services. More specifically, this study sought to understand nursing home residents choices to utilize hospice services, as well as understand differences LTC nurses have experienced in regards to these deaths. Interpretative Phenomenological Analysis (IPA) was utilized to extract themes and subthemes from 10 interviews that occurred with LTC nursing staff. Four main themes were extracted from the data. These main themes are: LTC nursing participant's positive view of hospice, their perception that residents view hospice very negatively, why residents choose to utilize hospice services, and why residents choose not to utilize hospice services. A number of subthemes were extracted as well. Content analysis was also utilized to extract one noteworthy concept that did not fit within the guidelines of IPA, which was a comparison of two resident deaths, one that occurred with and without the utilization of hospice services. These themes and the noteworthy concept pointed to a contradiction between the LTC nursing staff's positive view of hospice and their belief that their residents view hospice services very negatively.

ACKNOWLEDGEMENTS

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INTRODUCTION

Long term care (LTC) settings, such as nursing homes, are often a place for older adults

(age 65+) to live when they do not need the services of a hospital but are unable to live

independently or be cared for at home. There are currently around 15,650 certified LTC

facilities in the United States (Centers for Medicare and Medicaid Services [CMS], 2013). In

2012, these certified LTC settings were mostly at full occupancy (83%) with 1.38 million

individuals living in them, 1.2 million who were over the age of 65 (Administration on Aging

[AOA], 2013; CMS, 2013).

The average LTC resident is an 87 year old woman (National Center for Assisted Living

[NCAL], 2011), who most likely requires assistance with some activities of daily living, such as

bathing, walking, or toileting; and as her age increases, the likelihood that she will need

assistance increases as well (Day, 2006; NCAL, 2011). Twenty five percent of LTC residents

need assistance with one or two activities of daily living, and 75% need assistance with three or

more activities of daily living (Healthyaging.org, 2012).

So many older adults now rely upon care in LTC facilities that many expect to live in

such a facility until their deaths, leading to the epithet "God's waiting room" (Wallace, 2013).

Of the older adults in the United States who died in 2009, 27% were in a LTC facility at the time

of death, and this percentage increased to 38% for individuals aged 85 years and older (Federal

Interagency Forum on Aging Related Statistics, 2012). The likelihood of dying in a LTC facility

continues to increase as the age of the individual increases (Weitzen, Teno, Fennell, & Mor,

2003). By 2020, it is estimated that 40% of older adult deaths in the United States will occur in a

LTC facility (Oliver, Porock, & Zweig, 2005).

These LTC residents facing death have numerous options for their care at the end of their lives, one being the use of hospice services. Hospice services are focused on the caring, rather than the curing, of the dying, providing additional services for the LTC residents under their care. Almost all (89.4%) LTC settings provide some hospice services (National Center for Health Statistics, 2013) and many (78%) have a contract with a hospice provider (Wood, 2012).

Current estimates are not available regarding the percentage of older individuals in LTC settings that actually utilize hospice services. However, across all causes and settings of death for older individuals, 43% utilized hospice services at the end of their lives (Federal Interagency Forum on Aging Related Statistics, 2012). It may be possible this percentage is unrepresentative due to unexpected deaths in the older population, as those who die unexpectedly would not have the time to use hospice services. Although that is a possibility, when looking at those who died of cancer alone, a more expected cause of death, the percentage of hospice use is similar (Virnig, McBean, Kind, & Dholakia, 2002). Although uncertainty exists, this suggests that less than half of LTC residents use hospice services at the end of their lives.

Identified Concerns of Older Adults Near End of Life

End of life, usually considered six months before the death of an individual (American Psychological Association [APA], n.d.), can be a difficult time for older adults as well as for their families and loved ones. Many concerns can arise for the older individual during this time. Three concerns consistently identified in the literature pertain to pain management, communication regarding end of life, and involvement in treatment decisions.

A review of the literature identified pain and symptoms management as a significant concern for not only dying individuals, but also their families and medical professionals (Area Agency on Aging [AAA], 2013; Caruso-Herman, 1989; Maguire, Walsh, Jeacock, & Kinston,

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1999; Payne, Langley-Evans, & Hillier, 1996; Steinhauser et al., 2000). 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). Unfortunately, pain and symptoms management can become complicated with older adults due to regulations surrounding morphine, possible addiction to pain medication, and the possible side effects which include shortening of life (Bilsen et al., 2006).

Another concern identified in the literature includes older adults wanting to know, in terms they understand, what to expect from their illness and their approaching death (AAA, 2013; Steinhuser et al., 2000; Terry, Olson, Wliss, & Boulton-Lewis, 2006). During the end of their lives, these individuals are concerned about how their disease will progress, what will happen to their body, and what will happen as death occurs (Terry, Olson, Wilss, & Boulton-Lewis, 2006). Older adults may sometimes not be provided this information, as physicians may wish to preserve hope and may be uncomfortable talking about dying (APA, n.d.; Curtis, Patrick, Caldwell, & Collier, 2000).

Older adults are also often under informed about the various options for the end of their lives. When physicians do discuss end of life options, the discussion lasts for an average of five to six minutes, with the physician talking for 66% of the conversation (Tulsky, Fischer, Rose, & Arnold, 1998; Connors et al., 1995). This may lead to the older adult feeling confused about what to expect and unsure about options available at the end of life.

Older adults have shown a deep interest in involvement with end of life treatment decisions, but are often concerned that their preferences will not be taken into consideration (AAA, 2013; Caruso-Herman, 1989; Steinhauser et al., 2000; Terry, Oson, Wilsss, & Boulton-Lewis, 2006). Although it is known that older adults want to be involved in their treatment

decisions, end of life preferences may be ignored (Goodman, Esty, Fisher, & Chang, 2011; Prendergast, 2001). Even with an increase of documented advanced directives in the 21st century, there has been little effect on care before death as well as place of death, despite the wishes of the dying (Pitchard et al., 1998; Silveria, Wiitala, & Piette, 2014). This suggests that although older adults are thinking about end of life and creating plans, to show they want to be involved in the decision making, these plans are often being disregarded or simply not being looked into when necessary.

Identified End of Life Concerns of Older Adults Living in LTC

As with other settings, within LTC, concerns about pain management, communication regarding end of life, and involvement in treatment decisions, are common. However, research regarding these topics within LTC is limited. Although historically pain management in LTC facilities has been poor, there has been a recent increase in educational and behavioral staff interventions to improve the management of pain. These interventions have been successful in reducing pain among older adult residents near the end of their lives (Horner, Hanson, Wood, Silver, & Reynolds, 2005; Jones et al., 2004; Russell, Madeson, Flesner, & Rantz, 2010), as well as causing fewer side effects, higher psychological well-being, and lower depression scores in older adult LTC residents (Tse & Ho, 2011).

End of life communications within LTC settings has been known to be poor and infrequent, but this has also been improving in the recent past (Oliver, Porock, & Zweig, 2005), with end of life discussions increasing from 29% to 37% (Bradley, Peirie, & Wetle, 1998). Although still low, the change is positive. Much of the poor communication is due to LTC staff's discomfort talking about death with residents (Ersek, Kraybill, & Hansberry, 1999). Trainings have been shown to increase staff-resident communications, indicating that with a

simple intervention communication in LTC settings can see a positive increase (Burgio et al., 2001; Malloy, Virani, Kelly, & Munevar, 2010; Vasse, Vernooij-Dassen, Spiker, Rikkert, & Koopmans, 2010).

Within LTC settings, residents tend to be clear about decisions regarding their care (Gillick, Berkman, & Cullen, 1999). In contrast to other settings, LTC resident wishes are being followed, as residents of LTC who verbalize their wishes to staff have their end of life care wishes followed 75% of the time (Danis et al., 1991). In order to boost fulfillment rates beyond 75%, some LTC settings integrate staff training about end of life decision making. A one page end of life preference form has led to universally following LTC residents' wishes regarding CPR (Tolle, Tilden, Nelson, & Dunn, 1998), and trainings can increase the percentage of resident wishes being followed to near perfect (95%) (Morrison et al., 2005).

Identified End of Life Concerns of Older Adults Addressed by Hospice Services

Hospice services can often address many of the identified concerns in the literature that have been consistently reported by patients, their families, and medical professionals. For example, pain management is a fundamental aspect of hospice services. Those enrolled in hospice have superior pain management and significant symptom improvement (Elsayem et al., 2004; Meier, 2011; Wallston, Burger, Smith, & Baugher, 1988). Also, the longer an individual is enrolled in hospice, the more he or she benefits from pain and symptoms management (Christakis & Escarce, 1996; Han, Remsburg, McAuley, Keay, & Travis, 2007; Miller, More, & Teno, 2003; Wright et al., 2008). This suggests that hospice services can help alleviate the major concern of the dying, as well as their families and medical professionals, by helping residents die in a less painful manner.

Making the older adult, as well as families, aware of the dying process is also part of the hospice philosophy (Kehl, Kirchoff, Finster, & Cleary, 2008, "Signs of dying with suggested care", 2000; "The last stages of life", 2009). Aside from knowing what to expect as death occurs, individuals in hospice settings are generally allowed time to openly discuss their death (Field & Copp, 1999). Those in hospice also have the power to decide if they wish to have these discussions about death and at what length (Copp, 1997; Copp, 1999; Payne, Hillier, Langley-Evans, & Roberts, 1996). This open discussion, as well as discretion when needed, allow older individuals to feel more in control of their situation.

