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Hospice Families Shared Experiences With Time-of-Death Visits

Katherine S. Katzenberger
Abilene Christian University, ksk18b@acu.edu

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This doctoral project, directed and approved by the candidate's committee, has been accepted by the College of Graduate and Professional Studies of Abilene Christian University in partial fulfillment of the requirements for the degree

Doctor of Nursing Practice

Nannette W. Glenn, Ph.D.

Nannette Glenn, Dean of the College
of Graduate and Professional Studies

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Doctoral Project Committee:

Catherine Garner

Dr. Catherine Garner, Chair

Dr. Tonja Hartjes

Dr. Gibson

Dr. Linda Gibson

Abilene Christian University

School of Nursing

Hospice Families Shared Experiences With Time-of-Death Visits

A doctoral project submitted in partial satisfaction

of the requirements for the degree of

Doctor of Nursing Practice

by

Katherine S. Katzenberger, RN MN CHPN

April 2021

Dedication

I dedicate this project to my Lord Jesus Christ because without Him, I could do nothing. This project is also dedicated to hospice nurses everywhere who provide love and care to dying patients every day and especially to my Hospice family, who have given me so much love and support for this project. This project is also dedicated to the families who tirelessly give of themselves every day to care for their loved ones and for whom I desire to improve our support for them.

I also dedicate this work to my parents George and Carolyn Skinner, who, through their life and death, have taught me more than they could have ever imagined about working hard and reaching for your dreams. I carry you both with me every day, and I wish you could have been here to see this finished work. I know you are smiling down at me from heaven! Finally, I dedicate this work to my wonderful husband Greg and my children Stephen, Devon, Kristen, Alex, and Andrew. Your support has meant the world to me, and I could not have accomplished any of this without you!

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Most importantly is acknowledging that without the Lord’s guidance and empowerment, this path would have never been successful. God placed it on my heart to take this path, and without His guidance, this study would never have ever been completed. Lord, I look forward to what the next chapter brings and what you have for me to do!

Abstract

The death of someone we love is a life-altering experience and may happen in a variety of settings. Hospice patients may die in their homes with their loved ones caring for them in their last moments of life. Families may receive a visit at the time of death from their hospice nurse. Few studies have been conducted looking at the lived experiences of home hospice families that have received a visit at the time of death from hospice. To better meet these families' needs, the researcher conducted a study to explore and better understand their lived experiences. A qualitative phenomenological approach was used with Jean Watson's human caring theory providing the theoretical framework for the study. Eight letters were mailed to eight participants who agreed to participate in a telephone interview lasting less than one hour. I developed an open-ended interview guide to assist with the interview. The participants were the patient's primary caregivers and had lost their loved one between six and 13 months prior. Data were analyzed, and themes emerged under the headings of reason for time of death visit, meaningful tasks, and bereavement. Results showed families most desired to have someone present to handle the details and provide support. Showing respect for the person who had died was an important theme, as was the desire to have their loved one's death verified. Recommendations include educating hospice staff on the findings and hospice clinicians developing a time of death plan of care with families based on the study findings. By establishing the time of death plan of care, the family can be aware of what the time of death visit can provide to them for support and make decisions before the moment of death.

Keywords: bereaved, end of life patients, family member, home hospice patient, hospice care, and time-of-death visit

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Chapter 1: Introduction

Overview of the Problem Statement

The moment someone loses their loved one, it forever changes their life. Most adults will experience the death of someone they love in the hospital, nursing home, adult family home, or their own home. Their loved one may die suddenly from a cardiac event or accident, or they may have a life-limiting illness and be in hospice care. In 2017, over a million people died in the United States while receiving hospice care, and approximately half of these patients died in their homes with their family or friends providing their care (National Hospice and Palliative Care Organization [NHPCO], 2018). Many of these patients are cared for by family members or caregivers who may have minimal experience caring for someone at the time of death.

A time-of-death visit is defined as a hospice clinician visit that occurs when and where the patient died while the body is still present (Katzenberger & Nichols, 2019). This visit is made to support the caregiver or family who has just experienced the death of their loved one or patient. Supporting families in meaningful ways at the time of death can have a positive impact on their bereavement process and provide opportunities for family members to express their emotions (Roberson et al., 2018). Hospice practices in providing care at the time of death vary from one hospice to another. Some states require a time-of-death visit for death pronouncement.

In the Pacific Northwest home-based hospice where this project occured, many staff members have expressed discomfort about what to do to support families at the time of death. A process improvement project was completed several years ago that provided nursing and provider education; however, little information was found in the literature to create evidence-based practice as to what families find to be meaningful and supportive time-of-death care.

The problem identified was there is no evidence-based clinical guidelines for a time-of-death visit, nor was there standardized information for families about the range of services offered during this visit. The purpose of this project was to understand better the lived experiences of those who received a time-of-death visit to develop patient-focused clinical practice guidelines and the accompanying family education information or plan. Family input can provide insights into their perceptions regarding the most meaningful aspects of the visits and additional services that could support the family.

Background

Hospice care is intended to provide support for patients and their loved ones when they are diagnosed with a life-limiting illness and have a prognosis of six months or less (NHPCO, 2018). Hospice provides support and education for families in what to expect as their loved one declines and approaches death. Patients who choose hospice care have chosen not to pursue aggressive treatment for their illness, or there is no treatment available. Care focuses on comfort and quality of life (NHPCO, 2018). Care is provided in any place that the patient calls home, whether it is in a facility, their home, or someone else’s home. Patients may also have paid caregivers or live in a care facility (NHPCO, 2018). Hospice is a holistic approach to care and supports the family through the death of their loved one; families also receive 13 months of bereavement services after their loved one’s death. These services may include support groups, bereavement information mailings, phone calls, or in-person counseling (NHPCO, 2018).

When a patient dies on hospice, the family or caregiver is usually present and starts the after-death process. Hospice clinicians may be present at the death or may receive a call after the patient has died, and then a time-of-death visit may occur. A time-of-death visit is made to provide support to the caregiver or family who has just experienced the death of their loved one or patient (Katzenberger & Nichols, 2019). Support can be provided through supporting and facilitating death rituals that support families in their bereavement. This provides families with a way to remember and honor the life of their loved ones (Roberson et al., 2018). Death rituals can vary widely among cultures and religious practices, and hospice clinicians need to have knowledge about these so they are better able to support families at the time of death (Roberson et al., 2018).

In the United States, there are no standards for what happens at the time-of-death visit. States differ in their requirements for reporting an expected death (Price, 2012). In some states, the hospice registered nurse (RN) is required to visit the home or facility after the death to confirm the patient has died for the medical examiner’s office to release the body to the funeral home (Price, 2012). Notification is not required in other states or counties as the medical examiner’s office does not require notification before the body is released to the funeral home. In these cases, the hospice may ask the caregiver or family if they desire to have a visit after the patient has died (State of Washington, n.d.).

Since there are no consistent standards for the time-of-death visit, a family or caregiver may receive anything from no visit after the patient has died to a visit where the body is bathed and prepared for transport to the funeral home and emotional support is provided to the caregiver or family. The type of visit the caregiver or family member receives can be impacted by their understanding of what a visit would look like after the death, hospice staffing availability, and the staff member’s comfort level.

Purpose of the Study

The purpose of this qualitative phenomenological study was to understand the lived experiences of home hospice families who had a time-of-death visit from a hospice clinician.

This qualitative study was conducted with families of a home hospice agency in the northwestern United States. Face-to-face semistructured interviews were conducted with six to eight home hospice families who received a time-of-death visit from the agency's nurses. The agency approved this study and used their home hospice family database to recruit participants for me. The questions for the interviews were developed based on the literature review. The literature review results and exploratory study findings were then used to formulate clinical practice guidelines and create a standardized, evidence-based, time of death, family information and planning sheet. This was a tool for clinicians to use when preparing for and supporting families at the time of death.

The information sheet provided education to the families so they were aware of the supportive services they could receive from hospice if they desired a time-of-death visit. The goal was to meet the needs of the family while having a standardized approach to care. This process was similar to how hospice clinicians approach end-of-life care and education. There is a standardized approach, but the plan of care is individualized to meet the patient and family needs (NHPCO, 2018). By creating a standardized approach for the time-of-death visit, this tool can be used to educate hospice clinicians nationwide. It can help establish a more holistic approach to supporting the family and caregiver at the death of their loved one. Creating clinical guidelines based on the current literature and home hospice family shared experiences will provide clinicians with evidence-based practice for time-of-death visits. The family educational tool will explain the purpose of a time-of-death visit and provide families a standard for what they can choose to receive. Families need to understand this part of the patient plan for care, which can be modified based upon their needs.

Significance of the Project

A standardized approach to the care regarding a deceased patient and families' support is not only a hospice issue but also expands to the hospital setting, especially the critical care department, where death is not an uncommon occurrence. Clinicians can often find information on how to address the needs of the dying patient. The protocols and recommendations for supporting the family often stop with the patient's death (National Institute for Health and Care Excellence [NICE], 2015). When a loved one dies, this moment will be forever remembered by their family. In my 28 years of experience, I have spoken to many people who have shared their family's death experience with hospices and hospitals across the United States. Some family members have cried over the regret of how their loved one left the home, perceptions the body was not cared for respectfully, and not knowing they had options for supportive services. Others have expressed unanswered questions and guilt, wondering if the last dose of morphine they gave is the reason their parent died, while others have shared positive experiences.

The significance in researching the lived experiences of families ties directly to the need to provide patient and family-centered care. A study in Finland by Anttonen et al. (2011) evaluated the quality of hospice care provided to families. Anttonen et al. looked at different family experiences, including home visits after the patient had died. This study showed the lowest hospice satisfaction scores were around the support they received when the hospice visited at the time of death or shortly after that (Anttonen et al., 2011). Some of the identified concerns were the staff seemed rushed and sometimes uncomfortable. Other families did feel they received adequate support at the time of death. The study did not identify which behaviors were identified as supportive or nonsupportive to the family (Anttonen et al., 2011).

