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THE SOCIAL PROCESS OF DYING IN THE HOSPITAL: A GROUNDED THEORY STUDY

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**THE SOCIAL PROCESS OF DYING IN THE HOSPITAL: A GROUNDED
THEORY STUDY**

A Dissertation Presented

by

ALYSON R. PROKOP

Submitted to the Graduate School of the
University of Massachusetts Amherst in partial fulfillment
of the requirements for the degree of

DOCTOR OF PHILOSOPHY

September 2019

College of Nursing

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DEDICATION

To my daughter Olivia, who has made my life complete.

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Thank you to the village of people that supported both myself and my family throughout this journey.

To Cynthia Jacelon who has guided me from day one and whose unwavering support has gotten me to where I am today.

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To my husband, Matthew, whose support carried me through this adventure and whose zest for life will carry me through many more.

To my mother, father, sister, and brother for instilling in me that it is good to ask questions, push boundaries, and shoot for the stars.

ABSTRACT

THE SOCIAL PROCESS OF DYING IN THE HOSPITAL: A GROUNDED THEORY STUDY

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The majority of deaths in the United States occur in the hospital (Xu, Kochanek, Murphy, & Tejada-Vera, 2010). Because there is little understanding of the meaning behind this delicate social process for the patient, the purpose of this study was to develop a theory that describes the social processes one undergoes during the in-hospital end-of-life phase. Grounded theory methodology was chosen to understand this phenomenon and then explain it theoretically (Charmaz, 1990). The data used to develop the theoretical model was previously collected by StoryCorps and therefore components of secondary analysis were taken into consideration. Stories that are housed at the American Folklife Center at the Library of Congress were obtained, transcribed, and coded. Constant comparative analysis of the data allowed a preliminary conceptual model to emerge. The conceptual model of *hospitalization at end-of-life* is built off assumptions found in the literature and then moves through perspective groups to form a model of needs. Needs were both shared and individual. From needs, came social process. The social process was identified as *Being out of control* and described the deeper

psychological existence of each group who was experiencing end-of-life care. Persons from each perspective group describe their journey in the hospital, over time, as being influenced by each of the other perspectives but not their own. In reviewing the relevant literature on the social process during end-of-life, it was found that many social process models are grounded in the concept of needs. These comparable studies help strengthen the link between social processes and needs during end of life. Limitations of this study pertain to the use of secondary analysis. Each piece of the model was derived from bits of stories instead of understanding the entire process from each individual's perspective. Because of the preliminary nature of this study, there are many opportunities for future validation of findings and deeper understanding of the conceptual components.

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CHAPTER 1

RESEARCH OBJECTIVES

Introduction

Advances in medical technology have significantly improved disease management. However, as a result, the United States population appears to have lost sight of the basic human fact that everyone will eventually die. This denial of death is embodied not only in patients, but also care providers. An air of invincibility lurks in acute care settings, where most people take their final breaths (Bookbinder et al., 2005; Gardner, 2012; Kruse et al., 2008; Robinson, 2010). Although it is widely documented that the majority of people die in a hospital, there is still an overarching lack of acceptance of expected deaths from chronic illness.

The provision of end-of-life care (EoLC) within the hospital setting is considerably lacking, and this is partly due to the overriding pre-occupation with treatment and cure (Cintron et al., 2003; McBride, Morton, Nichols, & van Stolk, 2011; Evans et al., 2006; Larochelle, Rodriguez, Arnold, & Barnato, 2009; Willard & Luker, 2006; Moback et al., 2011). Many clinicians who provide end-of-life care lack adequate training in decision-making and communication surrounding the end of one's life. Innovations in healthcare have increased the complexities of the dying process, but also given the gift of time. The ability to give patients a dignified, comfortable death exists, and yet these care providers have little knowledge of how to facilitate it.

The goal of this grounded theory study was to explicate the end-of-life process in the hospital setting from the perspective of the dying individuals and those who personally witness their experience.

Purpose

This inquiry aimed at understanding the social process of adults who are hospitalized at the end of their life. A social process, as defined according to the philosophical roots of grounded theory methodology, pertains to the psychological processes one goes through over time, within the context of the associated social structure (Morse et al., 2009). The purpose of this study was to develop a theory that describes the social processes one undergoes during the end-of-life phase in a hospital setting.

To develop a theory that is grounded in the social processes surrounding end-of-life, it is important to consider all perspectives. Obtaining a comprehensive view of a theory together is a delicate process that involves in-depth investigation. Therefore, this study gathers a multitude of perspectives, from patients and family members to care providers.

The perspective of family members is both unique and valuable. Patients often lack energy when hospitalized and, as such, loved ones serve as their spokespersons, protectors, and benefactors.

Care providers also provide a unique perspective on individuals at the end of their lives. They are with the patient after the family leaves and when other providers give prognosis updates; They possess a comprehensive assessment of the patient's emotional, physical, and spiritual experience within this particular context. Understanding all of these aspects will provide a connection between the hospital setting and the patient's patterns of behavior.

Research Questions

The primary research question of this study is: What is the basic social process of adults who have been hospitalized during the end-of-life phase? Explicit areas of investigation into this question include:

1. What meaning is attributed to the process of being hospitalized at end-of-life, as described by those hospitalized?
2. What is the family member's perspective on hospitalization at end-of-life?
3. What is the care provider's perspective on hospitalization at end-of-life?

Data Sources

A secondary analysis of publicly available, archived data has been conducted. The data used for this study is in the form of stories found at the American Folklife Center in the Library of Congress in Washington DC. These stories were collected by StoryCorps, a non-profit organization who collects and shares stories about various aspects of life from diverse people in America. The stories are categorized at the Library of Congress into collections.

This database of stories is very similar to research databases in that it is a searchable collection of information. A preliminary search was conducted to ensure that stories which could help answer my research question existed. Stories that included the key terms "hospital" and "rites of passage - death" were tagged and sent to me as audio files.

Definitions

End-of-life: the period leading up to a person's natural death that cannot be altered by medical care.

Dying: the state of being associated with the end-of-life period, much different than someone who is actively dying, which constitutes hours or minutes preceding imminent death.

Social process: processes of the mind and behavior associated with cognition, such as memory, perception, and attention.

Hospital: an acute medical institution.

Researcher's Stance

My interest in hospitalization at end-of-life began very early in my career as a nurse. I worked in a large, acute care hospital on a medical floor where intensive palliative care patients resided. I cared for many of these patients and family members throughout their stay and felt honored to be with them during their final breaths.

Reflecting on these very moving experiences, I wanted to understand more. I want to understand what the patient is feeling, how those feelings are affected by the culture of the hospital, and what we can do to better understand this very important process in life.

The following is a list of my assumptions about terminally ill hospitalized adults.

1. Adults who are both terminally ill and hospitalized are experiencing a difficult transition. In my experience, these patients require much more emotional support from both family and care providers. Most people need time alone to reflect and accept before moving forward. Acceptance is not achieved by all, but is desired by most.
2. Nurses do not discuss the physiological, emotional, or spiritual experience of death with patients. Conversations about being terminally ill and what that means for the patient rarely occur.

3. The transition for family members is much different. They fight hard and long, sometimes too long. However, when it is clear that nothing more can be done, they are instantly ready for their family member's death and do not want the process to take long.
4. It is almost always assumed that the family is the voice of the patient. Difficult discussions regarding the physiological aspects of the dying process are often conducted without the patient to keep from frightening them. If there are no family members present, discussions surrounding the physiological process of death do not happen.

Overview of the Method

This study is a secondary analysis of existing data. The data consists of first-hand stories from people who have actually experienced what it is like to be dying while in the hospital, as well as second hand stories from loved ones and care providers who have witnessed the dying process. These stories were obtained from a database maintained at the United States Library of Congress in the American Folklife Center. This database is comprised of stories collected by StoryCorps, a group that seeks to discover and preserve the experiences of people here in the United States (StoryCorps, 2019).

This study is conducted on the basic principles of grounded theory. My hope is to develop a preliminary understanding, from which I will be better able to engage in true grounded theory research.