Overall communication, not just communication regarding the dying process, is another important aspect of hospice services. Person-centered communication and resident decision making are both high when using hospice services (Center to Advance Palliative Care, 2008). Communication between the hospice team and the resident is important not only to the dying individual, but also to the hospice team members and volunteers (Foster, 2002; Planalp & Trost, 2008; Way & Tracy, 2012). This increase in communication is beneficial for the resident, as his or her wishes and decisions are being heard, which may lead to a reduction of the concerns previously identified.

Limitations in the Current Literature Involving Hospice Services in LTC

A review of the existing literature on hospice in long term care presents some significant limitations, with dearth of information being one (Oliver, Porock, & Zweig, 2005). Although there is a substantial amount of research on end of life, there is limited research on end of life and hospice within LTC settings, particularly in regards to the differences between those who utilize and do not utilize hospice services within a LTC setting. An in-depth systematic literature

review found only eight studies specifically analyzing hospice services within nursing homes (Oliver, Porock, & Zweig, 2005).

When research does exist, much of it is out of date, with the majority being conducted in the 1980s and early 1990s. This is most likely due to hospice services being added as a Medicare benefit during that time. As a result, these data are generally outdated and focused on practices most likely no longer in place, not accounting for the recent training and knowledge gained within the field.

The lack of a clear definition of LTC setting, in regards to the physical environment and services provided (i.e. rehabilitation or assisted living) is an additional limitation. LTC, in some research, simply means any informal care of another for a long period of time, including care provided by spouses and family caregivers in the home (Grabowski, 2008). In other studies, LTC is used to reference only nursing homes (e.g. Grabowski, 2008; Steckenrider, 2000). More often, researchers do not state specifically what type of setting is meant by the term LTC, or a combination of settings are included and combined in analysis (e.g. John & Ribner, 1991; Nicolle & Garibaldi, 1995; Robertson & Cummings, 1991; Trail-Ross & Wright, 1998; Weinstein, 2000; Zedlewski & McBride, 1992).

A similar limitation is the operational definition of hospice. Hospice services can be used any place a person chooses to receive his or her end of life care. In existing research hospice services used in multiple settings, such as home hospice and inpatient hospice, are often analyzed together, or there is no mention of setting at all (e.g. Christakis & Escarce, 1996; Christakis & Iwashyna, 2000; Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007; Greiner, Perera, & Ahuwalia, 2013; Han, Remsburg, & Iwasyna, 2006; Han, Remsburg, McAuley, Keay, & Travis, 2007; Lackan et al., 2004; Virnig, McBean, Kind, & Dholakia, 2004; Wallston, Burger, Smith, &

Baugher, 1988). Due to this limitation, it is impossible to determine the effects of hospice within

a specific LTC setting, such as a nursing home.   Compounding this problem, hospice is also

sometimes defined as being part of palliative care (e.g. Christakis, 1998; Jennings, Ryndes,

D'Onofrio, & Baily, 2003; Meier, 2011; Vig, Starks, Taylor, Hopley & Fryer-Edwards, 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). These varied definitions and combined settings do not allow for an in-depth review of

hospice services in a particular LTC settings.

The participants of many previous studies are also a concerning limitation. In a majority

of the current research, the researchers receive their data from family members of residents

through surveys and interviews about end of life and hospice experiences of their relatives (e.g.

Dreyer, Forde, & Nortvedt, 2009; Oliver et al., 2014; Rickerson, Harrold, Kapo, Carroll, &

Casarett, 2005), often after the death has occurred (e.g Casarett et al., 2008; Kirkendall, Holland,

Keene, & Luna, 2014; Teno et al., 2004). Asking family members may not be the most effective

approach to learning about end of life and hospice; due to, family members being emotionally

charged following the death, (Forbes, Bern-Klug, & Gessert, 2004; Wright et al., 2008; Wright et

al., 2010), their limited contact with the dying family member (Port et al., 2001), and possibly

their overall limited experiences with death.

Some researchers have tried other methods, such as recruiting participants of dying

individual themselves (e.g. Cadigan, Garbowski, Givens, & Mitchell, 2012; Lawton, 2001;

Wright et al., 2010; Wright et al., 2008). This approach has been limited due to being rather

difficult. An additional method that has been used in previous research, although less frequently,

has been to recruit nursing staff, often hospice nurses, and study their experiences of resident

deaths (e.g. Ganzini et al., 2002; Ganzini et al., 2003; Hanson, Henderson, Min, & Menon, 2002).

Current Study

The overarching research focus of the current study was to understand LTC nursing staff's experience with hospice services as well as their perceptions of how their residents experienced hospice services. More specifically, this study sought to understand why some residents chose to utilize or not to utilize hospice services prior to death, as well as to understand differences nurses had noticed between deaths that did or did not use hospice services. This knowledge of nursing staff's perception of hospice, as well as their interpretation of their resident's perception, is important because LTC nursing staff are likely to suggest hospice services to residents (Hospice Care Team, 2003) and, as was already discussed, hospice may prevent some of the major concerns of the dying and is underutilized.

Given the limitations of the available literature, the current phenomenological study focused on understanding the experiences of LTC nursing staff as they worked with LTC residents near the end of their lives, with emphasis on the use of hospice services. The primary researcher interviewed LTC nursing staff since these individuals are often viewed as "the cornerstone of end-of-life care" (Bendiane et al., 2007, p.1) as well as the most trusted profession in the United States (American Nurses Association, 2014). Their routine, individualized, and long term interaction with older individuals near the end of their life (Bowers, Lauring, & Jacobson, 2001; Eika, Espnes, & Hvalvik, 2014; Pepper, Kane, & Teteberg, 1976; Radosevich et al., 1990; Robertson & Cummings, 1991) as well as multiple experiences regarding resident's end of life (Robertson & Cummings, 1991) address many of the limitations of previous studies.

LTC nursing staff may also experience the deaths less emotionally than the families do (Ablett & Jones, 2007), reducing another limitation of previous research.

For the purpose of this study, LTC setting was clearly defined as long term care taking place within a nursing home, where a resident lived and was able to receive a higher level of care than provided by other settings. This specification was to prevent confusion or combination of other settings, such as assisted living or rehabilitation, as well as to expand the limited research on nursing homes alone. Nursing homes were also chosen due to the LTC field being historically and continually dominated by this type of facility (Kitchner & Harrington, 2004). This clear definition of LTC was achieved by participant recruitment only occurring within nursing homes.

Hospice use was also clearly defined for the purpose of this study as extra services provided by a hospice provider within the nursing home, above services already received as a LTC resident. To be considered hospice use, the individual must have been using one or more services provided by hospice near the end of his or her life. Hospice use was determined by the LTC nursing staff participant.

METHODS

Phenomenological Research

Phenomenological research "describes the common meaning of a concept for several individuals of their lived experience" (Creswell, 2013, p.76), explaining an individual's experience in a universal way. The current study utilized interpretative phenomenological analysis (IPA) to identify themes and meaning across interviews with LTC workers. IPA, although relatively new, has become one of the most popular analyses for qualitative research (Smith & Osborn, 2008).

In phenomenological research, researchers are encouraged to be reflexive, increasing their awareness of how biases, personal identities, and experience can affect their work. To learn about someone else's experiences without the effect of bias would be truly impossible, as bias can have an effect in every part of the research design, analysis, and written summary (Smith, Flowers, & Larkin, 2009; Willig, 2001). In IPA, understanding and being aware of these biases is more important than the impossible task of trying to completely remove them (Smith, Flowers, & Larkin, 2009; Willig, 2001). When a researcher makes a statement about who she is, her beliefs, and her experiences, the researcher is better able to explore this bias and the intersecting relationships between herself and the research (King & Horrocks, 2010).

The primary researcher self-identified as a White heterosexual female, 24 years of age. She was using the current study to complete her master's thesis in counseling psychology with an emphasis in geriatric end of life care. The primary researcher had experiences in senior centers, long term care facilities, and as an in-home personal care assistant for an older individual with a life threatening illnesses. 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-one's where 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 6 month placement where she interacted daily with an older woman who was

nearing her end of life and was not utilizing hospice services. The primary researcher identified

two preconceived expectations: (1) hospice has many benefits for older individuals who are

living in LTC near the end of their lives and (2) many older individuals residing in LTC who

could benefit from hospice services are not utilizing them.

Purposive sampling

In IPA, small sample sizes are the norm (Brocki & Wearden, 2006). Having a large

sample size can take away from the meaning of each individual experience (Bowen, 2008).

Sampling in IPA tends to be "purposive and broadly homogeneous" (Brocki & Wearden, 2006,

p. 95). 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). The determined sample size was 10, for the present study, an appropriate sample size for

qualitative research as well as considered large for IPA analysis (Brocki & Wearden, 2006;

Smith, 2011). When using an IPA framework, data saturation is typically not a desirable goal

and was not utilized in the present study (Brooks, King, & Wearden, 2011; Hale, Treharne, &

Kitas, 2008)

Participant Selection

LTC nursing staff members were recruited from nursing homes that met the following

criteria: (1) in Colorado, (2) provided optional hospice services to residents, regardless of a

preexisting contract with any certain hospice provider, and (3) did not have a hospice ward on

site. Hospice services were defined as services provided by a hospice provider within the LTC nursing home, above what was already received as a LTC resident. Hospice use was determined by the nursing staff participants.