Additional studies demonstrate the significance of improved nursing care practice at the end of life. One study looking at the education and comfort of critical care nurses found that 91.5% of these nurses had never received instruction about how to care for a deceased patient, and there was no standardized procedure for care or support for families (Çelik et al., 2008). Of the nurses surveyed, 24.5% stated they did not provide any emotional support to the families at the death of the patient, and those who did mainly allowed the family time to be alone with their loved one (Çelik et al., 2008).

Another study looked at oncology nurses in a palliative care unit. Although most of the nurses did provide some emotional support to the families, the nurses desired more education as to how to support families at the time of death (Chan et al., 2013). They also desired more education on how to care for the deceased in a meaningful way for the families. One pilot study conducted in an intensive care unit compared nurses who received training in bereavement care and those who did not (Kurian et al., 2014). Of the nurses surveyed, about half of the nurses stated they needed further education to provide care to the family to meet their emotional needs at the time of death of their loved one (Kurian et al., 2014).

Another study interviewed nursing staff regarding their perceptions of how prepared they felt in having discussions and supporting veterans' families before and after the death of their loved one (Williams et al., 2012). Nurses often stated they did not feel they had enough training in how to support families before and after the death. This study found the families did feel supported even though the nurses did not feel confident in the care they provided after the patient's death (Williams et al., 2012). This study identified some key nursing behaviors that helped these veteran families through the first moments after the death of their loved ones

(Williams et al., 2012). These studies support that there is a gap in nursing practice on how to provide meaningful and supportive care to families during and after their loved one’s death.

Nature of the Project

The project design was a qualitative descriptive study guided by Jean Watson’s human caring theory. Participants were hospice families that had experienced the death of a loved one within the last 13 months and did receive a time-of-death visit. The study used existing research literature and guidelines on patient-centered care principles to conduct in-depth retrospective descriptive interviews. Following informed consent, the families were asked a similar series of semistructured, open-ended questions regarding their experience at the time of their family member’s death. The open-ended format allowed me to explore different statements that may be expressed throughout the interview (Creswell & Poth, 2018). Interviews were conducted by phone , lasting 30–60 minutes. The interviews were audio-recorded and transcribed for analysis. The data were analyzed using the approach recommended by Miles et al. (2020).

A qualitative study was most appropriate to explore the lived experience of the home hospice bereaved because a quantitative study would not present their story and their experience. Quantitative studies are usually performed when there is a significant amount of data on the subject and there is information known on the subject (Keele, 2011). Qualitative studies are about understanding experiences that provide feedback to create the next stage of operations in family-focused care (Keele, 2011). Using a semistructured interview guide, each person received a similar interview while also allowing the interviewer to explore any areas that required clarification or further investigation. The interview data allowed for a word for word transcription and allowed the data from multiple interviews to be sorted into similar patterns or themes. Quantitative surveys would have questions, but the answers would not have the family's story flow and could not adequately capture the lived experience (Keele, 2011).

A transcendental phenomenological approach was appropriate for this study because phenomenology studies a person's experience (Keele, 2011). Interviews are a standard method used to obtain information for these studies, and data encompasses the participant's responses and the interactions between the interviewer and the participant (Creswell & Poth, 2018). Phenomenological studies are also performed when very little is known about a particular topic (Creswell & Poth, 2018). Very little research was published about the lived experiences of home hospice bereaved who received a time-of-death visit. Therefore, this type of approach was appropriate to gain knowledge on the topic. Descriptive phenomenology studies look at the essence of the experience as described from the person's point of view (Keele, 2011).

Research Question

The PICOT question that drove this study was, What are the lived experiences of home hospice families who received a time-of-death hospice visit discovered through qualitative semi-structured interviews? The population was home hospice families who had experienced a time-of-death visit from a hospice clinician. The intervention was a phenomenological study of their experiences. The outcome desired is a deeper understanding of the most meaningful aspects of a time-of-death visit and any perceived gaps in care. This information will be used in developing clinical practice guidelines. The study was conducted over nine to 12 months.

Hypothesis

There is no hypothesis, as this was a qualitative study.

Theoretical Framework

The theoretical framework used in the study was Jean Watson’s human caring theory, as it encompasses the type of care that would be expected or should be expected in caring for families at the time of death. This theory contains 10 essentials for human caring, which evaluated the caring tasks identified in the study (Watson Caring Science Institute, 2010).

Definition of Key Terms

Operational definitions are provided to more clearly understand the terms used in the project paper:

Bereaved. A person who has lost a loved one within the past 13 months (NHPCO, 2018).

End of life patient. A patient who has a prognosis of six months or less (NHPCO, 2018).

Family member. Whomever the patient had identified as their support system, they may have been the caregiver of the one who has passed away (NHPCO, 2018).

Home hospice patients. Patients that received hospice care in their own homes; these patients were not being cared for in a facility (NHPCO, 2018).

Hospice care. Care provided for patients that have a prognosis of six months or less; the emphasis is on comfort care and quality of life. These patients do not wish aggressive care treatment (NHPCO, 2018).

Time-of-death visit. A hospice clinician visit that takes place where the patient died and when their body is present (Katzenberger & Nichols, 2019).

Scope and Limitations

This project was conducted at one very large outpatient hospice organization in the Pacific Northwest. The area was very diverse, not only ethnically, culturally, and spiritually but also economically. By choosing such a diverse area, the project provided an opportunity to learn and hear different perspectives.

The project’s limitations were using one agency instead of multiple agencies where different responses may be obtained. Letters were mailed, and the bereaved contacted me if they were interested in participating. It took time for a large enough sample; usually six to eight are obtained (Creswell & Poth, 2018).

Chapter Summary

Understanding the lived experience of home hospice families receiving a time-of-death visit from hospice is important. Hospice clinicians cannot know what support is most helpful and meaningful to the families unless they share their experiences. This project will give voice to the family members’ experiences. This information will be used to educate hospice clinicians on providing better care to their families after the death and creating an information sheet for families so they will have a better understanding of what a time-of-death visit can provide for them.

This project used Jean Watson’s human caring theory. The operational terms for this study were identified to assist in the comprehension of the project scope. The scope and limitations of this project have also been defined. This project aims to provide information that will help hospice clinicians better support their families during their time-of-death visits.

Chapter 2: Literature Review

Hospice provides care to not only the patient but also the family. The percentage of patients who are choosing to elect hospice is increasing, and as the U.S. population continues to age, even more people will be electing for hospice care (NHPCO, 2018). Hospice care can be provided any place the patient calls home, but for many, their family becomes the caregiver for the hospice patient. Often these family members have little to no experience with caring for and being with someone as they die, and caring for someone they love makes the death even more impactful (Lobar et al., 2006).

When a loved one dies, hospice families may receive a time-of-death visit from a hospice clinician, typically a nurse. The type of support the clinician provides can range from the pronouncement of the patient's death to bathing and preparing the body before the funeral home arrival. Sometimes no time-of-death visit may be desired by the family, and some states or counties do not require an RN visit to verify the death before the medical examiner releases the body (Katzenberger & Nichols, 2019). When performing a time-of-death visit, it is important to remember different religions and cultures grieve the loss of their loved one in many ways and utilizing varying rituals. The kind of care provided to their loved ones at the time of death can be important in their grieving process (Lobar et al., 2006). This review explored the current literature available to answer the research question: What are the lived experiences of home hospice families who received a time-of-death hospice visit discovered through qualitative semistructured interviews?

Evidence-Based Search Methodology

A literature search was conducted using four databases. The databases used included CINAHL Complete, Health Source, Nursing Academia, and Medline. Search terms were used to access possible research articles to include in the review. Search terms included *time of death rituals*, *time of death and hospice*, *postmortem care*, *postmortem care and hospice*, *time of death care and hospice, death care and family support*, *death care rituals and expected death*, *bathing rituals at death*, and *family support at death*. The search was filtered by date 2013 to present, all peer-reviewed, full text, and English. The literature was searched until saturation was obtained. Inclusion criteria were adult death, death care, expected death, and hospice death. Exclusions included child death, miscarriage, suicide, or traumatic death. Articles were initially chosen by title, and the total number included were 243 articles that were hand-searched by abstract, and duplicates were removed. Of the 243 initial articles provided, 41 articles remained. Each article was individually read, and articles were removed when care at the time of death was not addressed in the article. Most articles were about death but did not include any reference to the time of death, and others were not research studies, so they were excluded. The total number of articles left for the review was 14.

Findings

Death Rituals

One of the most common rituals found in the literature was bathing the body at the time of death. According to Rodgers et al. (2016), families in the acute care setting found bathing the patient after death to be a very meaningful and honoring experience. The study interviewed 13 oncology families who assisted in the honoring ritual after their loved one’s death. Many felt the bathing practice was significant both for their grieving process and spirituality (Rodgers et al., 2016). Many of the participants expressed they felt the practice provided them a chance to say goodbye and provided direction at a time when they otherwise would have felt frozen, not knowing what to do or how to act. By participating in the bathing rituals, several individuals reported feeling it was the last loving act they could provide and knew they would never forget it (Rodgers et al., 2016). Many family members stated the practice was so meaningful and honored their loved one. The study's weakness was the sample size of 13, and the study was conducted on an inpatient unit in one hospital (Rodgers et al., 2016). Strengths included the meaningfulness of the study, and this study can help build an evidence-based practice for nursing standards of care at a patient's time of death (Rodgers et al., 2016).