The grounded theory method was first developed by sociologists Glaser and Strauss (1967) when studying dying people in a hospital setting. The thought processes of hospital staff were difficult to quantify, so they began recording their conversations,

reflective afterthoughts, and moments of analytical breakthrough (Charmaz, 2006). Several decades later, Charmaz (1990) developed her version of grounded theory. While preserving the hallmark components of grounded theory, Charmaz (2006) transitioned away from any positivist notions and withheld views based on constructivism to allow theories to be more interpretive than exact (Charmaz, 2006). Charmaz's (2006) constructivist grounded theory is a method used to understand the world and explain people's understanding of it through theories. In this research project, the social process through which terminally ill patients engage in during hospitalization is theorized by listening to and analyzing the recollections of terminally ill patients, as well as the recollections of those who witnessed their demise first-hand.

Significance of the Study

Although EoLC appears in literature across disciplines, it is often used in a variety of contexts, and thus lacks congruency. For purposes of this research, the concept of EoLC in a hospital setting consists of the physical, medical, spiritual, and social care provided to patients and families once the focus of treatment changes from cure to comfort.

EoLC in the Hospital

An increasing number of people are dying in hospitals rather than at home (Bookbinder et al., 2004). The literature surrounding quality EoLC is primarily hospice-based, and inadequate to support the provision of EoLC in the hospital. Sufficient care guidelines that ensure an optimal end-of-life experience for hospitalized patients are long overdue.

The Healthcare Cost and Utilization Project (HCUP) reports the annual number of deaths that occurred in hospitals in the United States for 2009 was 757,800 (HCUP, 2009). With nearly 800,000 people dying in the hospital every year, it is clear that optimal EoLC is crucial. There are currently no well-defined guidelines that ensure that the provision of end-of-life is optimal. Thus, those who die in a hospital setting are experiencing suboptimal EoLC in regard to their expectations, preferences, and comfort (Choi et al., 2003; Larochelle et al., 2009; Sorensen & Iedema, 2011; Willard & Luker, 2006). The inadequacy of EoLC is a global phenomenon with numerous barriers, such as poorly educated healthcare professionals (Paice et al., 2007). Minimizing suffering, ensuring appropriate closure, and developing goal-specific interventions will help create best EoLC practices (Bookbinder et al., 2005).

As research evolves, medical care is advancing exponentially and the number of patients dying in hospitals is only going to continue to increase in accordance with our ability to treat and manage disease processes. This advancement in healthcare is creating a miniscule gap between cure and comfort resulting from the rapid transition between treatment focused care and care centering around palliation. Based on my experience, the transition to usually happens immediately after the final treatment attempt, and results in patients who are so intensely cared for that the idea of shifting that support to home is unimaginable. In the meantime, human beings are languishing in hospitals with needs that are not being addressed.

Dignity-Preserving EoLC

To preserve dignity during end-of-life, it is important to understand and identify patients' preferences surrounding their experiences with EoLC. Although the body of

literature on patients' EoLC preferences is small, it suggests that the majority of patients desire dignity-preserving care (Payne, Langley-Evans, & Hillier, 1996; Payne, Burton, Addington-Hall, & Jones; 2010). "Dignity is an inherent characteristic of being human, which can be felt as an attribute of the self, and is made manifest through behavior that demonstrates respect for self and others" (Jacelon et al., 2004, pg. 81). Conserving dignity during end-of-life should be an integral part of the care plan development (Ostlund et al., 2012). Dignified care also provides a lens through which health care professionals view the patient (Girsh & Chonchinov, 2002). Overall, dignity plays an integral role in optimizing patient experience, assisting with care plan development, and supporting a clear view of the patient in the correct context.

Preferences

Since patient and family member preferences must be assessed on an individual level to ensure personalized care, an understanding of the preferences of dying patients and family members reported in the literature can help provide a basis for exploration into this topic. Payne et al. (1996) interviewed 18 imminently dying patients residing in a palliative care unit in a hospital in England and found that they preferred the idea of a pain-free and quick death, in addition to the importance of maintaining dignity (Payne et al., 1996). Family members, however, preferred a peaceful death for their loved ones (Payne et al., 2010), as well as kind healthcare professionals and a home-like feeling (Evans, Cutson, Steinhauser, & Tulsky; 2006). Each of these studies was a descriptive, qualitative study with a small sample size (n=12-18). A small sample size is common in qualitative research. Their methodology is consistent with the exploratory nature of

qualitative research and helped identify preferences useful in this quasi-experimental research.

An interesting study conducted by Choi et al. (2003) interviewed 185 nurses working at an acute-care hospital in Korea to identify what their EoLC preferences would be if they were to die, as well as what their preferences are as healthcare professionals. These nurses identified being kept clean, being able to name a decision maker, knowing what to expect, and having someone to listen to their personal preferences if they were the ones dying (Choi et al., 2003).

In the provision of EoLC, a variety of healthcare professionals, including nurses, physicians, and social workers, have reported a preference for providing care that focuses on symptom control in the hospital (Lamont, 2005; Payne et al., 1996; Steinhauser et al., 2000; Willard & Luker, 2006). Moreover, ensuring a patient's comfort is seen as an essential component to providing EoLC to patients (Choi et al., 2003; Payne et al., 1996; Steinhauser et al., 2000; Willard & Luker, 2006). Hospice nurses identify family involvement and creating a sense of peace among patients and families as additional factors in optimizing EoLC (Lamont, 2005). Hospice studies can provide some insight for researchers studying acute care for end-of-life patients, although studies surrounding EoLC in a hospice setting cannot be generalized to the hospital. The research design and methodologies used in all four of these studies identified symptom control as an EoLC preference among health care professionals.

Cohesiveness of Care

The current EoLC in acute-care hospitals is often affected by major disagreements among healthcare professionals themselves, as well as between healthcare professionals

and patient/family members (Larochelle et al., 2009; Payne et al., 2010; Willard & Luker, 2006). Disagreements regarding care trajectories, on multiple levels, is a predominant theme in the literature, and can be found among studies that sampled patients, families, nurses, and physicians. The broad recognition of disagreements between several populations within the literature substantiates these findings. Concerns regarding practice variations among physicians, and an environment in which the personal beliefs and attitudes of physicians are solely shaping EoLC, were two major themes in a study conducted by Larochelle et al. (2009). This study was comprised equally of both physicians and nurses. Eleven hospitals in Pennsylvania provided the setting for this large study of 108 interviews. Both physicians and nurses expressed their concern regarding differences in EoLC among physicians, regardless of race, gender, or professional role (Larochelle et al., 2009). One variation in practice concerns whether to use a palliative care consultation. A lack of palliative care consultation is often observed (Payne et al., 2010) among a population that can directly benefit from the application of the principles of palliative care (Hillman, 2010). Disregard for specialty consultations, like palliative care, is common among physicians who identify with an authoritarian professional stance. This attitude also hinders patients and families involved in decision-making (Willard & Luker, 2006).

Complications arise when patients are not involved in care decisions (Curtis et al., 2002) and shared decision-making has a strong tie to the perception of a *good death* (Frank, 2009). For example, patient participation in care plan development has been shown to ensure a subjectively satisfactory experience with the dying process (Friedrichsen, Strang, & Carlsson, 2000; Royak-Schaler et al., 2006). After interviewing

30 end-of-life cancer patients, Friedrichsen et al. (2000) have identified patient participation as crucial in EoLC. Families of dying patients also attested to the importance of patient participation in care decisions in the focus groups conducted by Royak-Schaler et al. (2006). Both of these qualitative exploratory studies were conducted at major cancer centers. Patient participation has been further explored by Frank (2009), who identified communication, acceptance of prognosis, and a feeling of well-being as central to active patient participation (Frank, 2009).

Summary

It is essential to continue improving the delivery of end-of-life care. To develop improved models of care, we must first understand the patient experience. The patient experience can be understood through both self-reporting and gathering others' perspectives. The major goal of this study was to understand the meaning associated with the end-of-life process. This qualitative, grounded theory study enables us to extract the necessary data from patients to develop theory for testing. The findings of this study serve as a foundation for future, higher level research, in which theory, instruments, and interventions can be tested.