Participants were recruited using flyers placed around nursing homes as well as handed to nursing staff within nursing homes (Appendix C). All participants met the following criteria: (1) currently employed as a Certified Nursing Assistant (CNA), Registered Nurse (RN), or Licensed Practical Nurse (LPN) at a long term care facility; (2) had worked in a LTC facility, with direct resident contact, for one year or longer; (3) had experienced the deaths of one LTC resident who used and another who did not use hospice services at the end of his or her life; and 4) over the age of 18. Exclusion criteria included: (1) currently working for a specific hospice provider and/or (2) currently working as a hospice nurse. One participant was turned away due to the exclusion criteria.

All 10 participants self-identified their gender identity as female and their ethnic heritage as White/Non-Hispanic/European American. As can be seen in Table 1, participants ages ranged from 20 to 69 years of age. Each level of nursing position (Registered Nurse, Licensed Practical Nurse, and Certified Nursing Assistant) that was accepted for this study was represented, although there were more RNs than LPNs, and only one CNA. The participant sample had more individuals who had worked in their current jobs for one to five years as well as more individuals who had worked in LTC facilities total for more than 15 years. A range of higher education levels was present. The 10 participants, at the time of their interview, worked within six different long term care facilities in Colorado, as seen in table 1. Facility one, two, five, and six were for-profit facilities with 96, 90, 138, and 165 skilled nursing beds, respectively. Facility three and four were non-for-profit facilities with 64 and 125 skilled nursing beds, respectively.

Table 1.

Demographic Information of Participants

Participant Pseudo Name	Age Range	Job Title	Level of Education	Current Facility	Time Worked in Current Facility	Total Time worked in LTC Facilities
Becky	20-29	RN	College Degree	Facility 1	1 to 5 Years	1 to 5 Years
Liz	50-59	RN	College Degree	Facility 1	1 to 5 Years	6 to 10 Years
Ariel	30-39	LPN	College Degree	Facility 2	6 to 10 Years	More than 15 Years
Mari	60-69	RN	College Degree	Facility 3	11 to 15 Years	More than 15 Years
Tiffany	60-69	RN	2 Year Degree	Facility 3	6 to 10 Years	More than 15 Years
Ellen	60-69	RN	2 Year Degree	Facility 4	1 to 5 Years	More than 15 Years
Aubrey	20-29	RN	2 Year Degree	Facility 5	1 to 5 Years	6 to 10 Years
Jules	60-69	LPN	1 Year Certificate	Facility 3	11 to 15 Years	More than 15 Years
Joua	30-39	CNA	Some College	Facility 5	1 to 5 Years	6 to 10 Years
Isabella	50-59	LPN	1 Year Certificate	Facility 6	1 to 5 Years	More than 15 Years

Data Collection

The primary researcher interviewed all 10 participants. One, in depth semi-structured interview occurred with each participant. These interviews were audiotaped and transcribed by the primary researcher or a senior level research assistant. The audiotapes and transcripts have been kept in a locked file on a locked computer and will be destroyed appropriately to retain confidentially. Interviews occurred in a private area of the participant's LTC workplace or a similarly private place, such as the primary researcher's office.

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 rights as a participant of research. The participants began by answering questions to 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 LTC staff and lasted approximately 5 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 20 to 54 minutes.

The questions and probes (Appendix B) used in these interviews were created based on a review of the literature and discussions with experts who had extensive experience in long term care settings, and were modified after a class-based pilot study. The questions were created to develop an understanding of what hospice meant to the participant as well as her beliefs about what hospice meant to her residents. More specific questions, including the differences seen between one resident who used hospice services and one who did not, were created to understand detailed end of life experiences as well as reasons why a resident may have chosen to use or not use hospice services. All procedures were approved by Colorado State University Institutional Review Board.

ANALYSIS

Interpretative Phenomenological Analysis (IPA)

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 the experience and meaning of end of life and hospice services as experienced by LTC workers (Eatough & Smith, 2008). Analysis began with thematic analysis of each interview according to the IPA guidelines provided by Smith, Jarman, and Osborn (1999). NVivo version 10 qualitative software was used to assist in data analysis.

Stage One. The primary researcher and the senior level research assistant each transcribed five audiotapes verbatim. All transcripts were compared to the original recording by the primary researcher or the lab assistant who did not transcribe that interview, so each transcript was 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 yet created.

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

Stage Four. It was then determined by the primary researcher if these themes could be reduced into more inclusive categories and if there were "master themes" that encapsulated multiple of the 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 again back to the original transcripts for validation and refinement. The senior level research assistant also reviewed the forming themes and analysis to ensure that quotes chosen fit within the themes presented.

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

The following results section was based on the IPA criteria set by Smith (2011). Based on the criteria, this researcher considered an idea a theme or subtheme if it was present in at least four interviews. Quotes presented in this results section were nearly identical to the verbatim

transcription, except for names removed due to confidentiality, grammatical changes, extraneous words removed (i.e., "um", "you know", repeated words), and a reorganization of words for clarity or fluidity.

Using matrix coding in NVivo, the researcher determined if position within nursing staff had an effect on the themes and subthemes presented. As a result of having one CNA, this comparison only occurred between RNs and LPs. Due to the varying and small numbers of each nursing position within the participant pool (three LPNs, six RNs) the researcher used the percentage of each nursing position that endorsed a certain subtheme, out of total participants in that same nursing position, for the comparisons. For example, if three RNs endorsed a subtheme the percentage was 50%. If three LPNs endorsed a subtheme the percentage was 100%. This was done for every theme and subtheme. If there were 35 percentage points or more between the percentage of RNs and LPNs who endorsed a theme or subtheme, this was considered to be 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 35 percentage points the differences appeared to be practically significant. There were differences of this size noted in two subthemes. These are discussed within the following results.

Content Analysis

During the process of coding according to IPA guidelines, a noteworthy concept began to arise that did not fit within the IPA framework. The participants were asked to describe one death that occurred with hospice services and one death that occurred without hospice services. These stores led to rich data about the difference between deaths, particularly "good deaths" and "bad deaths," but did not fit within the meaning of hospice. Due to this data not fitting within

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the IPA, content analysis was performed for this small subset of data. Content analysis was performed using the guidelines provided by Hsieh and Shannon (2005).

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 as well as if hospice was utilized or not utilized.

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

Stage Four. The codes and labels were then organized and sorted into broader meaningful categories. The codes within each category were then counted to determine which had more support based on the present subset of data. In the case of the present subset of data, four categories were created and counted within this content analysis portion.

Establishing trustworthiness

Standards of trustworthiness in qualitative research have been created to determine the credibility and rigor of research without imposing quantitatively traditional terms (Morrow, 2007). In the current study, trustworthiness was developed and maintained through the following three strategies.

Member Checking involves the researcher returning to the participant for his or her view on a finding or interpretation (Creswell, 2013). In the current study, if at any time the primary researcher was uncertain about a phrase or of any meaning in the transcript, she first reviewed the original recording of the interview and then returned to the participant for

clarification. After the transcription process, whole transcripts were sent back to the eight

participants who consented during the interview to read over for accuracy, and five were

returned to the researcher. When the participant stated that there was a discrepancy between

what was said and what was transcribed, the response given during the member check was

considered correct. Minor corrections occurred in two of the member checks.

A **Researcher's Reflexivity Journal** was kept to help the researcher acknowledge and be

aware of any biases that were present during the research process (Morrow, 2005). This journal

was used throughout the research process, first to document notes, reactions, ideas, hypotheses,

and experiences during the data collection process. This journal also contained an ongoing

record of personal feelings, reactions, and experiences of the primary researcher. These personal

notes were later used to remain aware of biases and determine if these may have affected any

aspect of the research project. The writing of this journal was not used as research data but

simply to be aware of biases that may have been present, which is an important process within

the qualitative research design (Marrow,2005; Smith, Flowers, & Larkin, 2009; Willig, 2001).

After a review of this journal, no major biases were noted.

Thick Description is the use of rich and detailed descriptions of the participants for the

use 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 and verbally administered demographic survey (Appendix A). Also, verbatim

transcription and quotes were used in the analysis to confirm that the true content and meaning in

the interview is present in the analysis.

Four major themes emerged as well as a number of subthemes (Table 2). The first major theme that emerged was that based on the nurses' experiences and perceptions, residents viewed hospice very negatively, often fearing hospice and believing it meant immediate death. The second major theme built on the first; according to these nursing staff participants, these types of negative views were commonly why LTC residents did not utilize hospice services. The third major theme that emerged was how positively the participating nurses viewed hospice, finding it beneficial for residents, families, and LTC staff. The final major theme was that nurses believed residents who used hospice often did so after positive aspects of hospice services were explained to them by LTC staff. In addition to the four major themes identified above, an additional noteworthy concept emerged, as nursing participants compared two deaths, one with and one without hospice care.

Nursing Staff Believed their Residents Experienced Hospice Services Negatively

All 10 participants stated that, based on their experiences, they believed hospice had a very negative meaning to LTC residents. This negative meaning ranged from a dislike of new people brought in by hospice to a fear of the word itself. According to the participants' perception, to the residents utilizing hospice meant they were going to die immediately and hospice was something to be feared.

Dying Immediately. LTC nursing staff expressed that, based on their experience, their residents often believed if they used hospice services it meant they were going to die immediately. As Liz stated,

Table 2.