After-death rituals can be honoring and advocate for the religious and cultural needs of the patient and family. Olausson and Ferrell (2013) examined how nurses interpret after-death care and asked nurses to describe an example of an excellent after-death care situation they had seen or participated in. The study was conducted at an End of Life Nursing Conference, and the participants completed 196 surveys (Olausson & Ferrell, 2013). According to the results, nurses viewed bathing the body and preparing the body for the family as important, including following the family's wishes, such as with religious and cultural rituals. An example was provided of a Buddhist patient where no touching was allowed for eight hours, the patient was turned east before death, and Monks came and chanted as the soul left the body (Olausson & Ferrell, 2013). The nurse was able to honor the patient and family's religious rituals that were meaningful to them. Nurses also identified the importance of the family spending time with their loved one's body and participating in the death rituals as they desire (Olausson & Ferrell, 2013). Some nurses described their unit or facility performing their rituals when a patient dies, such as burning a candle, saying a prayer, or playing music. This study recommends the creation of an ADC (after death care) plan to assist the staff in knowing what the family desires for the patient's care before the death occurs to ensure fulfillment of the patient and family wishes (Olausson & Ferrell, 2013).

Another cultural and religious group with specific death rituals is Muslims. Muslims have specific death cleansing rituals when they die. Venhorst et al. (2013) looked at Islamic ritual experts in a migration context and their role in performing death rituals. The body is cleansed after death and requires approximately three people to perform the washing respectfully. The deceased needs to be turned and treated gently. Women can only be washed by women even after death (Venhorst et al., 2013). Muslims usually have washing teams with a ritual expert that leads the team. By performing the ceremonial washing, the deceased will transition into the next life peacefully. The study's weakness was it did not clearly define the sample size and how the interviews were conducted and analyzed (Venhorst et al., 2013). However, the study did provide important religious and cultural needs for these patients at the time of death.

Supportive Care Needs

Another area of care for families after the death reported in a study by Harrop et al. (2016) was feeling abandoned by their care team after the death of their loved one. This qualitative survey involved 1,403 respondents who identified communication after death to be an important aspect of their death experience. Strengths of the study included the large sample size and the wide range in the United Kingdom that received the public service survey for palliative and end-of-life care (Harrop et al., 2016). Additionally, it was delivered to stakeholders through the newspaper, internet, social media, presentations, and blogs. Responses were free text and included rich data; however, the study's weakness was the respondents to the survey either had great experiences or had very bad experiences and therefore may not represent the majority of the families (Harrop et al., 2016). Another weakness is the study's location since palliative and end-of-life care can vary from country to country. The study would have had greater application to my study had the study been conducted in the United States. Unfortunately, responses could not be explored further since the study was a survey and did not include an interview component (Harrop et al., 2016).

A study by Chan et al. (2013) completed semistructured qualitative interviews about bereavement care they received or delivered with 10 families and 15 nurses from an inpatient oncology unit in Hong Kong families. They identified the need to be kept informed regarding all aspects of care, including after the death. They expressed a need to understand the use of morphine and its effects on the body (Chan et al., 2013). Family members who had the chance to see their loved one or participate in after-death care felt it positively affected their bereavement experience. Nurses expressed a need for support after the patient’s death due to dealing with the family’s feelings of being wronged, helpless, frustrated, and confused. Nurses expressed the need for further education on how to support the bereaved (Chan et al., 2013).

In the United Kingdom, in a small English hospice, Martin and Bristowe (2015) conducted 10 semistructured interviews of nurses and health aides to discuss any challenges with carrying out the last office (care at the time of death) and involvement with the patient’s significant other. Many nurses stated they placed a high value on making sure the patient was clean, straight without medical equipment, and the room looked nice to provide the family with a peaceful view (Martin & Bristowe, 2015). The nurse stated she always took the lead from the family as to what she does to care for the body. A couple of nurses stated they felt caring for the patient’s body is spiritual and an honor. A few nurses stated that allowing the family to participate in the death care helped the family find closure and know what was happening (Martin & Bristowe, 2015). Most nurses stated they acted as gatekeepers for the family as they were concerned about the family’s negative psychological effects if they participated. More research is needed to discover the impact of having a family participate in the last office (Martin & Bristowe, 2015).

A Canadian study by Mohammed et al. (2018) interviewed 61 bereaved caregivers whose loved one received standard oncology care versus early palliative care while interacting with home care services. The study was a randomized control study with semistructured interviews. Grounded theory was used to analyze the data. Caregivers felt in some cases they were unprepared for the death but appreciated the ability to debrief with the palliative nurse or physician afterward (Mohammed et al., 2018). Caregivers expressed feeling in “function mode” due to so many people to notify, including the home care team for death pronouncement, family, and making funeral arrangements. One caregiver stated it felt like a day of organization and tasks (Mohammed et al., 2018). Caregivers were appreciative when home care took on administrative tasks and allowed them to grieve. There was no mention of any death rituals or care to the patient’s body. The study recommended more support and preparation by home care staff around what to expect at death and more support at the time of death for caregivers (Mohammed et al., 2018).

The care of dying patients in the Mayo Clinic in Rochester, Minnesota, was the focus of a study by Carey et al. (2018). The team completed telephone surveys of family members of 104 patients who died in the hospital. They used a “validated tool called the *Toolkit After-Death Bereaved Family Member Interview*” (Carey et al., 2018, p. 192). The team also added additional questions desired by stakeholders and from the literature to create a comprehensive tool. Descriptive statistics were used for data analysis as well as logistic regression models. The study primarily addressed care to the patient leading up to death. However, the study did capture many family members feeling they did not receive the emotional care they needed when the patient died (Carey et al., 2018). Family members also desired more information about what care would take place when their loved one died. Researchers concluded more education for staff is needed to meet families' needs when their loved one is dying in the hospital setting (Carey et al., 2018).

A study of 19 critical care nurses by Arbour and Wiegand (2013) looked at the nurses' role in caring for patients and families at end of life. The study was conducted through individual interviews and was audio-recorded. The transcripts were analyzed using a phenomenological analysis (Arbour & Wiegand, 2013). Nurses reported their role was to help protect the families' final memories of their loved one by making sure the patient looked good for the family and making a home-like setting by playing music and removing the tubes and equipment. Nurses also expressed supporting a family through death and managing symptoms was important (Arbour & Wiegand, 2013). Some people may find it surprising that critical care nurses with limited experience can feel anxious when caring for patients at end of life. These nurses need mentoring from more experienced nurses, so they feel equipped to support patients and families through the patient's death (Arbour & Wiegand, 2013).

An integrative review of how intensive care unit (ICU) nurses see their role at end of life was completed by Noome et al. (2016). The review included 20 studies from both the United States and other countries. Findings were divided among four categories: care for the patient, family, environmental aspects of end-of-life care, and organizational aspects of care (Noome et al., 2016). The review revealed information regarding care at the time of death, and some new recommendations for care emerged, which included providing a lock of hair, handprints of the deceased, and their identity bracelet. Some additional ways to make the environment peaceful would be adding music, adding a colored sheet or quilt, and dimming the lights (Noome et al., 2016). These additional recommendations could be very meaningful to families and should be considered as options for after-death care. The weakness of the review was the article only included ICU nurses, and no home care nurses were included (Noome et al., 2016).

Social Worker's Role at Time of Death

How families describe a 'good death' was the focus of a study by Holdsworth (2015). I conducted 44 interviews with bereaved family caregivers of deceased hospice patients in England. Six themes were identified, but two were related to the time of death, which are a presentation of the patient at the time of death and support after the death for protected grieving (Holdsworth, 2015). If the patient died peacefully and appeared at peace, this helped to reassure the family and contribute to their view of a good death. Family members reported receiving visits from the hospice staff right after the death and days later as very supportive and provided the family an opportunity to ask questions about any concerns they had after the death (Holdsworth, 2015).

Physician After Death Pronouncement

Physician behaviors that were viewed as compassionate or not as compassionate were the focus of a study by Mori et al. (2018). The study was conducted in Tokyo and had 92 people view videos that showed physicians with compassion enhancements and those without compassion enhancements at the time of death pronouncements. The statistical analysis revealed significantly lower scores with nonenhanced compassion videos (Mori et al., 2018). The study's strength was the large sample size, but the study was completed outside the United States and was with physicians instead of a nurse, though the information can be generalized to nurses. Study findings recommended physicians initiate the examination of the body as soon as possible, respectfully complete the exam, confirm the time of death using a wristwatch instead of a smartphone, and ensure the family the patient died without pain or discomfort (Mori et al., 2018).

An additional physician study regarding death pronouncement was conducted in Japan by Kusakabe et al. (2015), where 91 bereaved home hospice families completed a survey regarding physician time of death pronouncements. Kusakabe et al. (2015) concluded there were positive feelings for doctors of medicine (MDs) acting calmly and not rushed, having a suitable appearance, introducing themselves to the family, explaining the cause of death, and using a light and stethoscope when pronouncing. Negative results were found when the physician seemed rushed, left the patient disheveled, and did not verify the time of death (Kusakabe et al., 2015).

No Time-of-Death Visit

Katzenberger and Nichols (2019) performed a study where seven home hospice families were interviewed who chose not to receive a time-of-death visit. Their study revealed that some families prefer not to receive a visit to their home after their loved one has died. When the family has good social support systems and previous experience with death, and in this study, several had members of the families who were nurses, they appeared to do well without hospice support at the death (Katzenberger & Nichols, 2019). Several family members expressed a visit would have been an invasion of the family's "sacred" time with their loved one. The study did not explore if the families performed any death rituals though, one family did bathe the body prior to the patient leaving the home and stated it was a good experience for them (Katzenberger & Nichols, 2019). Several families did not understand why hospice would need to come out and did not understand what hospice would do at the visit. Katzenberger and Nichols (2019) concluded that more research is needed in understanding the unique support needs of the home hospice families, especially those with limited support systems.