CHAPTER 2

REVIEW OF THE LITERATURE

Introduction

This chapter explores multiple perspectives related to the social process of being in the hospital during the end of one's life. These perspectives emerged from the literature and are presented in order of significance based on the focus of inquiry: patient, family, and care providers, respectively. Each perspective is examined in-depth to uncover prominent themes. PubMed, CINAHL, and Academic Search Premier were used to conduct literature search. Search terms such as *patient, hospital, dying, end of life, and death* were used. My initial search produced 629 articles. Each article was then reviewed for pertinence to end of life; 50 articles were excluded which left 579. Next, articles that did not pertain to care but rather finances or policy initiative for example, were eliminated; 499 articles were excluded which left 80. Finally, articles that focused on pediatrics or settings other than acute care were not included; 60 articles were excluded which left my final number of 20. Additionally, research dating back to 2002 was included due to the limited number of published articles. The four central themes that emerged from the review were: Care components, symptom management, crucial conversations, and [patient's, family's, or care providers'] wishes.

End-of-life Care in the Hospital: The Patient Perspective

Understanding the social processes in which one engages while dying is complex. Insight provided by patients who were hospitalized during their end-of-life is crucial. Moreover, an article that utilized patient charts in the data collection process is also incorporated.

Care Components

It is important to examine the care components that patients have found to be important with regard to shared decision making (Virdun et al., 2015; You et al, 2014), such as having someone from the care team inquire about their values (You et al., 2014) and ensuring that the care they receive is not only respectful, but delivered with compassion to ensure the maintenance of dignity (Virdun et al., 2015). Regardless of the outcome, patients also wish to be questioned about the courses of action taken in an acute event (Virdun et al., 2015).

Patients express a hope for cure, while still remaining realistic about the terminal nature of their illness. Relief from pain, being allowed to die when the time is right, and comfort are considered essential care aspects. Although these aspects of care are in the hands of the professional care providers, patients tend to feel that, ultimately, their fate is determined by god (Torke et al., 2005). A study by Parish et al. (2006) highlighted an absence of these central care components in the patient charts. Indeed, neither psychological nor spiritual aspects of care were documented frequently in medical records, and not one patient chart mentioned cultural issues surrounding a patient's death (Parish et al., 2006).

Symptom Management

One of the most prevalent symptoms that requires adequate management during end-of-life care is pain. Although pain is a complex concept, being relieved or ideally free from pain is the goal for many (Lankarani-Fard et al., 2010; Jones et al., 2011; Torke et al., 2005). In a very interesting study conducted by Parish et al. (2006), documented

symptom assessments were compared to symptom report in nurse interviews. Not only was it determined that symptoms were rarely documented adequately, but there was also a significant difference between what was documented and what was reported. A central theme of powerlessness emerged from this investigation due to reported feelings of distress and poor communication regarding treatment choices (Parish et al., 2006).

Another investigation into symptom management discovered that both the report of symptom burden and the actual listing of symptoms varied largely between patients and proxies (Jones et al. 2011). Physical symptoms and overall well-being were directly related. Jones et al. (2011) administered the McGill Quality of Life Questionnaire (MQOL) to both patients and proxies. Within the MQOL, subsections on existential well-being were explored, and these highlighted additional differences in perspective. Proxies reported patient's quality-of-life to be much higher than what was reported by the patient. However, a more consistent rating of quality-of-life was achieved when patients were physically and cognitively unwell (Jones et al. 2011).

Crucial Conversations

Patients wish to discuss their prognosis (You et al., 2014) and what life is like when terminal, as opposed to the event of death (Knauf, 2005). It is difficult to critique the content of end-of-life care discussions, because they rarely occur, if at all. In Knauf et al.'s (2005) cross sectional analysis of prospective patient interviews, it was found that end-of-life care discussions only occurred 32% of the time. Similarly, Parish et al. (2006) has noted that end-of-life care is seldom discussed, even when patients broach the subject. Mack et al. (2012) have also found that end-of-life care discussions do not

always occur. Among patients who had documented end-of-life care discussions, the median for occurrence was approximately 30 days prior to death.

Patient Wishes

The two studies that address patient wishes explore completely different perspectives. Virdun et al. (2015) conducted a systematic review to identify what patients *wished* their care would look like. These care elements include: effective communication, expert care, respectful care, trust and confidence, and minimizing burden on families. In Virdun et al.'s (2015) study, only eight articles met the inclusion criteria, but these included testaments from over 1,000 patients. Conversely, Torke et al. (2005) attempted to illustrate the views of 23 terminally ill patients, and identified five entirely different elements. These five views were: let me die, hope for cure, relief of pain, in god's hands, and limited role of the physician. Not one of the identified concepts among the two studies were similar.

Outlier

Ando, Morita, Lee, and Okamoto (2008) studied 10 terminally ill cancer patients to determine the meanings they attributed to the concepts of illness and well-being. These 10 patients were interviewed about their transformation, from diagnosis to end-stage illness. In essence, while not everyone attributed positive meaning to this transformation, those who did reported higher levels of well-being (Ando et al., 2008).

End-of-life Care in the Hospital: The Family Perspective

Obtaining the perspectives of family members of terminally ill patients is crucial. Thus, this literature review includes four studies that utilized family members in their sample and one systematic review.

Care Components

Compassionate care is an overwhelming theme in this section of the literature. Compassionate care is described as being sympathetic and kind (Williams, Lewis, Burgio, & Goode, 2012), and is linked to maintaining patient dignity (Virdun et al., 2015). Comforting, consoling, and caring were also terms associated with being compassionate (Williams et al., 2012). Both Williams et al. (2012) and Riggs et al. (2014) conducted qualitative research studies that employed similar data collection strategies. Semi-structured interviews were used for both studies. Excerpts from family interviews highlighted feelings of physical presence as being associated with compassionate care. Indeed, family testaments in Riggs et al. (2014) read:

I remember sitting there... and people coming in and (seeing) that we had what we needed... “Do you need a pillow? I’ll get you a blanket.” ... I never felt alone. I felt like there were people out there that I could call on.... I just want to stress how secure I felt in the hospital, how cared for, that they cared about him, and they cared about me. (p.644).

Similarly, in Williams et al. (2012):

We were right by his side when he passed away We stayed around the bed and the nurses came in and were there with us. They talked to us.... It broke their hearts up there when he passed away. The nurses just cried. (p. 548)

Along with being compassionate, family members expected the nurse to honor the patient’s dignity, be attentive, and facilitate the final acts (Williams et al., 2012).

The expectation for care, however, was not always placed on the nurse. Spichiger's (2009) study comprised 10 family members who noted that they would be willing and happy to provide any care possible to their loved one if they had the financial means.

Crucial Conversation

Communication, conversations, and discussion topics occupy the majority of family reports on end-of-life care in the hospital. Every study that involved family members noted the importance of having conversations of some sort. All accounts of conversations appear to have occurred between the family and the care provider and excluded the patient.

Family members desire communication about their loved one's prognosis (Riggs et al, 2014; You et al., 2014) and current condition (Riggs et al., 2014; Williams et al., 2012). Answering questions about goals of care (You et al, 2014) and what happens after death (Riggs et al., 2014) is also an expressed need. However, needs were not always related to being on the receiving end of conversations: Family members in both Viridun et al.'s (2015) and Spichiger's (2009) studies conveyed a desire to express their opinions, be involved in care decisions, and be present for patient conferences.

Family Wishes

Wishes that stood out as separate from care components and crucial conversations were minimal. You et al. (2014) conducted a large study that involved over 200 family members and found that their most important concerns are: discussing prognosis, being given an opportunity to express concerns, and being asked if they had any questions. In addition to these primary needs, family members also want providers to inquire about

their own values (as opposed to patients) and be given the opportunity to make major care decisions (You et al., 2014).

Outlier

Jones et al. (2011) conducted a simple quantitative study to compare the reported differences in quality-of-life rating among families and patients. Significant differences in perceived quality-of-life were reported in both physical and psychological subgroups between families and patient: families consistently rated their loved one's quality-of-life higher than the patients' self-reported quality-of-life.