Common Themes and Subthemes in Participants Experience of Hospice Services as well as their Interpretation of their Residents Experience. Frequency of these themes and subthemes in number of participants who endorsed it.

Themes/Subthemes	# of Participants
Nursing Staff Believed their Residents Experienced Hospice Services Negatively	10
Dying Immediately	8
Feared	6
Why Residents chose not to Utilize Hospice Services	-
Old Views	6
Dying Immediately	8
Not Accepting of End of Life	4
Still Wanting to Treat	4
Already Trusting of their Current Facility or Doctor	4
Nursing Staff Experienced Hospice Services Positively	10
Medication Management	10
Superior Pain and Symptoms Management	8
Getting Medication Quickly	7
"More" for the Resident	9
More Staff	8
More Time	5
Emotional Support for Residents	8
Human Touch	7
Graduating Hospice	6
Resident Control	5
More than just Death	4
Support for Family	10
Helping Long Term Care Staff	10
Lighten Work Load	9
Emotional Support	6
Why Residents Chose to Utilize Hospice Services	-
Explain Hospice Services	7
Recommendation	6
Services Provided	6
Additional Noteworthy Concept	
Comparison of one Death that Occurred with Hospice Services and one Death that Occurred without Hospice Services	
Based on Content Analysis	
Based on Participant Responses	

Often times I have residents say "oh, no I don't want to go into hospice because I don't want to die," I think they feel like it means they are going to die sooner…they feel like [hospice] is going to cause their death to come sooner, that being in hospice means "oh, I'm gonna die faster."

Ariel also mentioned "A lot of people think that hospice means you're dying and you're going to die tomorrow… most people just think 'Oh, if hospice comes in you're going to die.'" As Ellen explained, after suggesting hospice, many residents asked her "does that mean I am gonna die next week?" Jules and Joua gave similar responses, in their experience residents often felt that hospice meant they were "going to die this second."

Feared. Although dying immediately could be considered a fear, six participants explicitly stated that, based on their interpretation, to their residents hospice meant something to be feared. As Isabella mentioned "[hospice] is very scary for them… I think there is still a lot of fear with it that people just don't understand". Aubrey remarked that "hospice can be threatening, because hospice is end of life care and that's not something most people want to face." Becky, Mari, Liz, and Ellen simply stated that their residents often feared hospice.

Why Residents Chose Not to Utilize Hospice Services

These fears, according to the nursing staff participants, may have been due to the "old views" that they believed their residents embraced regarding hospice services. The idea of "old views" was a strongly supported subtheme regarding why residents chose not to use hospice services. Other reasons residents chose not to use hospice services included: dying immediately, not accepting of end of life, still wanting to treat their disease, and already trusting their nursing facility or doctor.

Old Views. According to nursing staff participants and their interpretations, resident's fear of hospice was often due to the "old views" that they held regarding hospice services. Becky reported that "[residents] who have never been educated on it [hospice] might have old

views… that you go into hospice and die, that you're given up on... Hospice does have that stigma attached to it". Tiffany agreed, she maintained that in her experience, residents had some old ideas of what hospice entailed, and were unsure what it meant for their end of life care.

These "old views", or simply incorrect or outdated knowledge about hospice, was expressed by six participants for being a reason why residents chose not to utilize hospice services. In response to being asked why residents did not use hospice services, Ellen answered with "a lot of it is the stigma," and Becky explained that "the people who tend to have the [old] views tend to be the population that do not use hospice." In addition, Liz reported, "sometimes I think they are confused about exactly what it does mean, today". This subtheme indicated that residents often had incorrect knowledge of what hospice services provided and they did not know what modern hospice services could add to their care.

Many of the participants who endorsed the theme of "old views" also alluded to or explicitly stated that they believed this would change with time. As Tiffany stated

> The whole concept of hospice has really changed over the last 15 years, it used to be a separate facility where they go to die. Now we provide these services in their home, at the facility or wherever they are at. We're dealing with people in their 70s, 80s, 90s and what they remember is [the hospice] from many years ago… it's completely different from what they may have grown up with.

And Ellen explained, these old views will begin to disappear:

> As generations change, baby boomers are going to know, they know about that [hospice] now. People that are here [at the facilities] now that are 80 years old, when they were younger hospice was not even around, they didn't learn about it.

These participants had hope that the "old views" of hospice were starting to change and that this would lead to more comfort with hospice services, and hopefully more residents utilizing these services.

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Dying Immediately. As previously noted, to many residents hospice meant almost immediate death. As a result, dying immediately was also a supported subtheme for why residents chose not to utilize hospice services. As Ariel simply stated, when asked why residents may have chosen not to use hospice services, "the same reason, they think it means they're going to die." Liz expressed, when thinking about why a specific resident did not use hospice services, "I don't think she could get over that, if she went on hospice, it meant she was resigning to die." Ellen added, in her experience, "[residents believe] if you sign onto to hospice, it means you are going to die soon. They just choose not to do that, they do not want that attached to their name."

Not Accepting of End of Life. Four participants stated that a reason residents did not utilize hospice services was a failure to accept approaching death or that they met the criteria for hospice services. As discussed by Ariel, based on her interpretation and experience, "they're [residents] not ready to accept the fact of their own mortality … they're just not ready to accept." Aubrey's statement confirmed her similar belief, "it brings the reality too close to home for some of the people, I've known many family members who denied that their parent was going to die up until the day they did die… if you admit to hospice, you're admitting that [your] going to die." Isabella stated that, based on her perception, "some of them are either in denial or just think they don't need the extra help… they are not ready to say 'I'm okay with [using hospice services],'" and when asked why a specific resident did not utilize hospice services, she responded similarly with "I think probably a fear, and denial, that the situation was what it was."

Still Wanting to Treat. Similar to the previous subtheme was the idea that residents did not want to discontinue treatment. Four participants mentioned this was a reason why residents did not use hospice services, in their experience. Liz explained, when asked why residents may have not used hospice services, "some people just want to fight for every single day, they want

every single thing done that can be done and they are not ready to say 'okay, this is enough'" and

when asked why a specific resident did not utilize hospice services Liz responded, based on her

interpretation, "a reluctance to let go, they didn't want to give up, they still had hope to the very

end that there was gonna be a miracle cure, that they were gonna get better." Ariel also reported,

based on her perception, that residents did not use hospice because "they're not ready to accept

that fact that there is nothing we can do about that aortic valve. That there is nothing we can do

about that lung disease. There is nothing we can do about that cancer." Joua offered that

residents might not utilize hospice services because, while on hospice, residents cannot always

treat other illnesses, such as pneumonia. She discussed one resident with Alzheimer's disease,

> If she got sick they would take her off hospice, because she couldn't go to the hospital if she was on hospice. She would get pneumonia… and we couldn't take her to the hospital… So that would be one disadvantage, depending what they're on hospice for. Because Alzheimer's, they can live for years like that, so if they do get pneumonia, you can't treat it [if they are on hospice].

Already Trusting of their Current Facility or Doctor. Already trusting their facility or

current doctor was the most positive reason why residents chose not to use hospice services,

based on the participant's experiences; this subtheme was expressed by four participants. As

Mari discussed, in her experience,

> If someone has [a specific insurance] and they choose to go on hospice they can no longer use the nurse practitioner that they've built this relationship with…that nurse practitioner that has taken care of her for 5 years has to back out, and then it's someone new taking care of them, that's a good reason not to go on hospice.

Tiffany remembered a time when "The staff [at the facility] asked 'do you want hospice?'

and they said 'no, what you're doing for her is exactly what we would want anyway.'" Aubrey

made a similar statement that residents and family members felt that the LTC facility could do

"just as good of a job" as hospice, and when talking about a specific resident who did not use

hospice services, explained that she believed "her daughter elected not to do hospice, she felt like we'd [the facility] give just as good of care."

"Already trusting of their current facility or doctor" appeared to be the subtheme regarding why residents did not use hospice that was easiest for the participating nurses to accept. As Mari expressed previously, already trusting one's doctor was a "good reason not to go on hospice," and she also explained "we do death pretty good here [without hospice]. We honor that person." Ariel added that "we work with hospice and we do enough end of life care that even if [the resident] does not have hospice, we know what we need to get in place and we will advocate for that." Tiffany reported that in her experience, when residents did not use hospice services, LTC staff would pitch in a little extra to be sure the residents got what they needed during the end of their life. This may have been the easiest subtheme for the nursing participants to accept because the residents were still getting quality care from providers that the residents trust.

Although already trusting their doctor or facility seemed to be a rather positive subtheme, the previous two subthemes, "not accepting of end of life" and "still wanting to treat" seemed to suggest a real fear of end of life and death. This further supported the idea that residents believed using hospice services meant immediate death. These ideas seemed difficult for the nursing participants to accept. As will be seen next in the analysis, the nursing participants had a completely different view on hospice services. They would often discuss a positive aspect of hospice after sharing a resident's view they did not agree with. For example, participants would discuss the graduation of hospice after talking about how residents still wanted to treat their illness or discuss the emotional benefits of hospice after explaining how residents did not use services because they were not accepting of end of life.

Nursing Staff Experienced Hospice Services Positively.