Search Limitations

This literature review produced 14 studies related to the time of death of patients and supporting their families. Only a few of the studies were directly researching rituals or support at the patient's death. Only six studies were based around home settings as the majority were focused on death care in the hospital setting. Most of the studies were also conducted outside of the United States, where care practices and expectations of care are different from the United States. In the 14 studies, only five studies were hospice-focused through hospice, and palliative care was mentioned in several studies. The majority of the studies were focused on the family or caregiver's view, with six studies either including nurses or being conducted with just nurses caring for the patients.

Strengths

Most of the research included were qualitative studies. Using qualitative studies, I was able to capture rich information that allows the reviewer to understand better what may be important to the family around the time of death (Creswell & Poth, 2018). Semistructured interviews allow the researcher to explore information that may come up during the interview that can lead to information that would not have normally been captured (Miles et al., 2020). Some important information was discovered through the studies.

A major strength of the studies was that many provided positive, supportive care measures that were identified by families. In several studies, families expressed they felt more relaxed when their loved one "looks clean and peaceful." Several expressed the value of having someone call or stop by either soon after the death or days later to check-in, as they see these visits as supportive. One study discussed the importance of rituals and how they see caring for the body as an honor (Rodgers et al., 2016). Additionally, one nurse reported obtaining a lock of hair or making a handprint of the patient (Noome et al., 2016). The bereaved expressed the importance that the nurse or MD does not appear rushed and take time with the family. Also, treating the patient's body with respect and dignity was identified as important (Kusakabe et al., 2015).

Weakness

A weakness identified was only one study was conducted with bereaved from home hospice settings in the United States, and that study was more about leading up to the death instead of the actual death and support after the death. None of the studies focused on asking the bereaved in a home hospice setting what rituals, death care, or support they wanted or needed. None of these studies evaluated the level of importance or satisfaction each of these supportive measures or domains provided the family. Many studies stated more education in end-of-life care is needed for nurses, especially in hospital settings, about how to care for someone when they die and what families desire for support. Many of the studies that were initially included in the sample were about death and making sure the patient had a good death, but then there was no information about the time of death and what support was provided to the bereaved. There was also a very small number of studies that met the criteria. There were several commentaries or opinions about postdeath care but only a few research studies. More research is needed in these areas to support home hospice families so hospice providers can increase family satisfaction around their loved one's death and have a positive outcome for families' bereavement.

Theoretical Framework

Caring for hospice families after the death of their loved one requires compassion, caring, and sensitivity to their experience. Jean Watson's 1979 human caring theory encompasses the holistic and caring approach that hospice nurses should present at a time-of-death visit.

Therefore, it will be used to evaluate the data obtained from the bereaved family interviews. Watson's theory (Watson Caring Science Institute, 2010) contains 10 essentials to caring, and the concepts are represented in the modified model below for the bereaved family.

Figure 1

Jean Watson's Modified Model of Human Caring

Note. From "Core Concepts of Jean Watson's Theory of Human Caring/Caring Science," Watson Caring Science Institute, 2010, (https://www.watsoncaringscience.org/files/PDF/watsons-theory-of-human-caring-core-concepts-and-evolution-to-caritas-processes-handout.pdf). Reprinted with permission (see Appendix A).

By hospice nurses demonstrating the above caring essentials, they will be able to connect with the family in meaningful ways. Watson's caring theory can support the bereaved through showing loving-kindness, being present, cultivating spiritual practices, develop trust, supporting feelings, creating healing practices, attending to wholeness, creating healing environments, assisting with basic needs, and providing soul care (Costello & Barron, 2017).

Loving-kindness can be described as showing love and respect to the person; this is shown through the caring relationship between the nurse and the person. This is based on the nurse's moral and ethical standards and values. By showing love and respect to the person and themselves, they allow for the person to be more open to connecting, validates that they are unique, demonstrates acceptance of who the person is, and shows honor and preserves dignity (Watson Caring Science Institute, 2010).

Being present means the nurse is showing acceptance for any positive or negative feelings that the family may express. By being present with the family, the nurse is open to sitting with the family to hear their story and to listen without judgment. By demonstrating this, the nurse allows the family to feel they are safe to share their true feelings and their true selves (Iversen & Sessanna, 2012). The nurse can help the person to deal with their negative feelings by allowing them to express them. The nurse can encourage the family to participate in self-reflection of their situation and encourage positive feelings about their experience. This may be a time where spiritual support can happen; the nurse may offer a prayer, spiritual expression, or offer a chaplain as appropriate (Watson Caring Science Institute, 2010).

Another of Watson's caring essentials is cultivating spiritual practices through sensitivity and awareness to one's own as well as other's cultural or spiritual beliefs (Watson Caring Science Institute, 2010). This can be demonstrated by the nurse exploring and supporting what the family needs for themselves concerning their loved one's death. The nurse can help the family perform rituals that are meaningful to them and show respect and care for the person who has died. Tasks at the time-of-death visit can be presented in a way that promotes healing and provides comfort for the patient's family (Iversen & Sessanna, 2012).

Developing trust is essential to promoting a caring relationship. If the family member does not feel they can be open and share their thoughts and feelings without judgment, they will not have a caring connection to the nurse (Iversen & Sessanna, 2012). The nurse has to create a safe space for the family member to express their feelings and promote healing. The family also needs to feel heard and receive unconditional love and care. They need to feel the nurse is genuine and sensitive to their feelings and thoughts (Watson Caring Science Institute, 2010).

Supporting feelings is similar to loving-kindness and being present because in these three areas, the nurse has to be open and accepting of the family's feelings that may be positive or negative, and the family needs to have space to say them. By having the ability to express their feelings, it can help aid in their healing process. The nurse can hold their story by listening to them (Iversen & Sessanna, 2012).

Creating healing practices is one way the nurse can aid in problem-solving if needed with the family. For example, if the family is unsure of what they want to do to care for their loved one after the death, the nurse could offer suggestions or explore ways for the family to honor their loved one. The nurse uses the other aspects of caring to be aware of what interventions may be helpful or supportive to the family. The nurse can also help the family find techniques to express their feelings in meaningful ways such as journaling in ways that are meaningful to them (Watson Caring Science Institute, 2010).

Another of Watson's essentials to caring is to attend to wholeness by helping create an environment where teaching and learning can empower and promote unity (Bayuo, 2017). The nurse aims to understand the family's grief from their perspective. The nurse can teach about what the family can expect next while the nurse learns about the family's needs and desires to aid in healing (Iversen & Sessanna, 2012). By creating an open and caring environment for the family, they will feel safe to ask any questions they may have about the death or the next steps for them.

Another benefit of creating healing environments is to promote caring and openness, so family members will feel comfortable expressing their feelings of grief. The nurse can help create an environment that is therapeutic and promotes peace and respect, which will allow the family to feel comfortable with the nurse (Iversen & Sessanna, 2012). The healing environment should be holistic to meet the family's physical, emotional, and spiritual needs. This holistic approach can help meet the family member's needs as emotional needs are not the only needs the family may have. It is important the nurse is also aware of any spiritual or physical needs the family member may have and assist them as appropriate (Watson Caring Science Institute, 2010).

One way a nurse can demonstrate caring essential, assisting with basic needs (Watson Caring Science Institute, 2010), is when the nurse is intentional in the care provided. The nurse should always demonstrate respect for the needs of the individual and by showing privacy for the family. The nurse involves other family members as needed or desired and educates the family as appropriate. Showing respect and care to the deceased's body is very important, and involving the family in the care of the deceased as they feel comfortable can promote healing to the family member (Watson Caring Science Institute, 2010).

The final caring essential is soul care, and it is defined as being open to the spiritual forces and the unknown mystery of the dying process (Watson Caring Science Institute, 2010). This essential can be demonstrated by the nurse supporting the family by reframing that through death, the patient has obtained ultimate healing. The nurse can also aid the family in finding meaning through suffering, but the nurse should carefully approach this only if appropriate (Iversen & Sessanna, 2012). It is essential to show respect and care to the things that matter most to the family and provide an understanding of feelings the family may have about the death (Watson Caring Science Institute, 2010).

Watson’s human caring theory has been used in many examples of how care should be provided to patients in many types of nursing settings, including hospice. Watson’s theory demonstrates a holistic approach to care, which fits beautifully with the hospice philosophy, which is about providing holistic and meaningful care to patients (NHPCO, 2018). Iversen and Sessanna (2012) used Watson’s theory as the framework to educate multidisciplinary hospital teams about the support care patients could receive from hospice and how important early referrals are to support families. Bayuo (2017) used Watson’s theory to provide a more holistic approach to caring for patients at the end of life in the burn intensive care unit, while Costello and Barron (2017) used Watson’s theory to educate nursing students on how to care for their patients at the end of life. In all three examples, Watson’s theory was chosen due to the holistic and compassionate care the theory exemplifies and, therefore, is a perfect choice for the theory for this project.

If families do not feel they can be open and share their thoughts and feelings without judgment, they will not have a caring connection to the nurse (Iversen & Sessanna, 2012). The nurse must create a safe space for the family member to express their feelings and promote healing. The family also needs to feel heard and receive unconditional love and care. They need to feel the nurse is genuine and sensitive to their feelings and thoughts (Watson Caring Science Institute, 2010).

Conceptual Framework

The conceptual model used for this project was Bowen's family systems theory. This theory demonstrates how the family unit is integrated, and when a significant shift in the family dynamic occurs, this can have a large impact on the family unit as well as the individuals that make up the family (Kerr, 2000). In home hospice, tI have experienced family's coming together to provide round-the-clock care to their loved one in their final days. In this project, these family members were interviewed to share what their time-of-death visit experience was like and how they may or may not have found it to be supportive. Bowen's theory has been used with grief experience and how the family system handles grief differently. Each person in the family has different reactions to the death because each relationship is different (Brown, 2014).

Brown (2014) pointed out that Bowen had identified four groups of factors that affect how a family will adapt to their loved one's death. They include how sudden was the death? In the case of hospice patients, was the patient sick for many years? What was their diagnosis, how long had they known the patient was dying, or how long they were on hospice? The next factor was how wide is the support network for the family (Brown, 2014)? Is there a large extended family providing support, and does it extend beyond the family to the community such as a church or organizations they were involved in (Brown, 2014)?