End-of-life Care in the Hospital: The Professional Care Provider's Perspective

Ten articles addressed in-hospital EoLC from a care provider's perspective: two concerned physicians, while eight were in regard to nurses. Professional care providers was the largest cohort between the different perspectives. Only two of the four central themes were found among these articles: care components and crucial conversations.

Care Components

Challenges. A multicenter grounded theory study with oncology nurse specialists found that there are many challenges to end-of-life care in the hospital (Willard & Luker, 2006). These nurses felt that the foundational component to these challenges is rooted in a preoccupation with treatment. Other reasons identified include: the complexity in defining *dying*, the numerous treatment modalities that exist, and the upsurge in the public's expectation for treatment (Willard & Luker, 2006).

Conversely, in an effort to analyze end-of-life care in the hospital, Parish et al. (2006) conducted a retrospective chart analysis of 20 patients who died in a large teaching facility. Two separate nurses who cared for the patients whose charts were

analyzed were also interviewed. It was found that the documentation did not coincide with the nurse interviews; The documented assessment was often inaccurate (Parish et al., 2006). Moreover, psychological and spiritual care were frequently missing from documentation, although nurses did not report needing additional education on it.

The majority of the nurses interviewed in the study conducted by Parish et al. (2006) agreed that they required additional education in palliative care. Specific reported areas of weakness include: pain management, collaborating with families, communication skills, and the pathophysiology of terminal ailments (Parish et al., 2006).

Emotional elements. The emotional elements of end-of-life care in-hospital have been discussed by many. Nurses report these emotions as difficult and stressful (Popejoy, Cheyney, Beck, and Antal, 2009), and include: anxiety surrounding death itself (Hinderer, 2012), helplessness related to uncertainty (Calvin, Kite-Powell, & Hickey, 2007), and guilt and accountability (Johnson & Gray, 2013).

Johnson and Gray (2013) discovered that, although the struggles associated with challenging EoLC were correlated with powerful emotions, the more knowledgeable nurses were about EoLC, the more sophisticated their care became. Another method of coping with the emotional labor of EoLC involved emotionally disconnecting (Hinderer, 2012). Nurses who report distancing themselves emotionally claim to be more capable of coping.

Provision of care. In Calvin et al.'s (2006) qualitative descriptive study, nurses reported offering guidance as the most important piece of care provision. This guidance is delivered to both the family and the patient, since, according to 22 ICU nurses who

participated in a qualitative study conducted by Popejoy et al. (2009), a patient's family are considered another patient.

The care nurses feel that they should focus on the physical aspects of care (Thompson et al., 2005). Rather, these nurses not only focus on the physical aspects of care, but also consider the overall care plan to ensure that the care trajectory is appropriate and in place. A comparable group of nurses participated in Parish et al.'s (2006) study. Only 50% of the nurses felt that care needs were met in all of their patients (Parish et al., 2006).

Crucial Conversations

The literature surrounding communication with patients and families during the terminal phase primarily focuses on the lack thereof. One study investigated the type of communication utilized by nurses when caring for dying patients. Boyd, Merkh, Rutledge, and Randall (2011) engaged with 31 oncology nurses who reported using both active and passive listening techniques, as well as supportive counseling.

Unsatisfactory communication about the dying process (Knauft et al., 2005), the possibility of dying (Sullivan et al., 2007), or communication that is both forthright and articulate (Popejoy et al., 2009) has been documented by researchers. Physicians in Sullivan et al.'s (2007) study were more likely to speak with patients about the dying process if their patients were lucid and younger. Although conversations can be both complex and challenging, it is important to tell both the family and patients the bad news, since it transforms everyone's perspective (Popejoy et al., 2009).

Synthesis Across Groups

This review of the literature highlights the research surrounding terminally ill patients in a hospital setting. Perspectives that emerged were those of the patients, their families, and the care providers. The body of literature surrounding this topic is small, and mainly comprises studies that vary with regard to intent and perspective.

Thematic organization among the three perspectives reveals several similarities and differences. These include: care components (patient, family, provider), crucial conversations (patient, family, provider), wishes (patient and family), and symptom management (patient). Moreover, the care component group within the care provider subset was so large that it was divided into challenges, emotional elements, and provision of care. This reveals a major gap in the provider perspective literature, resulting from the absence of symptom management dialogue. Since this concept is at the forefront of patient focus, further inquiry into the provider view is warranted.

Patients feel that the most crucial component of in-hospital care is shared decision making (Virdun et al., 2015; You et al, 2014). Being involved in what happens next is valuable to patients. Decisions do not always need to be large to be impactful to be important. Just being questioned about their desired course of action can help patients maintain a sense of dignity and show them respect (Virdun et al., 2015). Conversely, families are more concerned that care be compassionate (Riggs et al., 2014; Williams et al., 2012; Virdun et al., 2015). Compassion can transcend both dignity and decision making, but it is important to ensure that each patient's conceptual definition of compassion is clarified, as this definition can vary greatly from person to person.

Compassion is not discussed within the provider-focused literature. Care components that were revealed to be most important to this group include: the challenges of this type of care, the emotional elements, and the provision of care. Dying is complex; It is not prescriptive, and it carries the weight of the unknown. The vast array of treatment modalities yields its own challenges (Willard & Luker, 2006). The personal, taxing, undesirable aspect of end-of-life care is felt most often by care providers (Calvin, Kite-Powell, & Hickey, 2007; Hinderer, 2012; Johnson & Gray, 2013; Popejoy et al., 2009).

Patients want to discuss their care (Knauf et al., 2005; You et al., 2014), but such conversations rarely, if ever, occur (Knauf et al, 2005; Mack et al., 2012; Parish et al., 2006). While families report being concerned with conversations of many types, conversations that involve the patient are not one of them. Rather, families report wanting conversations that involve them to a greater degree with the provider aspect of care. Not a single study mentioned the patient's involvement in these conversations. The same was found within the provider-focused literature. Nevertheless, a common theme is that these conversations are not even occurring, and this is largely concerning on multiple levels.

Lastly, patients want their pain controlled (Parish et al., 2006), and providers are not reporting any concern with pain or symptom management. The relation between symptom burden and overall well-being is intense (Jones et al., 2011). Two other studies have examined what patients desired from their end-of-life care, but the findings were not consistent. Moreover, there was no data saturation and the perspectives were remarkably different, which supports the argument that individualized care needs to be the standard.

This research aimed to help expand our understanding of the complex social processes surrounding the feelings one experiences during the in-hospital end-of-life

period. The data on this subject remains limited and there are many gaps within the literature, as presented above. Before we can improve care, we must better comprehend the meaning behind each key perspective. In addition to the hope that new ideas will emerge, there is a need for a more in-depth exploration into patient involvement in end-of-life care discussions, preoccupation with treatment, symptom management dialogue, and how to gain a general consensus among and within perspectives.

Theoretical Framework: Symbolic Interactionism

The philosophical basis for grounded theory is symbolic interactionism (SI). Symbolic interactionism is a social psychological theory that concerns human behavior and its associated constructs (Blumer, 1969). The main premise of SI is that reality is socially constructed and that we act based on our understanding of those constructs (Blumer, 1969). Pragmatism is thought to be highly influential in the development of SI (Rodgers & Knafl, 2000). Pragmatism addresses the understanding of reality in relation to social constructs.

While grounded theory has historically been based on the philosophy of SI (Aldiabat & Le Navenec, 2011), there is a high degree of congruency between both the conceptual make-up and assumptions of these theories (Aldiabat & Le Navenec, 2011). Moreover, the philosophical aspect of SI will not only help me collect data in a meaningful way, but also better understand the human behavior I am studying. This particular study focuses on the patient's voice and silences the voices of the healthcare providers. I really want to capture the patient's perspective, in as uninfluenced a manner as possible.

The main concepts of SI are: the self-concept and the object (Aldiabat & Le Navenec, 2011). These two concepts concern how the patients view themselves as an object through the process of role-taking, or so-called *looking glass self* (Aldiabat & Le Navenec, 2011). This theory has provided guidance for interpreting the self-reported human behavior I have theorized.