All 10 participants expressed that, to them, hospice had a very positive meaning. All participants stated that they had more positive than negative experiences with hospice, and four added that they *never* had a negative experience with hospice. For those who did discuss a negative experience, it was often a single incident and caused by logistical issues (i.e. hospice paperwork) or a particular hospice staff member. For these LTC nursing staff participants hospice meant more than just death; it meant medication management, more staff, more time, emotional support for residents, human touch, resident control, helping families, and helping long term care staff.

Medication Management. Medication management was a broad subtheme endorsed in all 10 interviews. The most important aspect of medication management discussed in eight interviews was the superior pain and symptom control hospice provided. When asked what the best service hospice provided was, Jules responded that it helped with "keeping them out of pain." Isabella offered "I've seen people that could have had a really horrible, awful, painful death be very comfortable [due to hospice]." Aubrey explained that hospice provided "a lot more relaxants, a lot more pain medicine than what we would have [at the facility]."

Within the subtheme of medication management, another important aspect arose; hospice provided medication much more quickly than the LTC facility could. As Ariel explained, in her experience,

> [Hospice] makes it very easy for me to get what I need quickly, quicker than I could just by calling the doctor and waiting for them to call back. When they say "Hey this is XYZ from hospice" they'll get a response faster than "Ariel from this facility", I think that's a big benefit for the residents… if someone if getting kind of gurgully and we want to do a scope patch, they [hospice] can get those things in place a lot faster.

Becky also stated, to her a big benefit of hospice was

The ability for me to get medications very quickly, because, when patients are declining, they can decline rather rapidly. In a matter of an hour or three hours, you might need to get atropine, you might need to increase the dose of morphine, and if you're just working with a primary care physician from a clinic they may not have them. It's hard to get them [residents] what they need [without hospice].

The medication management portion of hospice was an important subtheme to these LTC nursing staff participants. As Isabella clearly stated "there is no reason for [the residents] pain to be a 9 out of 10. That is not okay in my eyes." Keeping residents out of pain, and therefore preventing one of the previously discussed fears of the dying, was an extremely important aspect of hospice services to these participating nurses.

"More" for Residents. Nine participants expressed the idea that hospice simply meant "more" for their residents than the LTC facility could provide alone. This idea of "more" was explained in a number of ways, but most commonly was explained as hospice having more staff and more time for the residents.

Eight participants stated that, to them, hospice meant having more staff for the residents under their care. As Becky remarked "[with hospice] you really get two nurses, two social workers, you get two people to help you with resources." Tiffany explained that her facility only had six social workers and four Chaplains, for over 300 residents. She went on to say that hospice could bring in more people and more resources, and "that's the big advantage [of hospice]." Ellen added that "in long term care, it is having an extra aid come in… it's just that extra set of hands, an extra ear to listen." Isabella mentioned that "[hospice] means there is more eyes being laid upon that person, they get extra attention… I just think it is more dignity for that patient." Joua explained that this was especially helpful with more difficult residents, "we had one guy, he was very Alzheimer's, [and hospice] would bring in two or three people just to deal with him." Additional staff brought in by hospice was a subtheme where a difference was noted

based on nursing position. A higher percentage of the RNs (100% of RNs) endorsed this theme, compared to the LPNs (33% of LPNs).

In addition to having more staff, having more time was also an important aspect of hospice services. Five participants expressed that hospice workers could provide more time for the residents. As Liz expressed, "they have more time, they're not worried about providing day to day care [to all residents] so they can come in and sit with the residents or send people to do that, and with their families." Jules made a similar statement, "they have all day… they have more patience, they have more time, and they do not rush anybody." Joua added that "[hospice] has more time, it's nice for [the residents] to get that extra attention."

After explaining that hospice could provide more for the residents, participants expressed their wishes that their facility had the time and staff to offer what hospice does. This occurred in eight interviews. As Joua stated, "we're usually busy, as CNAs, you can't always spend as much time with them as you'd like… it's not that we don't care, we just don't always have the time." Aubrey made a similar statement, "it's nice to have somebody [hospice] come in and do some of those extra things… when you're a nurse for 30 people, you can't do that, realistically." This may indicate that participants felt their facilities were understaffed and hospice allowed for the extra staff and time unavailable to residents otherwise. Tiffany expressed it the most directly, saying, "If the nursing home could staff sufficient social workers and other support people, I don't think we would need so much hospice."

Emotional Support for Residents. Eight participants expressed the importance of emotional support for residents provided by hospice. Aubrey explained that, in her experience, "[hospice] specializes in death, they are very skilled at handling the emotional needs of somebody who is working through all the stages of death and dying." Tiffany stated that the

"emotional side" of hospice was the "most important service." Ariel mentioned that "we don't know [when the resident will die], but in between now and when that time comes [hospice] is gonna help them deal with their emotions." Liz reported that she felt "[hospice] provides emotional support… helping people come to terms with it [end of life], letting them feel okay with it."

A few participants felt that hospice was more able to deal with the emotional needs of the residents than the LTC staff alone. This was not simply due to the time involved, but also because of the training and expertise involved in being a hospice worker. As Aubrey said,

> They [hospice] specializes in it [end of life] and when you specialize in something, you learn what works and what doesn't work and how to interact with family members and patients… sometimes I don't know the right thing to say, and hospice has experienced it a lot more… they know what they are doing and I trust them because they have done this for a long time.

Human Touch. Extra services provided by hospice, such as music therapy or additional bathing opportunities, were expressed as important in all interviews. When these extra services were broken down into more specific categories, the services that were most supported were those involving more human touch, such as bathing and massages, which was mentioned in seven interviews. As Joua remembered "hospice would come in and do the baths… [A specific resident] got three baths a week, she was spoiled!" Ellen stated, when thinking about a certain resident, "hospice was there, bathing her every day, and just providing that comfort." Jules mentioned hospice residents "get longer baths … [Hospice residents] get a lot of human touch" and when thinking about a certain resident, Jules remembered "they would take her hands and they would lotion and would just rub and rub each finger, it was so nice to watch, so loving."

"Human touch" tied back to the previous subtheme of hospice providing "more." Due to hospice having more time and more staff, they could spend a longer amount of time with each

resident individually. Hospice had the means to give a resident a long bath each day, while the LTC facility alone did not. Again, when discussing these extra services, participants expressed that they wished they had time within the facility alone. As Jules clearly stated, in regards to bathing, "we [LTC staff] have to get them in and it's like 'hurry up' because we have eighteen thousand other people to clean." She went on to explain that this is just the way things are within a LTC facility when hospice is not present.

Graduating Hospice. Although participants believed their residents had the previously discussed negative views of hospice services, particularly that hospice meant immediate death, these participants did not want their residents to have these beliefs. Six participants explained that residents could come off of hospice services, also known as "graduating hospice", as a way to dispel the idea that hospice meant one is going to die immediately. As Ariel stated

> [Residents think hospice means] "You're going to die tomorrow," that's not what it means… I try to remind people that I've had residents that graduate from hospice. [Hospice] puts these things in place for them, and they do so much better that at the six month evaluation [hospice] says "you don't need us anymore."

Jules similarly remarked, when hospice was mentioned, she believed her residents thought "'am I going to die?'" and she reported she told them that it did not mean they are going to die immediately; she explained that she has "seen so many people over the years [use hospice], because they have 6 months to live, and then they get better… they meet the criteria, they rally, and they get better."

Resident Control. Five participants stated that resident control was an important benefit of hospice services, and residents who used hospice tended to have more control than residents in LTC alone. As Becky explained "[hospice] can be whatever you want it to be… that's all up to the patient and their family, depending what they want." Isabella remembered that hospice allowed a specific resident to "stand up and take charge, she decided on her own what she

wanted and [hospice] followed it to the T." Aubrey reported that hospice gave a resident "a little more autonomy over his life" and Liz explained that on hospice "residents have a little more say in their care, instead of 'oh, this is protocol, the doctor wants you to do this.'"

"Resident control" is another subtheme that tied back into the concerns of the dying discussed in the introduction. These participants expressed that hospice allowed residents to have more control and feel more sure that their wishes were going to be followed. This suggested that the use of hospice services can alleviate another major fear of dying individuals.

More than just death. Although most of the previous subthemes allude to the idea that hospice was for more than just the last few days of life, four participants directly acknowledged this subtheme. As Becky said,

> To me, it's just another stepping stone. A lot of people might see it as "oh, they have 6 months to live," but that's not necessarily true. That's not what hospice is about, it's just a different way of caring for someone.

Liz also explained that, in her experience,

> [Hospice] doesn't necessarily mean that you're saying "oh, I'm gonna die," you are just getting some help… I try to make sure people realize it's not a short term "oh my god, you're gonna die" but it's a longer term "we're gonna help you through this process."

Isabella added, to her, "[hospice] doesn't mean that they are dying tomorrow… it doesn't mean it's going to happen immediately, [hospice] does [evaluations] at 6 month intervals, so it doesn't, in any way, mean tomorrow."

The "more than just death" subtheme clearly demonstrated the difference between what hospice meant to the nursing staff and what they believed hospice meant to their residents. Even though, in these participants' experiences, residents emphasized the death aspect of hospice, these LTC nurses mentioned *more* than the end of life and death meaning of hospice. They focused on the services hospice provides and the benefits for the residents.