The third factor is what was the role of the deceased (Brown, 2014)? Did the patient hold the role of bringing the family unit together? The role of the patient in the family can widely affect the degree of adjustment the family member has to the death. The fourth area is how cohesive is the family unit? Is it a mature family that is open, or are they more closed and rigid? This can also affect how the family copes at the time of death (Brown, 2014).

When interviewing the family member, it will be important to understand the relationship the family member had with the deceased, as this would impact how they may see the support provided to them. For instance, if the patient was a spouse, and they held a significant position in the family, the adjustment to the patient's death could be more difficult, and therefore the reaction at the death could also be more impactful (Brown, 2014). In this case, the supportive measures they need could differ widely from someone who lost a spouse who had Alzheimer's disease for many years and sees the death as a blessing. Their need for support at the time of death could be felt differently by the spouse. This was an important area to consider when interviewing family members and the impact the death had on them and the family unit. This theory assisted in guiding the interview questions for the project (Brown, 2014).

Bowen also stated that death rituals could be very impactful and important to the family unit. He discussed how funerals could assist families by bringing the family unit together and helping them by coming as close to the death as possible while in the security of friends that can provide support. Bowen sees the participation of rituals as a family as an opportunity for growth and can assist in repairing estranged relationships (Brown, 2014).

Chapter Summary

The care of the patient after death and support for the family is not an area that receives any focus from The Joint Commission on Accreditation or the Centers for Medicare and Medicaid, and therefore can often be overlooked in its level of importance with leadership. The death of a loved one is an emotionally difficult time, and families who are caregivers especially need to feel supported. There is a gap in the literature showing what type of death care and support is desired and needed for home hospice families. One of the barriers to performing these studies is interviewing families that experienced a death in the home. It can be challenging to connect with families because these families are grieving and may not wish to relive their experience. This literature review has provided support for the need for further studies that identify what supportive care is desired and seen as meaningful to hospice families at the time of death of their loved one.

This project will help to close the literature gap regarding the shared experiences of home hospice families about receiving a time-of-death visit from hospice. Jean Watson’s caring theory is an appropriate pairing for this project, as it identifies what caring and supportive measures the hospice clinicians used during a time-of-death visit. The measures were divided into one or more of the 10 caring measures identified in Watson’s theory to conclude which measures the families identified they received and which measures they believed to be supportive (Costello & Barron, 2017). Bowen’s family systems theory provides the framework for the family unit’s importance and how death can impact each family differently (Brown, 2014). This framework providences guidance for the interviews as the family shares their lived experience of the time-of-death visit.

Chapter 3: Methodology

Home hospice families are usually alone with their loved one when they die. After the death, the family will contact hospice so hospice can notify the funeral home, doctor, medical examiner if needed, and the equipment company that the death has occurred. Families are asked at that time if they would like a visit from hospice. In some states, this is required because nurses must verify the death, but in other areas of the United States, families can decide if they would want a visit. Hospice time-of-death visits can vary by the clinician in how they provide support at these visits (NHPCO, 2018). The purpose of this study was to uncover what families express was meaningful to them about hospice clinician visits after the death of their loved one and to identify additional needs of families that might not have been met during the visit. This information may inform hospice clinicians on how best to support families at the time of death.

Project Design

In order to capture the qualitative data needed for this research study, a retrospective, phenomenological approach was used. The purpose of the interviews was to capture the essence of the experience of home hospice families who received time-of-death visits. By conducting the interviews, I explored the meaning of the time-of-death tasks or rituals provided for the family and which of those provided the most significance. The method used in this study was a transcendental phenomenology as the data were collected from several families who experienced a time-of-death visit in the home. The data were analyzed by finding common themes from the interviews, and the data analysis was based on the themes identified (Creswell & Poth, 2018).

The family members had the opportunity to share their experiences. Since there is a dearth of studies regarding the meaningfulness of hospice time-of-death visits, this study provided essential insights into their significance and the aspects most meaningful to hospice families. The family's experiences can inform hospice staff about the importance of these visits for families at the time when they have suffered a significant loss.

Methodology Appropriateness

A transcendental phenomenological approach is more focused on the description of the participants' experiences and less on the researcher's interpretation (Moustakas, 1994). The experiences of bereaved families may vary, but the topic of interest is focused on the experiences with the hospice clinician at the time of death. I used the data from the population of interest to develop both a textural and structural description of the lived experiences.

Feasibility and Appropriateness

This project design was appropriate to answer the research question, and the study was feasible. In order to discover and capture the shared experience of home hospice families, I had to go to the source for information, which in this case was the home hospice families. The study was feasible because the hospice agency was willing to contact families through letters inviting them to share their stories. The families only reached out to me if they desired to participate. The hospice has over 500 patients on their service per day, with approximately 10 or more deaths per day. The hospice's time of death rate was approximately 45% to 50% of all deaths, and most of the time-of-death visits were to home hospice families.

Measurement Tools

A purposeful sampling of home hospice deaths was used at the hospice agency in order to obtain rich data that provided important details and depth from the interviews so themes could be uncovered (Coyne, 1997). Family members were originally going to be screened for addresses within the two primary counties of the hospice agency so that face-to-face interviews could be conducted. However, due to the COVID-19 pandemic, face-to-face interviews were not possible.

Phone interviews were conducted, which allowed for families to participate no matter where they currently lived.

Eligible families were invited to participate in the study and were chosen for an in-depth interview based on the family member’s willingness to participate in the interview. Interviews were conducted between six and 13 months after the death of the patient. Bereavement services for families were provided during this time frame, so if families needed extra support as a result of the interviews, they did have access to it. Interviews about their loved one’s death could be too difficult for families if conducted closer than six months after the death, so six to 13 months was the chosen time frame (Katzenberger & Nichols, 2019).

The data collection tool was a semistructured interview guide. The basic interview questions included:

- Tell me about your loved one and why they were on hospice?
- What was your role in caring for your loved one?
- Tell me about the day and hours just prior to their death?
- After they died, why did you want a hospice clinician to come out to the home?
- Please tell me about what happened when the hospice clinician arrived and while they were with you?
- Looking back, were there any questions or tasks you wish the hospice staff would have asked or done?
- What education was provided to you about what staff could do to support you at the time-of-death visit?
- Of the things you had mentioned that hospice did when they came out at the time of death, what was the most meaningful to you and why?

- Is there anything else you would like hospice clinicians to know about supporting families at the time of death?

I recorded the interviews and field notes were taken during the interviews to ensure the data collected would be accurate. Demographic data collected included basic demographic information to describe the participants, such as gender, ethnicity, and relationship to the deceased. Interviews were conducted by phone using a semistructured interview guide, which allowed for follow-up questions and discussions in areas the subject felt was important to them. Unclear statements or further exploration was prompted as needed to ensure the family member's experience was fully captured.

Institutional Review Board Approval and Data Collection

This study was submitted to the institutional review board (IRB) at Abilene Christian University (ACU) and the host organization's research committee prior to beginning the study. I had the approval for the study from the director of hospice, but the hospital research committee had to also approve the study. The hospital's legal team required additional information, as did the educational department, and they halted all student activity for several months due to COVID, which caused a delay in the original timeline. The approval was completed by submitting the study with the committee at their monthly meeting, where they could ask questions regarding the research study and the data collection process. The committee was contacted, and I was instructed to meet with them after the IRB approval process at ACU. I performed a similar study in the past, and the study was approved.

The prospective participants were contacted by letter from the hospice agency inviting them to participate in a 30- to 60-minute phone interview regarding their experience with a time-of-death visit. The letter included the study's purpose, the potential benefits from participating, and the potential risk of reliving emotional experiences. The letter did provide my phone number to call if they were interested in participating in the study. When the participant called, they were screened to see if they understood they would be interviewed, and the detailed consent forms were reviewed. The participant was told the interviews would be recorded for accuracy of the data. If the participant agreed to the study, a phone interview was scheduled. Each participant was read the consent forms in their entirety, and each received a copy of the forms in the mail.

When determining the sample size for this qualitative study, redundancy was an essential factor and not necessarily a specific number of participants. Phenomenological studies vary widely on the number of participants needed for a study and can be from one to over 300 participants (Creswell & Poth, 2018).I sampled to a level where data were being repeated multiple times. This study's sample contained approximately six to eight participants to ensure saturation of the data was obtained and the experience of the families had been captured (Cleary et al., 2014).

Data Analysis

I used a software called Rev Scribe transcription app, which allowed for the recording and the transcription of the interviews. This software has been used in transcribing sensitive medical record information. A typed copy of the word for word transcript was sent to my secure school email, and the transcripts were compared with the recording for accuracy. The interviewer notes added information regarding emotions and interruptions in the dialogue. The transcripts were analyzed by reviewing the transcripts many times, looking and marking themes and important statements or phrases. The transcripts were kept locked in a password-protected laptop that was locked in a cabinet when not in use. The themes were aggregated under key headings of the reason for the time-of-death visit, most meaningful task at the time-of-death visit and bereavement. Watson’s human caring theory provided a context for examining the importance and details of being present, respect, spiritual care, and physical support that are important to holistic care.

A codebook was kept throughout the analysis process, and emotions were also noted from the field notes. I recorded any thoughts while analyzing the data. Each transcript was coded individually, and then the data were sorted together with the other interviews, and data were placed under the correct category or theme. Maintaining meticulous records was essential along with the codebook to ensure data accuracy and reliability (Hesse-Biber & Leavy, 2011). Rigor for the study was met as I and the Doctor of Nursing Practice (DNP) project chair reviewed the themes and quotes from the transcripts that supported the themes. The chair was also provided access to the recorded data for verification. This process helped to aid in the authenticity of the collected data (Creswell & Poth, 2018).