CHAPTER 3

THE METHOD

Introduction

The majority of deaths in the United States occur in the hospital (Xu, Kochanek, Murphy, & Tejada-Vera, 2010). Because there is little understanding of the meaning behind this delicate social process for the patient, the purpose of this study was to develop a theory that describes the social processes one undergoes during the in-hospital end-of-life phase.

Grounded theory methodology was chosen to understand this phenomenon and then explain it theoretically (Charmaz, 1990). This investigation is slightly different than a typical grounded theory study in which the researcher engages directly with the participants and their surroundings, conducts interviews, participates in observation, and employs interpretation accuracy techniques. The data used in this investigation is taken from previously recorded stories. This chapter will explicate the processes that were employed, including design, data collection, data management, analysis, and trustworthiness of the data.

StoryCorps

StoryCorps is a national foundation that was founded in 2003 with a focus on preserving the stories of individuals throughout the United States (StoryCorps, 2019). Recording booths were set up across the country in public places to serve as the story telling stations for participants. The storytelling occurred in an interview format with two people and a facilitator. These interviews were recorded and are housed at the Library of

Congress. A comprehensive database is managed by the reference librarians and is searchable for public use.

The use of StoryCorps data in published research is limited, however a significant amount of non-research based articles have been published. Oral history has become more popular with the rapid advancement of virtual culture. Out of 406 published journal articles, three were identified as research articles. Table 1 provides a description of each research article.

Table 1 Research Literature involving StoryCorps

Citation	Method	Sample	Outcomes
Davidson (2011)	Descriptive correlational study examining phonetics in American English by comparing spontaneous speech between recorded interviews (StoryCorps) and spontaneous sentence generation by participants.	19 English speaking college students and 17 StoryCorps interview audio files.	Stop releases were affected by the place of the stop. Variance in the phonetics differed between black and white speakers but not between male and female speakers.
Galuska, Hahn, Polifroni, and Crow (2018)	Narrative analysis study identifying experiences that produce joy in nurses. Interviews were recorded with StoryCorps before they were transcribed and analyzed.	27 Registered Nurses with at least one year of experience.	Themes associated with evoking joy in nurses were: fulfilling purpose, the wow factor, meaningful connection, and practice environment.

Savundranayagam, Dilley, and Basting (2011)	Descriptive mixed methods study investigating the StoryCorps process. Participants evaluated the experience and whether it had an impact on their relationship with their family interviewer after they recorded the story.	42 people with memory loss and 27 family members	Participants reported their experience as meaningful and felt it reaffirmed their relationship with their loved ones.
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Literature that utilizes StoryCorps for data collection is still emerging. Although not one of the identified studies analyzed previously collected StoryCorps data, each used StoryCorps in an innovative way to compliment the research process.

Design of Study

Research Design

Although data collection strategies are not consistent with a traditional grounded theory study, the subsequent analysis and theoretical interpretation are in accordance with the grounded theory process. The results of this investigation are preliminary and serve as a guide for future explorations of this nature.

Grounded theory employs a qualitative methodology and was first used by researchers Glaser and Strauss in 1967. Nevertheless, this method has evolved over the last 50 years, and Charmaz's (1990) adaptation will be used in this study. As with other grounded theory methodologies, Charmaz's version is rooted in symbolic interactionism and emphasizes the importance of understanding the world through the meaning behind social constructs. Charmaz's (1990) approach uses philosophical aspects of

constructivism, which allows the theoretical results of the process to be interpretive rather than exact. This study utilizes Charmaz's (1990) grounded theory methodology to develop a theoretical model that describes the social process of dying in the hospital.

The data used to develop the theoretical model was previously collected by StoryCorps and therefore components of secondary data analysis were taken into consideration. Secondary data analysis in a broad sense refers to the use of data that was collected for purposes other than its current use. Answering new questions with existing data is an emerging approach to qualitative methodology that increases feasibility, decreases cost, and overall allows for the expansion of the body of literature needed to support nursing practice (Gleit and Graham, 1989). Largely, the impact of this design is related to the completeness of data used in this study and will be discussed later in the limitations section.

In this instance, using StoryCorps truly increases the value of the data in that it is fulfilling social justice. StoryCorps creates opportunities for many people who may not typically be involved in research. It broadens our understanding and opens our eyes to all people in the country instead of a small group at one or two facilities.

Data Collection

The process of data collection began with communication between myself and the references librarians at the American Folklife Library within the Library of Congress. Upon initial request, I explained my project and the type of stories to which I was looking to gain access. The search term "death" revealed over 10,000 results; "dying" produced 208; "rites of passage - death" & "hospital" resulted in 571. This final search was used for this study. A preliminary review of the database was conducted to ensure the stories

matched my intent. The first review of the final search was to ensure studies pertained to adults as opposed to pediatrics, this brought the list down to 488. From there story descriptions were reviewed for specific location as the hospital, only 85 stories remained after this step. The final step was to ensure the stories were about dying. This left me with 29 stories. Nineteen were used for active data analysis and the final ten were used to ensure my preliminary theoretical statements were consistent.

The database includes several different story identifiers: city, state, initiative, interview description, facilitator, storyteller name, storyteller relationship to interviewer, interviewer name, keywords, keywords – subject, keywords – general, keywords – people, and keywords – places. An initial review of each database component was conducted to reveal a list of stories that meet the inclusion criteria. Because it is difficult to truly capture the essence of each story using only database identifiers, the inclusion criteria for primary story selection was initially broad. Stories that contain insight into dying in a hospital were selected. The selected stories were sent back to the reference librarians for audio file request. I then listened to each story before performing transcription. Similar to the inclusion criteria for the literature review, stories that focus on patient care, from any perspective, were included. Articles regarding education of patients, measurement testing, and policy initiatives will be discarded.

Data Management and Analysis

Data collected in for this study is in the form of previously recorded interviews (in audio file format). Each file was transcribed and uploaded into NVivo software. This software allowed for the organization and identification of thematic categories. The three primary methods of analysis, consistent with Charmaz's (2006) approach, will be: a)

grounded theory coding; b) memo-writing; c) theoretical sampling, saturation, and sorting. The study proposal was submitted to the Institutional Review board at the University of Massachusetts, Amherst and was deemed *Not Human Subjects Research* and thus full IRB submission was not required. A copy of the IRB waiver can be found in Appendix B.

Grounded Theory Coding

Grounded theory coding forms the foundation for interpretive analysis (Charmaz, 2006). This crucial stage in theoretical development involves identifying both actions and processes to define what is actually occurring (Charmaz, 2006). There are two stages of coding, initial (or line-by-line) and focused coding. The initial phase allows early theoretical ideas to emerge and suggests areas for further data collection. The focused phase involves categorizing larger groups of data by synthesizing and identifying conceptual components of the data (Charmaz, 2006).

The stories that were used as data in this study were found because they referenced an individual who experienced dying, first or second hand, in the hospital. The entire story was never solely about this experience but rather mentioned it sometimes just in passing and others for a couple minutes. There were a couple stories where the subject was raised multiple times in different parts of the dialogue. Before I could begin line-by-line coding, I had to go through and identify which parts of the story referenced the experience of dying or witnessed the dying process in the hospital. Although only these identified pieces of the story were coded, every story was listened to in its entirety to ensure I had sufficient context for interpreting the content specific pieces.

Line-by-line coding revealed many emerging ideas. A list of early codes are found in Table 2.

Table 2 Initial Codes

Communicating	Fostering honesty	Having physical support	Being treated kindly	Being with the person dying	Feeling sad
Fighting for life	Giving the patient what they want	Laughing	Being at peace	Family as a separate patient	Total health mind body soul
Talking	Dignity	Blessing and opportunity	Giving up and having faith	Hard on caregivers	Listening
Providing hope	Suffering	Strength can't always overcome	Vivid memories	Tell their story	Not prolonging death

After I completed the initial coding phase, I looked at my codes and revisited them. This allowed me to look at the substance with a more conceptual lens. I was able to look at the actions as well as processes and began to form my higher-level conceptual codes, known as focused codes. Focused codes along with their corresponding theoretical component are found in Table 3.