Support for Families. All 10 participants expressed that, to them, a main purpose and meaning of hospice was to provide support to the family of the dying residents. Liz stated that hospice "provides additional support before the death, helping [families] come to terms with it, letting them feel okay about it." Liz also added that hospice, in her experiences,

> Helps families to think, not so much in terms of survival, but in terms of comfort and peace…helping families not feel guilty, [families] are always like 'oh, I didn't do enough, maybe if I had done something different', [hospice] just helps them to understand that this is out of their hands and their not responsible for it.

Aubrey explained that hospice provided support for families and "provides [families] with an extra measure of comfort and safety." Ariel asserted that hospice

> Provides support for families… the [hospice] nurse on call will sit with the families… the [hospice] Chaplin can be called in to speak with the families and provide support… and [hospice] is present up to 6 months to a year after somebody passes, and I think that's such a good thing because sometimes people are not ready for their person to go.

This subtheme of family support was especially important, it was the first subtheme that did not focus on the resident alone, demonstrating that participant's perceived hospice as not only beneficial for residents, but also for others in the residents' lives. Also, in discussion about family support, participants expressed that hospice is around not only before and during the death, but after the death to assist the family. As Mari stated "grief does not end at the point when the person passes… there are still many things that can trigger grief, to help someone to concentrate on that, the grieving process of hospice" was a benefit of the after-death services provided.

Helping Long Term Care Staff. It was previously explained that hospice helped residents by giving more time and more staff. These aspects also had another perceived benefit; according to nine participants, they helped the LTC staff, as these extra people left less work for the LTC staff to do. As Joua explained, in her experience as a CNA, "we're usually busy… it's a

relief for us to not have to give one more shower, it's like 'wow, thank you hospice'…it's just less work for us to do." Aubrey stated that "for me, as a nurse or an aid, [hospice] means a little bit of relief for me, because they come in and they do the extra stuff that I can't always provide." Liz added that "the nurses and CNA's are spread so thin that it's hard, to get [the residents] the extra care [without hospice]."

Six participants also expressed that hospice provided emotional support for the LTC staff. As Liz expressed, in her experience hospice was "support for the nurses too, I had a lot of hospice nurses talking to our [LTC] nurses and helping them though the dying process, as well." Ariel added "it's not just the family that has lost a family member, because a lot of times, these residents turn into our family" and hospice helped the LTC staff with closure. Ellen simply reported that hospice is "somebody for our [LTC] staff to lean on."

These benefits to LTC staff, while mentioned in most interviews, were not the most important aspects of hospice to these participants. The topics that came up more often and had more discussion time dedicated to them, within and between interviews, were the benefits listed in previous subthemes that focused on the residents themselves. Illustrating a level of care and respect for the residents, these participants did not immediately think about the benefits for themselves; rather, they immediately thought about the benefits for their residents.

Why Residents Chose to Utilize Hospice

According to participants, many residents had incorrect or insufficient information about hospice services. As a result, many LTC nursing participants expressed that they needed to explain, or even market, hospice to their residents and the residents' families. Participants stated that after an explanation many residents become more comfortable with the idea and chose to use hospice due to this recommendation and due to the services provided.

Explain Hospice Services. Seven participants stated that they often had to explain hospice, as their residents had incorrect knowledge or no knowledge of what hospice was or what hospice could do for them. As Ariel explained,

> I have to do a lot of education [about hospice], "and this is what it's good for, and this is what it does." I have to educate more on why this is a good thing for them, and why it's good for your family, and last but not least, why it's helpful for me.

Isabella added, in her experience,

> It usually takes some talking and education, that this doesn't mean [death will occur] tomorrow, it doesn't mean its next week, it could be a year from now. But if this is the care that you need at this point in time, let's get it for you.

The explanation that these participants provided included informing the residents that hospice was about more than just death and that the services could be used for more than just the few days before death. This suggested that the LTC nurses were trying to dispel the previously discussed negative views that they believed their residents held.

Some participants expressed their wish that hospice would be responsible for increased explanations and marketing of services. Isabella clearly exclaimed, "I think hospice should promote themselves more and I think facilities need to use them more." Ellen explained,

> Hospice could push their educational opportunities for staff, or families, or residents council in the building. Set a time once a year that [hospice] comes in, meet with residents, and go through it. [The facility] usually has to ask for that, and it should come from the hospice side.

Recommendation. According to these participants, after the LTC nurses explained hospice services, residents were more likely to utilize the services due the nurses' recommendation; this subtheme was mentioned by six participants. As Ellen explained, in her experience, "once you sit with them [the residents] and explain what it's about, then they get it, and most of them will choose that route." Isabella made a similar statement,

I think a lot of times people don't understand what it is, and once you explain that it will actually benefit them in the long run, they will get more care, more attention, and some special treatment they are more willing [to use hospice].

As Becky commented

I think residents choose to use hospice because the conversation is stimulated by a healthcare worker, whether a nurse or a social worker, that's usually when they start thinking about it. It always takes a while.

Becky emphasized that the resident needed to trust the healthcare worker for the recommendation to be taken seriously. Utilizing hospice due to a recommendation was a subtheme where a difference was noted based on nursing position. A higher percentage of the LPNs (100% of LPNs) endorsed this theme, compared to the RNs (33% of RNs).

Services Provided. Once hospice was explained, LTC nursing staff stated that, in their experience, another reason why residents chose to use hospice were the services provided. As Tiffany explained, her residents utilized hospice due to "the services, the backup, the counseling, that kind of thing … the emotional part, over and over and over again." Ellen and Joua both stated that their residents chose to use hospice, often after the explanation, due to the extra support and attention hospice provided.

Other Noteworthy Concept

Comparison of one death that occurred with hospice and one death that occurred without hospice, based on content analysis. Participants were asked to describe one death that occurred with hospice services and one death that occurred without hospice services, all participants provided a story for each. This subset of data was coded using content analysis rather than IPA, as previously described. 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 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).

The "good death" categories included the codes: family acceptance, proper and sufficient

medication, respect for residents wishes regarding the dying process, a quick process, good

quality of life before death, peaceful death, and nearby presence of family. The "bad death"

categories included the codes: resident denial of the dying process, family denial of the dying

process, pain, loneliness, fear, poor quality of life prior to death, abrupt death, long or drawn-out

death, and failure to meet the residents wishes regarding the dying process. The stories often had

positive and negative codes and clusters, due to complexity of the dying process.

When reviewing the coded "good" and "bad" deaths compared to whether they used

hospice or not, a pattern emerged. This pattern suggested that when using hospice, a death was

more likely to have positive aspects and less likely to have negative aspects. Although no

statistical analyses were performed due to the small number of participants, these numbers and

the pattern are presented in Table 3.

When looking at the aspects of a "bad death," many more participants stated that the

death that occurred without hospice contained aspects of a "bad death" compared to the death

that utilized hospice, nine and four participants respectively. When reviewing at the aspects of a

"good death", the pattern was less drastic, but still clear. More participants stated that aspects of

a "good death" were present when the death occurred with hospice compared to the death that

occurred without hospice, 10 and eight participants respectively.

Table 3.

Comparison of "Good" and "Bad" death in regards to whether hospice was utilized or not.

	Aspects of a "Bad Death"	Aspects of a "Good Death"
Death Occurred with Hospice	4 participants	10 participants
Death Occurred without Hospice	9 participants	8 participants

Comparison of one death that occurred with hospice and one death that occurred without hospice, based on participant responses. When participants were simply asked what differences they noticed between the deaths they described, participants expressed many. Six participants stated that the dissimilarities they noticed between the deaths were due to hospice. For example, Ellen reported that a difference she noticed between the two deaths she described was

> The family support after the death, which I think is really important because you just never know if they have that outside support, some families don't… Gave me peace of mind, knowing someone is going to be checking in with them, providing them the reading material or different options if they are struggling.

Tiffany also explained that family support was a difference she noticed, with the death that occurred with hospice having more support and more acceptance.

Aubrey mentioned that, when comparing the two deaths she spoke on, the family that used hospice handled the death much better. Also, she stated that "[with hospice] there was another set of eyes, I knew that person was being taken care of… the hospice nurse fought for her patent." Additionally, when asked which death had more benefits, Aubrey confirmed it was the death that utilized hospice services.

When questioned about differences noticed, Isabella stated "the level of understanding, the level of pain, the level of services each death got, the attention, not only from staff but from the outside support services of hospice, even family support was totally different." Isabella exclaimed "most definitely, yes" when determining that hospice was the reason for those positive differences. She responded with "very much so" when clarifying that the death that occurred with hospice had the more positive aspects of the differences she listed.

Joua explained "the hospice death definitely had more care and concern over them, because of the extra time and resources." Jules added that the death that occurred with hospice was more likely pain free, due to the medication management, and that "the one [on hospice] was just led into it a little better." When asked if the process was more peaceful, she agreed with a boisterous "yes!"

The remaining four participants stated that there were no differences between the deaths, or mentioned differences that did not pertain to hospice services. For example, Liz explained that there were "differences in personality and … they had totally different needs and totally different wants" and Becky stated that "in one case the patient was non-verbal, it was a lot more progressive." Ariel and Mari reported no major differences.

DISCUSSION

Research Focus

The overarching research focus of the presented study was to understand LTC nursing staffs experiences with hospice services as well as their perception of how their residents have experienced hospice services. The findings point to a contradiction between these LTC nurses' positive experiences and their own meaning of hospice, and what they perceived to be the more negative experiences and meaning of hospice for the residents themselves. The meaning of hospice to these LTC nursing staff members was exceedingly positive. When they did have a negative experience, LTC nursing staff often blamed it on logistical issues or a specific staff member, rather than on hospice as a whole. This indicated that even with the possibility for poor experiences, LTC nursing staff still viewed hospice positively.