Interprofessional Collaboration

This study was conducted at my hospice agency, where I works as a manager. The hospice agency provided approval for the project. The hospital, which owns the hospice agency, provided review and approval after the project had been approved through the Abilene Christian University’s IRB (see Appendix B). I worked closely with the hospice director and the quality department to pull the appropriate data for contacting home hospice families who received a time-of-death visit. Only the families that met the study criteria were contacted. Results of the project were shared with over 150 clinicians after the project was completed.

Practice Setting and Target Population

The population included only those patients who died in the home setting within six to 12 months prior to the study. The hospice administration allowed me to mail a letter explaining the study and requesting their participation in the study. This helped ensure the privacy of the deceased patient and their family. If the next of kin was interested in being interviewed, they contacted me.

Risk and Benefits

Researching with families in grief should be approached with the utmost sensitivity. I have over 29 years of working with patients and families at the end of life. I must know about working with grieving families as well as have resources that are available to the families in the event they are in need. These families had the support of bereavement services and support groups provided through the hospice agency. The risk to the family was they could become tearful or upset during the interview. I was aware and sensitive to the family member's needs and stopped the interview if needed and obtained support for the grieving family member.

The benefit to the family member in participating in the study was helping to enrich the time-of-death visits for future families. They had the opportunity to share the story of their loved one's death to someone in hospice and ask any questions they had. This experience can assist them as well in their healing process by helping improve care for others.

Timeline

This study's timeline was approximately one year, starting from the time the project received IRB approval. As previously stated, the approvals were obtained close to the holidays of Thanksgiving and Christmas. The letters were not mailed until the beginning of the year out of respect for families who were grieving their first major holidays without their loved ones.

Timelines were also difficult to predict as to how quickly participants would come forward willing to be interviewed for the study. The participants received a letter inviting them to participate in the study, and they contacted me to schedule a phone interview. A timeline for the study was provided in the appendix (see Appendix C).

Chapter Summary

Multiple studies have been performed in the hospital setting regarding rituals performed at the time of death, but few studies have addressed home hospice time-of-death visits. Filling this gap in the literature will assist hospice clinicians in creating an evidence-based approach in supporting their home hospice families after the death of their loved one. The hospice clinician will be given valuable insights into the care and support these families want and need from hospice when they visit at the time of death. The timeline for this study was provided in Appendix C.

Chapter 4: Findings

The purpose of this qualitative phenomenological study was to understand the lived experiences of home hospice families who had a time-of-death visit from a hospice clinician. This qualitative study was conducted with families of a home hospice agency in the northwestern United States. Semistructured interviews were conducted by phone with eight home hospice families who received a time-of-death visit from the agency's nurses.

Data Collection

The target audience was families whose loved ones had died between nine to 13 months prior and had a time of death hospice visit after their loved one died in the home. Eighty letters were sent, and nine people responded. Only eight people were interviewed, as the ninth person stated she was unable to remember any details. The participants' demographic data included all Caucasian women except for one Caucasian male and were all identified as the patient's primary caregiver. Half were the patients' wives, two daughters, one daughter-in-law, and one grandson. The timeline since the death ranged from seven to 13 months since the death. The majority was 11 or 12 months since the death of their loved one.

Although the original study called for a face-to-face interview, due to the outbreak of COVID-19, the interviews were performed by phone. Each participant had the consent form read to them and was sent a paper copy in the mail. Each participant was recorded after providing verbal consent to the interview. The interviews used a semistructured interview format and ranged from 30 minutes up to one hour.

Data Analysis

The recordings were uploaded through the Rev Scribe transcription app, a word-for-word transcription service widely used for research and medical transcription. The transcription audio and the transcribed documents were sent to this researcher’s secure school email account. Each transcript was reviewed, and themes were identified describing the lived experience of having a time-of-death visit after their loved one died. Data coding followed Miles et al.’s (2020) protocol by assigning meaning to the descriptive or inferential information. This allows the researcher to quickly find, pull out, and cluster segments related to the questions. Themes were defined by reading through each of the interviews many times and looking for common reasons participants stated why they chose to do something, how they felt during the time-of-death visit, or how they perceived a particular task. This process enabled the clustering of common themes. The major themes identified were clustered under the rationale for choosing a time-of-death visit, the most meaningful tasks performed, participants’ comfort level with hospice staff, and bereavement support. In qualitative research, an interview guide is a tool used to obtain information in order to identify themes for a more in-depth discussion of the data.

Reason for the Time-of-Death Visit

Three participants received the time-of-death visit because the hospice staff was in the home at the patient’s death. All participants who had a staff member that was already present identified it as a positive experience. Themes for the reason of the time of death included the uncertainty of the after-death experience, need to verify the death, and closure.

Uncertainty of the After-Death Experience. As expressed by one participant, “I’ve never experienced death in the passenger seat like that. I didn’t know who to call or what to do. Someone said call hospice when it happens, and we will walk you through.” One daughter stated, “So we really didn’t need anyone to come do anything. I think it was just about having acknowledgment of somebody coming and saying, ‘Okay, it’s over. Are you okay? What do you need?’”

Need to Verify the Death and be a Part of the Closure Process. One wife stated that she wanted death verification and a sense of closure. One participant was the daughter-in-law who was a hospice nurse, and she wanted the visit because their regular nurse had called after the death and offered to come out. She felt her visit would be helpful and stated she still needed that type of support and direction that the nurse could provide. One widow said she was unsure why the hospice aide and the social worker came, but she was happy they did. One participant who had the chaplain present when the patient died stated, “She was not scheduled to come that day; she must have just felt something that we needed her. When she arrived, my mother’s breathing was very raspy, and she died very soon after she came.”

Most Meaningful Tasks at Time of Death

Participants were asked which tasks the family felt were the most meaningful at the time-of-death visit. Several themes emerged, including handling of details, spiritual and family support, showing respect for their loved one after the death, and the comfort level with the staff who visited.

Handling of Details. All participants stated that having someone assist them with the details when the family is focused on the significance of the loved one’s passing and their grief as the most significant and helpful task hospice provided. One participant said, “Having all the paperwork and everything is taken care of for me at that moment was huge.”

The participant went on to say, “Having to take care of those details when it is so emotional, it is beyond annoying; it has the potential to stir up so much stuff.” Another participant stated, “The most meaningful thing was navigating us through that time in our life because we had zero idea how to go through the storm; they’ve been through this thousands of times with other families.”

Spiritual and Family Support. Supporting the individual family members in the home, meeting the family's need for spiritual support, and modeling care for the individual were also widely expressed by most participants. One person expressed appreciation and commented, "The chaplain stayed and talked and prayed with us." Another participant stated, "The nurse spent time with each person and was providing support for each person individually. She was very caring; she answered all of our questions and made sure we each knew what to expect." A daughter stated the nurse gave each person a chance to say goodbye and asked if "we wanted a lock of hair."

S**howing Respect for Their Loved One After the Death.** These additional actions added to their feeling of support and care by the staff. A daughter stated:

> The thing that was really profound for me was when she went into his room, and she sat down, and she talked to my dad and stroked his legs and held his feet. She was just so comfortable with the death, and that was profound and powerful.

Another family member reported, "The nurse came and closed his eyes, took me in her arms, and supported me, including my children. When the social worker came, they gave me a big hug and big support."

Having the patient bathed was mentioned in a couple of interviews but was not a common theme among all family members. Several participants noted they appreciated the patient was left clean and the bed and room were straightened. Disposal of medications was also mentioned as something a couple of the participants found helpful.

Comfort Level With the Staff Who Visited. Nurses made almost all time-of-death visits and sometimes with additional staff, including the chaplain, social workers, and hospice aide. A common theme was the personal nature of the relationships with the nurse related to the types of comfort offered after the death. The personal nature of the hospice relationships was essential to family members. One participant said she would not have had the person come out if she had not already known them. As one participant stated:

> She knew who each of us was. There was an intimacy she already had that made it not weird to have her come in and be a part of that time. I don't know if it had been someone we did not know that we would have had that same sense of comfort.

A daughter stated:

> It didn't feel clinical; it felt very much like she was sad for her mother's passing as well. They came and talked about her by name. They really got her and spoke about her as a real person instead of simply a patient who had died.

Bereavement

Many participants mentioned how meaningful receiving handwritten cards from their care team was to them and the follow-through after the death with support from bereavement services. Families reported a sense of caring and support rather than just being dropped after the patient died. Many participants also said they appreciated it when the care team had stopped by to see them, and it helped provide closure for them. Several participants mentioned the bereavement letters they received and just knowing they could reach out and attend groups if they wanted or needed. One participant stated, "If I do need help or some support, they are available anytime, and so they are just a phone call away." One participant said she took part in the grief counseling after the death and stated it was "absolutely amazing as I was experiencing complicated grief." Another stated, "We got letters in the mail, and they know you are going through this. If you want counseling, yeah, just top-notch."

Areas for Improvement

Many stated they could not think of any way hospice could have improved. Overall, the participants were positive about the care they received and praised the clinicians that provided care for them. Participants wanted more information about the physicality of death, and reassurance about comfort meds hastening death was identified. Participants who provided constructive feedback were thanked for their insight, and notes will be shared with the hospice staff while disseminating the project’s information. One daughter stated she would have appreciated some education about what the body would do after death. She said, “I did not realize the body fluids would release, and having the bowels release was a surprise to me.”

Another participant acknowledged needing a further understanding of how providing the comfort meds did not hasten his grandmother’s death. The grandson stated he could have benefited from a discussion regarding medications. One participant stated the nurses are often rushed when making their visits and need to slow down a bit. This was expressed only by one person.

Another participant added she had a previous hospice experience, and the staff at that hospice had instructed, “We will be contacting your nurse and social worker. Just sit tight. You don’t need to do anything, just do what you need to do.” She would have liked the hospice staff to tell her what to do while she waited for hospice to come.