Table 3 Focused Code Details

Focused code	Theoretical Component
Unified intentions	Assumptions
Shared versus individual needs	Process
External locus of control	Process
Divided perspectives	Outcome

From my focused codes, came my conceptual model. The conceptual model is explained in detail in Chapter 4.

Memo-writing

Memo-writing occurred simultaneously with coding. This process allowed the investigator to analyze her thoughts about the codes, recognize thoughts about the analytic process, and highlight the connections made (Charmaz, 2006). Memo-writing is a crucial phase in the analytic process. The central components of the theory are developed in this phase in the form of categories. These categories are then elaborated in the next step, known as theoretical sampling (Charmaz, 2006).

Memos in the form of free-writing analytical thoughts about the data were a key piece of theoretical development. The amount of data I had along with the deeper questions about meaning needing to be pulled from pre-recorded stories truly required reflective thought. An example taken from one of the most pivotal memos in the analytic process:

Family, patient, and HCP are all people who are existing in this world. They all have separate needs as well as needs that are shared; how can we make everyone happy? Patients' needs are often thought to be based on their physical state, family needs are often emotional, and HCP needs are moral evidence based.

Theoretical Sampling, Saturation, and Sorting

Theoretical sampling involves refining and expanding categories derived from memo-writing. The purpose of theoretical sampling is to develop categorical properties. I used an additional ten stories to ensure no new themes emerged and I had in fact reached saturation. Once I confirmed saturation, I sorted them into preliminary theoretical statements and began to develop my conceptual model. This method of

sampling, saturating, and sorting ensures that categories are strong and that the analyses are powerful, both of which are necessary to draft a theory (Charmaz, 2006).

Trustworthiness

Trustworthiness is a component in qualitative research that ensures rigor. In adhering to traditional approaches towards trustworthiness, the following strategies were utilized to maximize credibility, dependability, confirmability, and transferability.

Credibility

Investigator. Credibility involves engaging in activities that will result in findings that are both likely and probable (Lincoln & Guba, 1985). One such primary method involves ensuring credibility in the research setting. I have spent seven years as a bedside nurse working with the study population and have spent 13 years in a hospital setting.

While the data was being confirmed and the analysis was being conducted, I engaged in peer review with my supervisor, who is proficient in grounded theory methodology. I also conferred with two other members of my committee, one of whom is knowledgeable in acute care environments and the other whom has ample experience communicating with dying patients in the hospital.

Data. Data collected regarding participants and the context of their in-hospital experience was vetted based on self-report. Because of this, findings from this study will need to be confirmed with participants in a future study. It is necessary to clarify that these are stories and not accounts from people who have been evaluated for their credibility.

Dependability

Dependability is a standard that must be met once credibility has been established (Lincoln & Guba, 1985). Triangulation is a process used in relation to both methods and data sources that involves using multiple approaches of inquiry to facilitate comprehensive understanding (Lincoln & Guba, 1985). Analyzing accounts from, not only the individual who is terminally ill, but also care providers and family members, allowed me to triangulate my data sources and strengthened my analysis.

Confirmability

Confirmability is the aspect of trustworthiness that outlines the process by which the findings were determined (Lincoln & Guba, 1985). I kept a journal that served as an audit trail of theoretical development from data collection through data analysis. These notes are clear and organized so that an outsider could read them and observe the progression from problem identification to theoretical development.

Transferability

Transferability in qualitative research is similar to generalizability in quantitative research, in that it suggests that the findings of the study can be applied to other similar situations (Lincoln & Guba, 1985). Fittingness cannot be completely determined until others use the findings, although using thick description is the most reliable way to ensure transferability.

CHAPTER 4

THE CONCEPTUAL MODEL OF HOSPITALIZATION AT END-OF-LIFE

Introduction

Hospitalization at end-of-life is a common experience for many. The acute care setting, however, is primarily focused on curing illness as quickly as possible, not on understanding the experience of the other (Moback et al. 2011). When treatment options run out, the focus of care is shifted away from the patient as an individual because the treatment continuum no longer applies. Nonetheless, despite having exited the treatment continuum, the patient, their family, and the care provider continue to experience the hospital and all that that implies. Exactly what this process looks like and what meaning is ascribed to the experience coinciding with this process, however, remains unclear. Therefore, it is necessary to understand the social process that encompasses hospitalization at end-of-life. This chapter describes the conceptual model that was developed pursuant to this study.

Model Development

The conceptual model for hospitalization at end-of-life was developed as a result of this grounded theory study based on nineteen publicly available stories that provide insight into both the firsthand and secondhand experience of dying in the hospital. Details of each story are provided in Table 4. Overall, perspective was gained from two patients, three care providers, and fourteen family members.

Table 4 Stories: Detail and Description

Interview ID	Storyteller Name and Perspective Group	StoryCorps Interview Description
DDA000469	Eloise Family member	Rhonda Raglon (56) talks with Eloise Clarke (59) as Eloise remembers her daughter, Antoinette Sherman. Toni was killed on September 11th at the Pentagon, where she worked as an accountant.
DDB000893	Regina Family member	Ted Eytan (42) interviews, Regina Holliday (?) about her experience with the medical system during her husband's illness. Regina remembers the way that the doctors, nurses and hospital staff treated her while her husband was under their care.
DDC000503	Kathy Family member	Kathleen (Kathy) Fennimore (48) tells StoryCorps facilitator Katherine Brook (26) of her childhood memories of her father, Verner Wallace, and describes the ways she found room in her life for religion at age 12.
DDC000509	Anna and Raquel Family members	Raquel Feliz (39) and her sister Ana Feliz (44) share memories of growing up and hopes for their family's future.
DDE000090	Joana and Emily Family members	Joanna Lee (28) talks with her mother, Emily Eberwein (54) about Doug Eberwein. Doug suffered cardiac arrest 2 years ago, and they talk about that experience and his recovery.
DDE000137	Yvette and Cy Family members	Yvette Saliba (30) interviews her father, Sy Saliba (66) about meeting her mother, Patricia Saliba. Sy and Yvette remembers when Patricia became ill.
DDE000600	Carrie Family member	Carrie Schneider (24) interviewed by SC Facilitator Yazman Peta (30) about her mother (Angela Kay Schneider) who passed away from pancreatic cancer last year
SFD000071	Jody and Alex Family members	Jody Spaziani, 50, tells facilitator Alex Lyon, 24, about his family and taking care of his mother who has Alzheimers.