The limited prior research has focused on hospice nurses, with results suggesting that although they saw their jobs as stressful, they also found their works to be fulfilling and providing an opportunity to serve a purpose (Ablett & Jones, 2006; Evans & Hallet, 2006; Foxall, Zimmerman, Standley, & Captain, 1990; Payne, 2001). These studies indicated that hospice nurses tended to view hospice, in general, as positive and fulfilling a need of the dying population. The present study suggested that LTC nurses have a similar view, as they indicated that hospice provided a positive service to residents.

Raudonis, Kyba, and Kinsey (2002) found that LTC nursing staff do not have adequate knowledge of hospice services while Cramer, McCorkle, Cherlin, Johnson, and Bradley (2003) suggested when hospital nursing staff members are more knowledgeable of hospice services, they view it more positively and are more likely to talk with residents about hospice services. This indicates that if LTC facilities could increase the knowledge they provide to nursing staff,

there may be an increase the positive view for staff and residents. It is possible this was why the participants of this study had an extremely positive view of hospice services, as the majority were RNs and LPNs who had worked within LTC settings for a number of years and had therefore received adequate education on hospice services. Although there were no major differences between the one CNA and the other participants in regards to how positively they viewed hospice, the CNA interviewed also had worked in LTC for many years, and therefore may have had more knowledge and a corresponding more positive view of hospice services.

Regardless of the positive meaning of hospice for LTC nurses, the findings suggested that participants perceived that their residents experienced hospice services more negatively than the nurses themselves did. According to these nurses' experiences, to most residents hospice meant something rather negative and appeared to be feared. This may extend from an overall fear of death, as suggested by the participants.

Although little research was found interviewing residents on end of life topics and no research involving residents' experiences of hospice services were found during the literature review, previous studies have determined what patients are looking for in a "good death." These qualities of a "good death" seem to be 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). This may indicate that residents' views of a "good death" is congruent with the services provided by hospice.

These previous findings regarding what residents look for in a good death were supported when nurses in the present study were discussing the difference they noticed in deaths that occurred with and without hospice services. An additional research focus of this presented study

was to understand differences that nurses noticed between deaths that occurred with and without hospice services. Results suggest that aspects of a good death, such as those described in previous research, were more likely to occur when hospice was utilized and aspects of a bad death were more likely to occur when hospice was not utilized. When asked what differences were noticed, participants included differences such as family support, pain management, and the level of care for the resident; all being more positive when hospice was utilized.

The presented study also sought to understand why residents chose to or not to utilize hospice services. The participating LTC nurses provided multiple reasons why residents did not utilize hospice services. Many of these reasons were due to resident's incorrect or outdated knowledge regarding hospice services, as presented in the subthemes old views and fear of immediate death. As will be discussed in the practical implications, previous research has supported this finding of residents and older individuals having a lack of information regarding hospice services (Mor, Hendershot & Cryan, 1989; Vig, et al., 2010) and residents with less information regarding hospice services are less likely to utilize the services (Casarett, et al., 2005). Another reason why residents did not chose to utilize hospice services related to not being ready for end of life, as supported by the subthemes not accepting of end of life and not wanting to end treatment.

Fears of the Dying

Previously discussed were the three fears of the dying consistently found in the literature: dying in pain, communication regarding end of life, and resident control/knowing one's wishes will be followed. The participants in this study discussed pain management and resident control with enough endorsement to be considered a subtheme. Suggesting that these participants believed hospice services could help prevent these fears. They knew that hospice services could

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help prevent a resident from dying in pain, could allow a resident to have control over how the end of their life progresses, and could assure residents that their wishes were being followed. The last fear, communication regarding end of life, was discussed by a few participant but not enough to be considered a subtheme. However, when it was discussed, it was the belief that hospice provided more information about end of life and death, therefore attempting to dispel the final fear previously discussed.

Difference in Subtheme Endorsement Based on Nursing Position

Differences based on nursing positions were noted in two subthemes in the present study, more staff and residents utilizing hospice due to recommendation. A higher percentage of RNs than LPNs endorsed the subtheme of "more staff." This difference may have occurred because RNs felt that they had a larger work load, more residents to care for, and/or had more responsibilities within the nursing home due to having a higher position than the LPN group. Based on an increased workload, having additional staff come in to care for the residents may have been more noticeable or more appreciated at the RN level. Also, the RNs may have worked more directly with the hospice staff, so they may simply have been more likely to notice the additional people.

The second subtheme where a difference was noted was residents choosing to utilize hospice services due to a nurse's recommendation. A higher percentage of the LPNs endorsed the subtheme compared to the RNs. This difference may have been due to LPNs typically spending more time face to face with the residents compared to RNs. For example, LPNs are more likely to do baths or help residents up in the morning, which are longer face to face activities than RNs may partake in. Those with longer and more face to face contact may have

simply been more likely to discuss hospice as well as more likely to hear the residents say it was

due to a recommendation that they chose to use the services.

PRACTICAL IMPLICATIONS

Lack of Information on Hospice Services

Although hospice is for the end of life, meaning up to six months before death or longer

if the diagnosis remains terminal, the use of hospice does not mean death will occur in the next

few days. Based on the results of the present study, these nurses' interpretation of residents'

experiences was that using hospice services meant one was giving up on life and was going to

die immediately. This suggests that residents need to be more aware of what hospice really is,

that services can be used for many months during end of life, that there are many benefits to

hospice services, and that utilization of services can extend one's life.

The overall lack of information about hospice services for residents has been shown in

previous research. In general, slightly over half of older individuals (53%) are unfamiliar with

hospice and slightly less than half (48.5%) reported that they knew it was available if they

needed services (Mor, Hendershot & Cryan, 1989). Vig and colleges (2010) found that older

adults and their families often have misconceptions of hospice and these older adults are often

unaware of what a "hospice appropriate" patient is; for example, they believe that a hospice

patient needs to be currently actively dying, be a cancer patient, must be someone without any

family to support them, or would need to move to a hospice facility.

The lack of resident knowledge about hospice is further supported by previous research

findings that physicians fail to discuss hospice with 43% of hospice appropriate patients (Snyder,

Hazelett, Allen, & Radwany, 2012). Additionally, as discussed in the introduction, 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, congruent

with the presented results, that older adults may have a lack of knowledge of hospice services. It

has also been suggested that LTC nurses themselves may not have adequate knowledge on

hospice services, so therefore cannot share that information with their residents (Cramer,

McMorkle, Cherlin, Johnson, & Bradley, 2003; Raudonis, Kyba, & Kinsey, 2002). However,

the current study did not support this.

Suggested Intervention

The results of this study suggested that if residents knew more about hospice, especially

that hospice can be used for months before death occurred and that the use of hospice services

was not something to be feared, then more residents most likely would utilize these

services. This idea was supported when the nursing participants discussed that in their

experiences, residents tended to use hospice services only after they were explained in depth, as

many residents seemed to maintain outdated views or misconceptions. This result suggested that

creating an informative intervention with general information explaining hospice services to the

residents as well as to LTC nursing staff and encouraging them to share with their residents, may

increase the number of older adults utilizing hospice services. This intervention may be most

effective in an interactive or small group lecture format, instead of a passive approach such as

creating brochures to place with LTC facilities.

Existing research has supported this idea that an increasing the information regarding

hospice services may increase the likelihood of utilization. As previously discussed, when

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) and when hospice is suggested, residents are more likely to enroll in hospice and have a

high quality of care (Casarett, et al., 2005). As shown in the current study, residents are more

likely to utilize these services when recommended by their nurse. Previous research has also

indicated that individuals who participate in outpatient services that routinely discuss hospice

care have an increase in hospice use (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), suggesting that more informed

individuals are more likely to utilize services.

Emphasizing that hospice is for end of life, meaning up to 6 months, and not only for

one's immediate death will be an important distinction to make for residents and LTC nurses.

Marketing the benefits of hospice within this informative intervention may also help residents

feel more comfortable using hospice services and LTC nurses more comfortable discussing the

services. Research has identified multiple benefits of hospice services that could be included in

this informative intervention. For example, those enrolled with hospice have been shown to have

superior pain management, as discussed in the introduction, as well as significant symptom

improvement and more frequent social interactions when compared to conventional care

(Elsayem et al., 2004; Meier, 2011). Individuals who use hospice services have a higher quality

of life prior to death (Bakitas et al., 2009) and a higher quality of death when compared to those

who do not use hospice services (Wallston et al., 1988). Additionally, the use of hospice can

extend a person's life for up to two months longer than those who choose not to use hospice

(Meier, 2011; Temel et al., 2010). This last benefit may be especially important to older adults

at the end of their lives. This benefit of longer life may help dispel the idea that hospice is "only

for the very end."

Also important to include are the benefits for the residents' families, especially since their

families are often making these decisions for residents who are cognitively unaware or unable to

act autonomously. Previous studies have found that hospice is beneficial to the families of the dying. Hospice team members keep families up to date on the patient's condition and give the families an overview of what to expect during the dying process, making it easier when the death occurs (Kirkendall, Holland, Keene & Luna, 2014; Meier, 2011). Families of hospice patients have also been shown to have less anxiety and greater satisfaction with involvement in care (Kane at al., 1985). Also provided for the families are after-death services, including grief counseling and assistance with after death arrangements.