Study Strengths

The strengths of this study included the willingness of the participants to share their experiences. The qualitative data provided rich insights into the home hospice family’s experiences in receiving a time-of-death visit. This study will provide hospice clinicians with valuable information to help guide them as they care for their families at the time of death.

Hospice agencies may choose to make adjustments in their time of death practices due to this study.

Study Weaknesses and Limitations

One limitation was the study was conducted at a single hospice agency in the Pacific Northwest. The study population was very homogenous, as the study participants were White and English-speaking. All participants reported having a positive hospice experience. An additional limitation of this study was the interviews were all conducted by phone instead of in-person due to the COVID pandemic, which limited my ability to observe body language.

Chapter Summary

The interview results provided many essential points for hospice nurses to be aware of when providing care to families at the end of life. There were many themes identified from the families. These findings represent an important sampling of families who desired a time-of-death visit. The themes of the uncertainty of the death experience, needing death verification, and need for closure were reasons identified for receiving a time-of-death visit. In the area of most meaningful tasks, themes identified included having someone assist them with the details during a time when the family is focused on the significance of the loved one passing and their own grief, supporting the individual family members in the home, meeting the family’s need for spiritual support, modeling care for the individual, showing respect for the loved one’s body, and the comfort level with the staff who performed the visit were significant findings. The results of this study will be useful to train current and future hospice nurses for the important work of caring for the family after their loved one has died. Based on the interviews, one can conclude that how a family member views the last moments before and after the death can significantly impact their grief experience. Many participants acknowledged how much they appreciated the hospice staff’s follow-up, support, and the bereavement department.

Chapter 5: Discussion

The study results showed what home hospice families found to be meaningful to them when a hospice clinician performed a time-of-death visit. Hospice clinicians will be able to learn from this study as to what areas were identified as meaningful and can incorporate these into their practice. This study can also provide insight for educating current and future hospice nurses for hospice leaders and educators. This chapter addresses how the study meets the DNP essentials and provides recommendations for future research.

Interpretation and Inference of Findings

The study's findings included how the results were viewed using Jean Watson's human caring theory as a lens for interpreting the results. Many of the themes identified used more than one of Watson's caring theory's essentials as defined in Chapter 2 and therefore was not broken out by individual essentials for a clearer discussion of the results. Three of the eight research participants already had a hospice staff member present when the patient died and were appreciative of having the hospice nurse present when the patient passed away.

Being Present and Assisting With Basic Needs

Based on the participant responses, the hospice staff demonstrated several of the caring behaviors such as being present with the family and after the patient died and having someone assist them with basic needs such as what to do next after the patient's death. The hospice nurses and staff also created a healing environment by providing support to the family immediately after the death and the grieving process.

In reviewing the data for the meaningful tasks performed at the time-of-death visit, many of Jean Watson's caring practices were identified as significant. Participants identified the importance of having someone present to walk them through what to do after the death. Therefore, the essentials of being present and assisting with basic needs were demonstrated.

Loving-Kindness, Supporting Feelings, Spiritual Practices, and Creating Healing Environments

Participants also identified the essentials of loving-kindness, supporting feelings, spiritual practices, and creating healing practices (Watson Caring Science Institute, 2010). These were shown by the loving and caring ways the staff showed respect to the patient after death by either bathing the patient and making sure they were positioned and clean before the funeral home arriving. The staff also provided individualized care and attention to each family member present. They made sure anything they needed was completed, including any spiritual practices the family wanted before the patient's body being removed. Trust was either already developed when the current case manager provided the time of death visit or in these eight experiences. The staff developed a trusting relationship with the family by the way they cared for the participant and the patient's body.

Support Feelings, Attention to Wholeness, and Loving-Kindness

The bereavement follow-up by the case manager teams or the bereavement department was positive and met the caring essentials of support feelings, attention to wholeness, and loving-kindness (Watson Caring Science Institute, 2010). The letters and cards showed the participants that hospice truly cared about the death of their loved one, and the participants appreciated knowing the bereavement services were there should they be in need. The participants that did access the services had positive experiences that were assisting them in the healing process.

This study provided insight into our home hospice families' lived experiences about the care and tasks they found to be supportive. A critical area of discussion is the difference in what the literature provided and what this study’s results showed regarding what one would have expected as far as the most meaningful tasks provided by hospice.

In the literature, there were many studies completed in the inpatient setting. Those studies seemed to show that bathing and support to the participant were the most significant tasks performed by staff. In this study, those areas were identified as significant, but the primary tasks stated as most meaningful were helping the participant navigate what to do next. Perhaps this was identified as the most meaningful task because navigation is not as assured as in the inpatient setting. In the inpatient setting, many things are automatically taken care of by the staff, and the family is not the primary caregiver of the patient in the hospital. In the home setting, all participants were identified as the primary caregiver and were present with the patient at death. They have been providing the patient’s hands-on daily care; therefore, the participants may not have felt as strong of a need to provide hands-on bathing of the patient at death. For these families, they needed to know what to do now that their role as caregivers has ended. Having the support and making sure their loved one was clean and treated with respect were still important and meaningful but not identified as the number one most meaningful task by families.

Implications for Leaders

The results of this study provide hospice staff and hospice leaders with insight as to what hospice families want at a time-of-death visit. These findings provided the families with a voice to let hospice clinicians know the importance of what they do when they provide a visit after the patient has died. These findings can provide vital training for time-of-death visits for new staff and experienced staff as well. In my experience with hospice, many clinicians have expressed discomfort with performing time-of-death visits as they have expressed uncertainty about what to do. These findings can provide opportunities to have an open discussion with staff about how to care for families and discuss with families before the death what can be provided at a time-of-death visit. A time-of-death plan of care can be established with the family by discussing what they may want after the patient has passed away. When working with families, the plan of care should include recommendations from this study's findings regarding the tasks the families found to be most meaningful. Staff can help guide and mentor the family through this process, which can be beneficial, especially for those who have never experienced a loved one's death.

Further research is needed to explore areas of the country where time-of-death visits are required for all hospice patients to compare any data differences. Research is needed to test the benefit of establishing a time-of-death plan of care. All participants in this study had a positive experience and were Caucasians. Further studies that included participants of different races and participants who were not satisfied with their experience at the time-of-death visit are also essential to add to the literature.

Relationship to DNP Essentials

This project and the outcomes relate to the foundational knowledge of the DNP essentials. In DNP Essential I, the scientific underpinnings for practice, this research project met this essential through the research study examining the lived experience of home hospice patients who received a time-of death-visit. The study themes demonstrated what these families found to be meaningful and supportive when the hospice staff visited after their loved one's death. These findings can have a positive impact on future families through the education of hospice staff. These findings will be shared with the organization within the next few months so the organization can provide a higher quality of care at the time of death.

Doctor of Nursing Practice Essential II, organizational and systems leadership for quality improvement and systems thinking, holds a critical part in improving services through training and educating staff (American Association of Colleges of Nursing [AACN], 2006). The proposed plan will be to publish these findings to broaden the reach of the study findings. By educating hospice staff on the tasks of a time-of-death visit that are most meaningful to the families, the quality of care can be improved, and families will be positively impacted.

Doctor of Nursing Practice Essential II is clinical scholarship, and analytic methods for evidence-based practice (EBP) are demonstrated in this project using qualitative interviews in nursing studies (AACN, 2006). These studies offer unique information provided by the participant, which is their lived experience, and the data are rich and helps nurses understand the impact of their actions. This study helped close a gap in the literature and evidence as very few studies included home hospice family's experiences at the time-of-death visit. Data were collected through phone interviews, recorded, and analyzed using qualitative data analysis.

Doctor of Nursing Practice Essential VIII is the advanced nursing practice by learning and demonstrating the ability to design, implement, and evaluate a research study to advance the nursing practice (AACN, 2006). A DNP can lead the way in process improvements by conducting research studies to obtain accurate, evidence-based data. Doctors of Nursing Practice can provide education by using their knowledge and expertise to help educate the next generation of nurses through the use of scientific data to advance nursing scholarship.

Recommendations

Based on the data analysis of this research study, some key recommendations arose. The first was that hospice staff needs to be educated on the findings of this study. Opening a dialogue about the significance of a time-of-death visit and sharing family statements can have a powerful impact on hospice staff. Time-of-death visits should be discussed with families before the death and develop a time-of-death plan of care to share what rituals or tasks they would like to receive.

The time-of-death plan of care can serve as an educational tool for families so they know what care hospices can provide if they choose to receive a visit.

Recommendations for Future Research

Future studies will help increase the evidence surrounding what is meaningful for families at the time-of-death visit. Future studies should focus on families in states where the time-of-death visits are mandatory to evaluate if these families will provide different outcomes than in this study. Future studies could test a time-of-death plan of care to assess if a time-of-death plan of care positively impacted home hospice families. Additional studies could focus on minorities to acquire additional information for hospice staff.

Chapter Summary

In summary, a qualitative research study was performed to learn about the lived experiences of families who received a time-of-death visit. Eight participants shared these experiences and provided rich data for future education around how hospice staff can help give meaningful care to hospice families, even if the team has not met the family before a visit. This study helped close a gap in the literature regarding the lived experiences of home hospice families who received a time-of-death visit. The data were analyzed, and important themes emerged. Recommendations were made to educate the staff so the quality of care support can be provided to families. Developing a time-of-death plan of care can give guidance to families and staff to increase support needs. Publishing this study will provide hospice staff with insight and valuable information when caring for families at the time of death. Future research studies can focus on minorities’ lived experiences and families who receive a time-of-death visit and whether they wish to receive it. This DNP project has provided essential insights and skill development to help advance the work for hospice nurses and the families for whom they provide care.