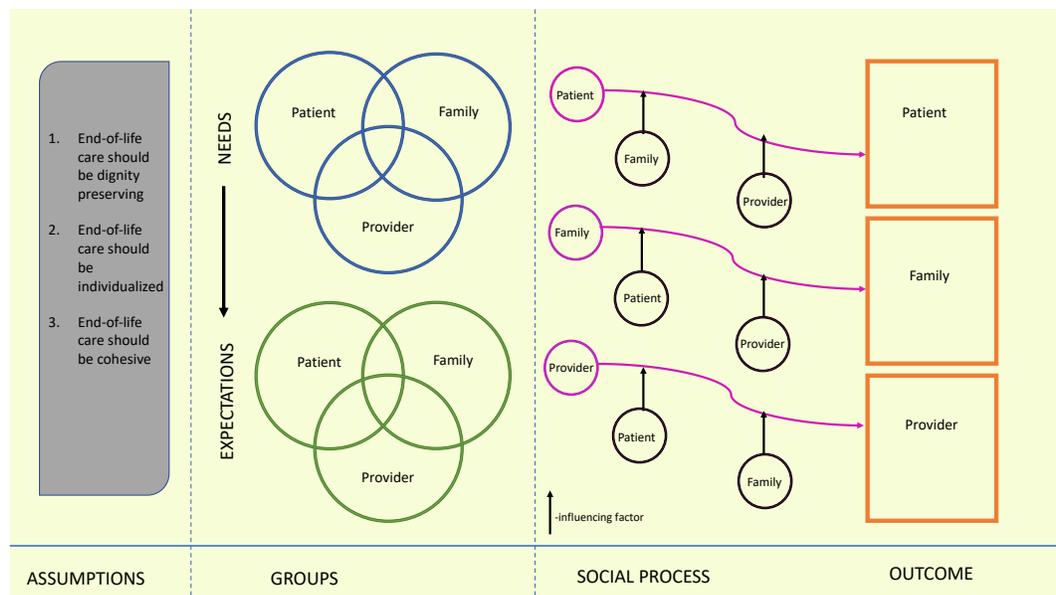
MBY008342	Bob Family member	Bob Stocco (56) tells facilitator Virginia Lora (25) about his mother Doris. She baked famous blueberry pies, and when she died, the family ate the last one she ever baked.
MBY007007	Alicia and Rita Family members	Rita Janesko (64) is interviewed by her daughter Alicia Janesko-Hutchings (34) about Rita's late husband (and Alicia's father), Mike Janesko.
MBY006899	Leon and Tammy Family members	Tammy Noteboom (48) interviews her mother Leone Rowan (68) about marriage, childhood, and the death of her best friend Lois.
MBY006095	Meenakshiundaram and Srinivasean Family members	S. Srinivasan (55) talks to his friend, M. Meenakshisundaram (58) about the death of the Guru, Yogiari, on July 12, 2006 in Malaysia.
MBY005833	Bert Family member	Bert Martinez (48) talks to facilitator, Alejandro De La Cruz (28) about his wife, Anita Synder, who passed 3 months ago.
MBY004651	David Family member	David Ragland (42) speak with his sister-in-law (35) about the life and eventual death of his beloved wife Kristin Ragland. She died of a brain tumor that she had been battling for a few years.
MBY005376	Edward Patient	Raina Perry (30) interviews her husband Edward Perry (37).
MBY005252	Dov Patient	Steve interviews his son Dov about his experience with cancer.
ATD000345	Chuck Care provider	Chuck Carnes (67) is interviewed by his friend, Dr. Vicki Patryla (63) about his tenure at Atlanta Hospital Hospitality House (AHHH), his belief in helping others and his special memories of patients at AHHH.
MBY007797	Lynn and Emily Care Providers	Lynn Meadows (61) and best friend Emily Frey (50) talk about their work as midwives, nurses, and in palliative care.

DDE000108	Steve and Stephanie Care Providers	Steve Yost (63) interviews his wife, Stephanie Yost (60) about a miracle of God she experienced with a hospital patient at Florida Hospitals.
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Model Description

Conceptual models are used in grounded theory to provide a visual representation of the components within a theory, and more importantly, the relationships between them (Charmaz, 2006). In this case, the model describes a theory about end-of-life hospitalization. The main components of this theory are the assumptions, groups, social processes, and outcomes. Key to this model are the three perspectives of end-of-life hospitalization: the patient, the family, and the care provider. Figure 1 shows the model of hospitalization at end-of-life.

Figure 1 Model of Hospitalization at End-of-life



The model begins with the important assumptions that have emerged from literature on end-of-life care in the hospital setting. As such, the model assumes that end-of-life care should be:

- dignity preserving,
- individualized, and
- cohesive.

These assumptions serve as the gateway through which each group begins the social process of hospitalization at end-of-life. They did not emerge from this study but rather, represent congruence between perspectives that is elucidated in the end of life care literature. Patients, providers, and family members come together to begin this process with the same assumptions, feeding off each other in terms of reinforcing their expectations and needs. While some of these needs and expectations are shared among the various groups, others are not shared; moreover, the process also includes individual needs and expectations. The social process, therefore, is invariably an extension of these needs and expectations.

Essentially, the groups move toward a meaningful experience by way of the social process. This social process looks different for each group. The meaningful experience is the outcome of the social process, and can be divided on the basis of each group's unique perspective.

Assumptions

These assumptions are essentially the preconceived notions shared by each group. Regardless of involvement in the process, there is near-universal agreement that end-of-life care should be dignity preserving, individualized, and cohesive. Using these assumptions as a starting point establishes a sense of common ground, which is an important facet of this theory. Knowing that each group is on the same page, with the same goals, even before the process begins, creates a sense of togetherness that can help

to illuminate the next part of the journey, and serve as a salient point for buy-in when testing this theory.

End-of-Life Care Should be Dignity Preserving

Dignity is one of our core rights of individuals. Each person should be treated in a manner that is consistent with their own philosophies, and valued for those philosophies. Dignity at end-of-life has been studied by many, with a wealth of published literature exploring the issue of dignity at end-of-life; as such, this idea has invariably been translated into the acute care setting. Given that people who are dying want their dignity, they experience a lack of dignity as an overwhelming sense of dissatisfaction. When dignity is not maintained, the effects are both physical and psychological. Dignity also correlates strongly with positive energy, this affecting the will to live (Chochinov, 2012).

Family members want dignity for their loved ones, regardless of the stage in the dying process. Ensuring dignity personifies caring for the individual; as such, family members see attention to dignity as an important means of respecting their loved one who may have lost their independence (Davies, Rait, Maio, & Iliffe, 2017). Being gentle, kind, and caring is thought to promote dignity in patients. These social aspects of nursing care are central to good nursing care, and serve as building blocks for holistic patient care (Davies et al., 2017).

Although these assumptions represent overarching themes from the current body of published literature, the theme of dignity and the attributed meaning for the family was spoken about in one of the interviews used for this study. There was no interview prompt for dignity, this was a candid conversation. This highlights the applicability from evidence-based research into practice and supports the use of assumptions in this model.

There were so many little incidents, many of which you can no longer recall in detail. Almost insignificant incidents, but significant at the time. So small that you could gloss them over, but really meaningful to her sensitivities for her sense of privacy, for the dignity of who she was. Because illness has a way of stripping you almost like the death of a thousand cuts. One little bit at a time, just robbing you of your humanity, robbing you of your dignity. (dde000137)

Although the primary focus of care providers in end-of-life care is palliation, regardless of the care setting, there is a strong sense of responsibility for ensuring the patient's life is a dignified one (Brodtkorb, Skisland, Stellbo, & Skaar, 2017). Other aspects of care that promote dignity include focused care, nurse-patient relationship, and therapeutic communication. When dignity is actively sought instead of being passively achieved, it encourages conversations that may not have otherwise happened, creates bonds between patient/family and caregiver, and contributes to the creation of an overall environment that is supportive (Brodtkorb et al., 2017).

End-of-Life Care Should be Individualized

Respecting patient preferences is a crucial tenant of quality end-of-life care. These preferences are often discussed in terms of care being individualized or personalized. Not only do patients want their care to be tailored to their liking, their family members and care providers do as well. Discussions between providers and patients during end-of-life are essential in ensuring that care is individualized (Tang et al., 2014). In the absence of thorough communication between provider and patient, a proper understanding of the patient's preferences cannot be achieved (Winkler, Reiter-Theil, & Lange-Riess, 2009)

In some instances, patients may be unable to communicate their preferences at the end-of-life. In such situations, the family will often assume the role of surrogate decision makers. As care providers, we often assume that family decisions are representative of the patient's actual preferences when the patient is unable to clearly express such

preferences themselves. A study by Waller et al. (2017) investigated the ability of substitute decision makers to predict patient care preferences during end-of-life. While there were many aspects of care that the substitute decision makers were able to predict, there were also a number of inconsistencies. Suggestions included not only discussing end-of-life care preferences but keeping a record to ensure accuracy of understanding.

End-of-Life Care Should be Cohesive

Agreement, collaboration, and commonality are all important components of cohesive care. Care that is cohesive generally involves the patient, family members, and care providers being on a united team. Shared decision making is another key component of cohesive care (Virdun et al., 2017). Shared decision making involves the clinical expertise of the provider group, combined with the informed judgment of the patient, and support from the family. Effective communication, integrated care, and respect for one another are essential for ensuring that care is cohesive (Virdun et al., 2017).