Overall, if an informative intervention was created based on general knowledge of hospice services and benefits of hospice services for the resident as well as their families, this researcher believes, based on the results of this and previous research, that older adult residents would be more likely to utilize hospice services. This informative intervention may be presented to older adult residents themselves, as well as to their families and appropriate medical staff, in particular LTC nurses. Although including primary care physicians in hospice interventions has 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) as well as are often the facilitators and coordinators between residents, families, and physicians regarding end of life plans (Cramer, McCorkle, Cherlin, Johnson, & Bradley, 2003). This suggests that it is important to include LTC nurses in the hospice intervention along with primary care physicians and other appropriate medical staff. The more people that know the benefits of and barriers to hospice services, the more likely that the intervention will have an effect.

As discussed in the introduction, the creation and implementation of this study were some of the strengths. The study focused on LTC nurses, clearly defined LTC as a care taking place within a nursing home, and defined hospice as hospice services being provided within that nursing facility. These aspects addressed limitations of past research.

An additional strength was that the themes and subthemes were found similarly across all six nursing facilities the participants were chosen from. Also, except for two subthemes, themes were found across nursing positions. This indicated that these ideas and themes were not specific to one facility or nursing positions.

One limitation of the present research was all 10 participants were of one self-identified ethnic group and gender, as well as all currently living in Northern Colorado. Although this indicated that these results are likely transferable to other individuals from a similar background and geographic location, it did not allow for an analysis of individuals of more diverse backgrounds. It also prevented a comparison between diverse groups of participants. Similarly, having only one CNA was a limitation of this study, as it was difficult to determine if other CNAs would have similar responses, particularly a CNA who has not been in the field for as long.

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

An additional limitation is the possibility that LTC nurses may have such a positive view of hospice services due to their own needs being met when hospice is included in a residents care. For example, participants of the current study expressed that hospice often means less work for the LTC nurse. As one participant clearly expressed, hospice means one less shower for her to do. This assistance to LTC nurses may be influencing their perception and creating a more positive meaning than they would have otherwise. Due to the multiple other positive experiences and meanings of hospice, it is unlikely this was the sole cause of the positive meaning, but it could be an influencing factor.

FUTURE DIRECTIONS

Increasing the amount of research on hospice within nursing homes, particularly differences between residents who utilize and do not utilize hospice services should be a focus of future research. Modern studies are necessary as the field has drastically changed since hospice became a Medicare benefit in the 1980s which is when much of the current literature was originally published. Studies should be created to reduce the limitations presented in the introduction, including large qualitative studies regarding LTC nurses beliefs and knowledge on hospice which would lead to more generalizable results than the current study, allowing for determination of if the present themes are similar across the larger nursing population.

Although this study indicated that the participating nurses believed, based on their perception, that their residents' views of hospice were more negative, it is important to gain an accurate understanding of residents' views by asking them directly. The nursing staff participants were creating these perceptions and beliefs based on their experiences, rather than the actual experiences of the residents, which may have led to an incongruence between the actual and perceived experiences of the residents. Future studies should focus on the residents' experiences of end of life and hospice services. These studies could be done in both a qualitative and quantitate design to ensure generalizability, while also truly understanding a small number of participants' experiences. Although this method would lead to rich data, interviewing patients and the dying is a difficult approach due to ethical as well as logistical issues (Hewlett et al., 2006).

Similarly, studies involving comparisons between LTC nurses who work in facilities without hospice wards, such as the present study, as well as LTC nurses who work in facilities

with hospice wards and hospice nurses may allow for a deeper examination of nurses perceptions of hospice services. These comparisons may allow for researchers to determine if the positive view found in the current study was only due to the participant's needs being met when hospice was involved in a residents care or if this positive view would be seen across nursing participants. These studies would also allow more information on perceptions of hospice services of those who work within hospice, near hospice, or simply interact with hospice when a resident choses to bring in the services. This could lead to more helpful information regarding specific staff interventions to increase hospice use.

Additional research on the previously suggested interventions would be of benefit. Researchers should determine if such an intervention truly would affect the percentage of older adult residents who use hospice services prior to their deaths. Also, it would be important to determine if differing interventions led to a more positive outcome, for example, interventions for residents versus for LTC nursing staff.

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APPENDIX A: VERBAL DEMOGRAPHIC SURVEY

Thank you for your willingness to be being 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) in a long term care facility
- You must have worked in a long term care facility, with direct resident contact, for one year or more
- You must have experienced the death of an older adult resident who used hospice services *and* did not use hospice services prior to their death
- You must be 18 years of age or older.
    1. **Gender Identity:**   Male   Female   Transgender

    2. **Age:** _____

    3. **Ethnic Heritage**:

                             African American

                             Latino/a

                             Asian American

                             Native American

                             Multi-Racial

                             White/Non-Hispanic/European American

                             Other, please explain:_____

    4. **Religious Affiliation:** _____

    5. **Job Title:** _____

    6. **Highest level of education:** _____

    7. **How long have you been working in long term care facilities?**

                             1-5 Years

                             6-10 Years

                             11-15 Years

                             More than 15 Years

    8. **How long have you been working at this long term care facility?**

                             1-5 Years

                             6-10 Years

                             11-15 Years

More than 15 Years

9. **In general, please estimate how many residents you have cared for that <u>used</u> hospice services prior to their death?**

<div style="text-align: center;">

1-5 Residents

5-10 Residents

10-20 Residents

20-50 Residents

More than 50 residents

</div>

10. **How many residents, do you estimate, you have cared for that <u>did not use</u> hospice services prior to death?**

<div style="text-align: center;">

1-5 Residents

5-10 Residents

10-20 Residents

20-50 Residents

More than 50 residents

</div>

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, this recording will be on a locked computer and will be delated 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 within long term care settings.

1. What does hospice within long term care mean to you?

> If needed

>> Tell me more about that

>> Could you explain a little more?

2. What, do you think, hospice means to your residents?

> If needed

>> Tell me more about that

>> Could you explain a little more?

3. Have you had more positive or negative experiences with hospice?

   a. Tell me about some of the positive experiences
   b. Tell me about some of the negative experiences

4. What is your experience with why residents might choose to be on hospice?

> If needed

>> Explain a little more

>> What do you mean?

5. What is your experience with why residents might choose not to be on hospice?

> If needed

>> Explain a little more

>> What do you mean?

6. What other thoughts on hospice or end of life of long term care residents you want to share?

Now, I am going to switch focus and ask you to think about two older adult residents, living in long term care who you knew well near the end of their life. One resident who used hospice services near the end of his or her life and one resident who did utilize hospice services.

1. First, let's talk about the older adult resident that you knew fairly well whom you worked with within a long term care facility near the end of his/her life and who did not use hospice services before his or her death
   a. What do you recall about this individual?
   b. Tell me about his/her death
   c. What stood out most about his/her end of life experience for you?
   d. Why did you choose this person? (Possible probes)
      If uncertain:
         What made him or her come to mind when I asked you to select one resident?
   e. What, do you believe, led this individual to not use hospice services?
2. Now, think about an older adult resident that you knew fairly well whom you worked with within a long term care setting near the end of his or her life and who used hospice services before his/her death.
   a. What do you recall about him/her?
   b. Tell me about his/her death
   c. What stood out most about his/her end of life experience for you?
   d. 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?
   e. Why did you choose this person? (Possible probes)
      If uncertain:
         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 hospice may have been the reason for those differences?

If uncertain or do not have an answer:

Research suggests that those who use hospice services during the end of their life sometimes have a difference experience than those who do not utilize hospice services, does that fit with your experiences?

If still uncertain and more specifics are needed (multiple options):

1. Research suggests that those who use hospice services have less pain, how does that fit with your experience of these two residents?

2. Research has found that those who use hospice services have more open communication with providers, does that fit with your experiences?

3. It has also been suggested that those in hospice during the end of their life have a better understanding of the process of dying, does that fit with your experience of these two residents?

4. Do you have anything else you wish to say about these two experiences or residents?

Research Participants Needed

End of Life and Use of Hospice Services as Experienced by LTC Nuring Staff
Principal Investigator: Tammi Vacha-Haase

Would You...

-Like to volunteer to help a CSU counseling psychology student with her research on end of life care and hospice?

-Consider partaking in a 45 minute interview occuring at your workplace?

I'm Looking for Individuals Who...

-Are currently on the nursing staff of a Long Term Care Facility (e.g. CNA, RN, LPN)

-Have worked on the nursing staff at a Long Term Care Facility for at least one year

-Have worked with one resident who used and one resident who did not use hospice services prior to their death

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EOL & Hospice Interview
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Research Participants Needed

End of Life and Use of Hospice Services as Experienced by LTC Nuring Staff

Would You...

-Like to volunteer to help a CSU counseling psychology student with her research on end of life care and hospice?

-Consider partaking in a 45 minute interview occuring at your workplace?

I'm Looking for Individuals Who...

-Are currently on the nursing staff of a Long Term Care Facility (e.g. CNA, RN, LPN)

-Have worked on the nursing staff at a Long Term Care Facility for at least one year

-Have worked with one resident who used and one resident who did not use hospice services prior to their death

Please contact:
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Principal Investigator: Tammi Vacha-Haase