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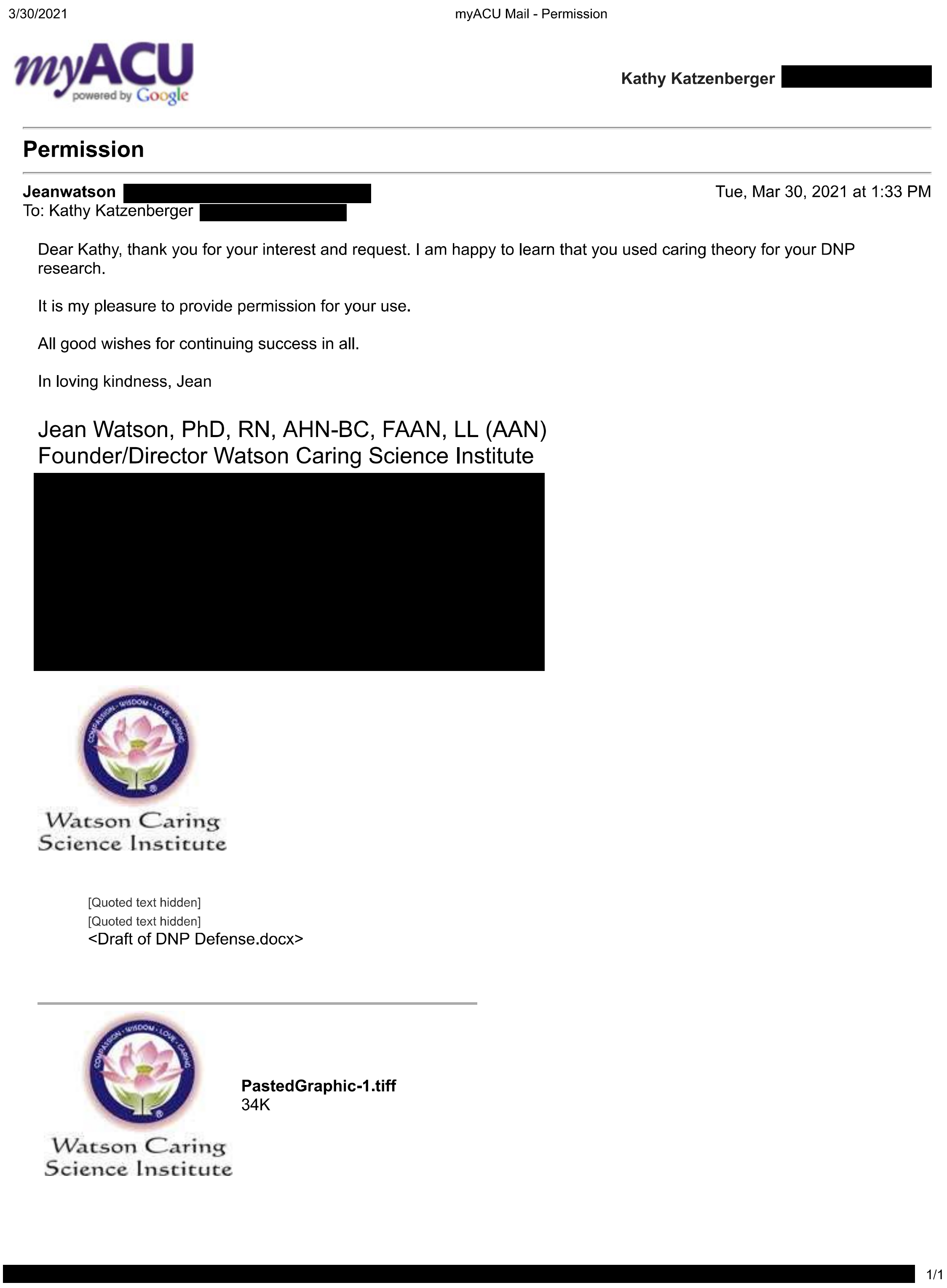
Appendix A: Permission from Watson Caring Science Institute



3/30/2021 myACU Mail - Permission

myACU powered by Google

Kathy Katzenberger [redacted]

Permission

Jeanwatson [redacted] Tue, Mar 30, 2021 at 1:33 PM
To: Kathy Katzenberger [redacted]

Dear Kathy, thank you for your interest and request. I am happy to learn that you used caring theory for your DNP research.

It is my pleasure to provide permission for your use.

All good wishes for continuing success in all.

In loving kindness, Jean

Jean Watson, PhD, RN, AHN-BC, FAAN, LL (AAN)
Founder/Director Watson Caring Science Institute

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Watson Caring Science Institute

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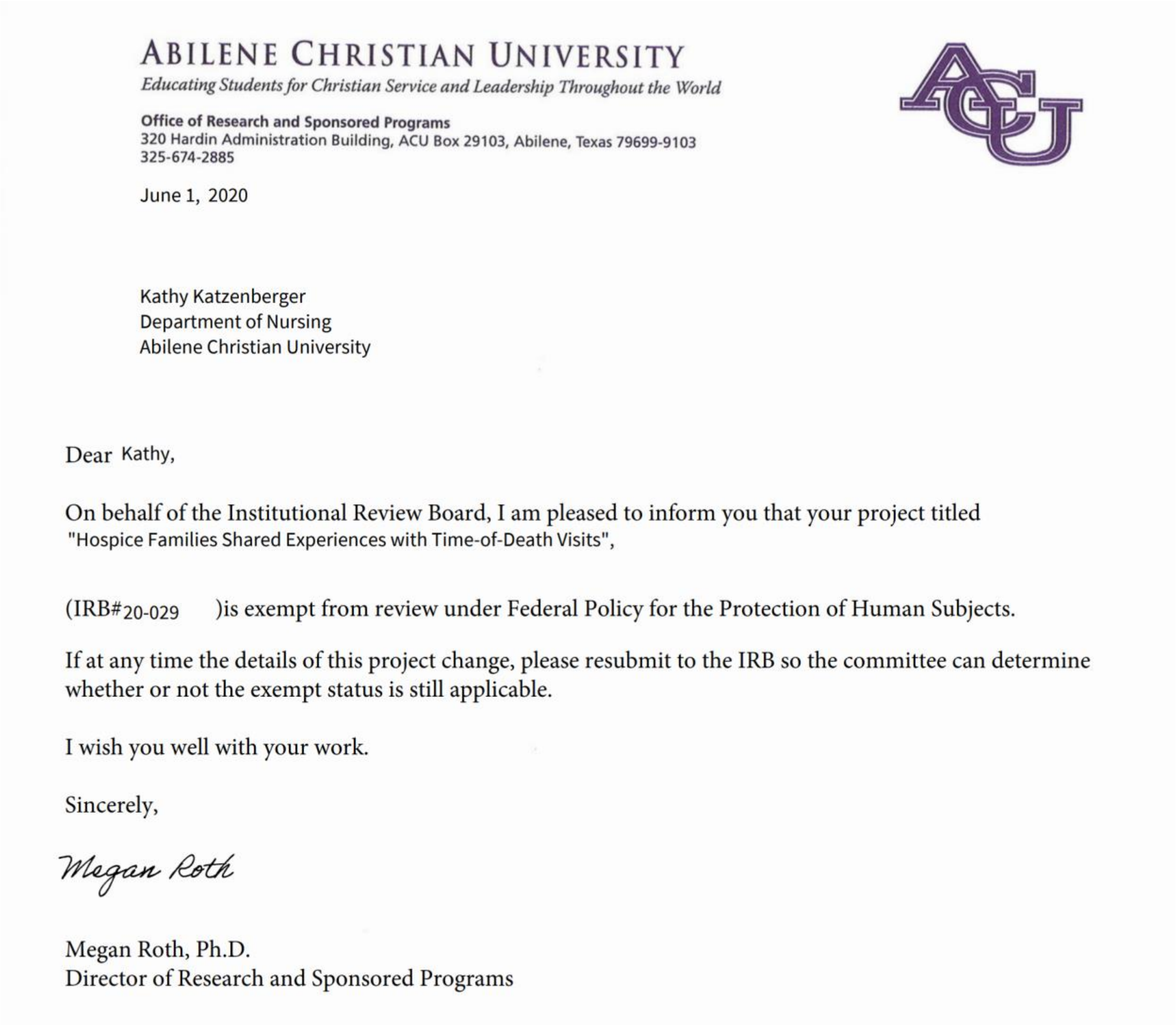
Appendix B: IRB Approval Letter



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Office of Research and Sponsored Programs
320 Hardin Administration Building, ACU Box 29103, Abilene, Texas 79699-9103
325-674-2885

June 1, 2020

Kathy Katzenberger
Department of Nursing
Abilene Christian University

Dear Kathy,

On behalf of the Institutional Review Board, I am pleased to inform you that your project titled "Hospice Families Shared Experiences with Time-of-Death Visits",

(IRB#20-029)is exempt from review under Federal Policy for the Protection of Human Subjects.

If at any time the details of this project change, please resubmit to the IRB so the committee can determine whether or not the exempt status is still applicable.

I wish you well with your work.

Sincerely,

Megan Roth

Megan Roth, Ph.D.
Director of Research and Sponsored Programs

Appendix C: DNP Project Timeline and Task List

December 2019	Proposal Defense Approved
February 2020	Complete Ethics Training Preparing IRB Documents
March 2020	Submit Application to IRB EvergreenHealth Places all Educational Programs and Research on Hold due to COVID
June 2020	Negotiations of Affiliation Agreement Between EvergreenHealth and ACU
July 2020	Affiliation Agreement Approved EvergreenHealth Research Committee Approval ACU IRB Approval EvergreenHealth Hold Lifted Accessed Data Base to Recruit Participants First 20 Letters Mailed Began Interviews
August–September 2020	Mailings to Recruit Participants Interviews Conducted Interviews Transcribed Interviews Completed in September
October–November 2020	Data Analyzed Findings Written Inactivation of IRB
December–January 2021	DNP Paper Edits
February 2021	Final Defense