Groups

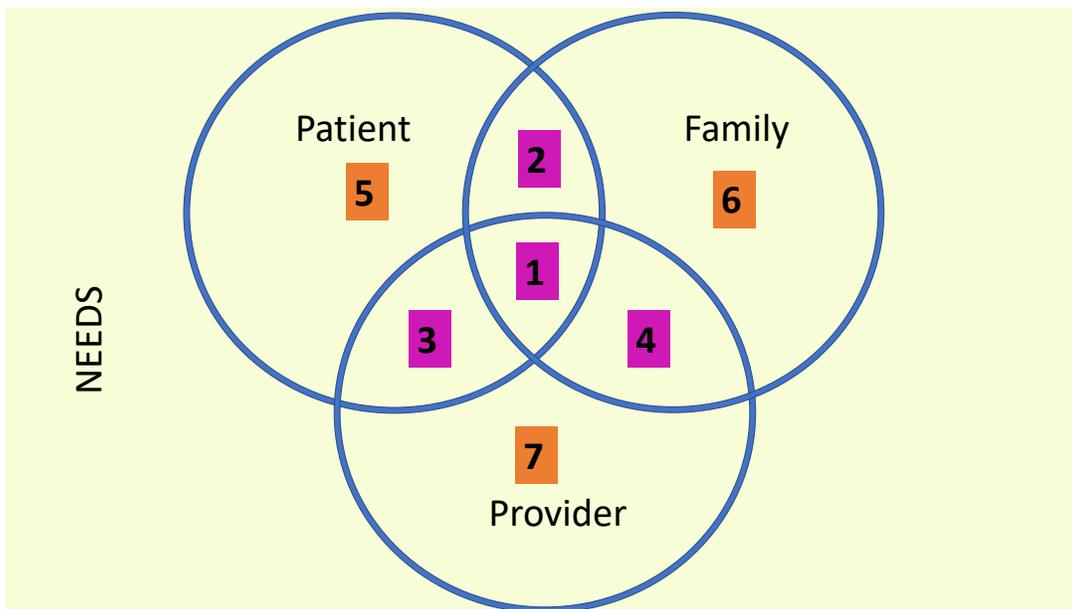
Each of the groups presented here constitutes a separate entity with its own set of needs. Some of these needs may be shared with other groups, either one or both groups. When so shared, these needs are reconstituted into expectations. In the context of end-of-life care, the line between needs and expectations is direct and unwavering. For instance, if a patient were to need pain control, there would be no logical reason for them to not expect it. If a family needed communication from the care providers, there would be no reason for them to not expect it. If the care providers needed the patient to engage in conversation regarding treatment options, there should not be any reason for them not to expect the patient to do so. Multiple detailed examples of this process will be highlighted

in Chapter 5. The three groups of interest in this study are the patient, the family, and the care providers. While the perspectives of each group are represented in the data, family insights featured much more prominently than those of other groups.

Model of Needs

The model of needs serves as the conceptual foundation for the theory of hospitalization at end-of-life. This model provides context for the social process of hospitalization and sets the bar for expectations across groups. Needs are separated into shared and specific. Each group shares a number of needs with other groups, as well as having its own specific needs.

Figure 2 Model of Needs



Needs 1–4 are shared, while needs 5–7 are specific to their corresponding group.

The attribution of needs can be described thus:

- Needs 1: Shared needs among patient, family, and care providers.
- Needs 2: Shared needs between patient and family.
- Needs 3: Shared needs between patient and provider.

- Needs 4: Shared needs between family and provider.
- Needs 5: Patient specific needs.
- Needs 6: Family specific needs.
- Needs 7: Care provider specific needs.

Needs 1: Shared Needs among Patient, Family, and Care Providers

Collectively, patients, providers, and families need favorable communication, care that is tailored to the patient's desires, and the presence of laughter.

To engage in favorable communication. Communication is a two-way exchange that involves not only talking but listening. Presence, facial expressions, and tone also serve as communication methods. Being able to establish a relationship with another person, regardless of role, requires communication techniques that are reflective and articulate. Dov is a patient with terminal cancer who is often admitted to the hospital for symptom management. Dov states:

I can only talk about my approach, and myself but it has always been that the best thing for me has been talking directly about it and listening and then giving the person who may be happy or angry and letting them have that. Address it. But not speaking about it, I mean like you are talking to someone with no hair and who is throwing up and trying to pretend like everything is fair and not wanting to address it and it's like the elephant in the room. (mby005252)

As Dov points out, having someone talk directly about the issue at hand is very valuable. Addressing issues upfront allows those involved to share a common understanding. People often feel unsettled by the unknown. Alicia and Rita, daughter and wife of Mike, respectively, discuss the frank nature of the doctor who gave them the news about Mike's terminal illness.

I remember he came in the room and he was a real quick walker and quick talker and he said to your dad "I'm going to be brutally frank", and Mike said, "I wish

you would”, and he said, “OK you got two years, nobody beats it, you got it, nobody beats it.” (mby007007)

The energy of the person delivering the message plays an important role in the ability of the person receiving the communication to actually understand their meaning. As Rita observes, “He was a quick walker and quick talker”; this description provides a visual descriptor of how the doctor presented himself. It seems as though Mike, Rita, and Alicia were amenable to the quick nature of Mike’s doctor; however, not everyone appreciates this approach. Regina, the wife of Fred, talks about the disconnected nature of multiple different exchanges she had with providers.

When I got to the office hours, he never closed the door or stopped taking phone calls, he never turned the computer to face me he never stopped talking to the nurse about the parking problem in the parking lot. (ddb000893)

Four days after he had additional testing and four days after Fred had been admitted to the facility, an on-call oncologist came in the room and she was very busy, and I remember her looking at things and checking a chart and then we were just waiting for her to say something. She didn’t say anything. Finally, we asked do you have results of those extra tests, bone scan and PET scan that he had. She just looked at us and said you mean nobody has told you. No one has told us (ddb000893)

Communication is also a way of establishing a meaningful connection with someone. Lynn and Emily, both nurse practitioners, talked about the touching nature of their patient encounters.

Both you and I have the ability to connect with people quickly and get into a trust and a rapport. I think we both share that. We are both good communicators and we can go into a room and just touch someone. That is the way that we are similar. We have been able to be a part of people’s lives which is such a sacred thing. (mby007797)

To participate in patient focused care. Patient focused care refers to the idea that the patient should be making informed decisions, participating in discussions about their care, and feel their self-described emotional, physical, and spiritual state is

acknowledged and being addressed. One of the basic assumptions of hospitalized care is that care should be individualized. Patient preferences should be at the center of the hospital care model; as such, other people and events exist only as spokes at the periphery of this wheel.

Participants in this study revealed an underlying assumption that the patient should be given what they want or what they desire, with this assumption being shared by all groups. However, it can often prove difficult to determine what someone truly desires in the moment. In the presence of someone who is dying, most care providers feel an exaggerated need to make their wishes come true, embracing a final opportunity to set things right.

Steve, a nurse working in Florida, spoke about a patient he cared for years ago when critical care transport was very rare. His patient was visiting from Mobile, Alabama, and desperately wanted to go back home. He was traveling in Florida when he became ill, but was too unstable to be transported back home with basic ground transportation. There was an Adventist Church conference in the area, and among the attendees were a couple pilots. Steve felt very strongly about getting his patient back home where he wanted to die. Here he says:

On Thursday morning after a restless night of thinking what to do, I found myself walking over to the conference office to ask the president of the Adventist Conference to see if we could borrow a plane. (dde000108)

While take a private jet to return a patient to their home might be a bit extreme, it is nonetheless a great example of the kind of mountains people are willing to move to make someone's exit from this world as meaningful as possible. A meaningful experience can also be something as simple as letting the patient feel raw emotion, letting

them know that what they are feeling is normal. Decisions can be difficult, and a number of external influences can act to shape how someone feels about their emotions, or about the decisions they want to make about their care. Dov, our patient from earlier who has terminal cancer, spoke about the reality of emotions and the importance of the patient choices:

Let them be happy or cry or whatever and don't try to take away those emotions because there are a lot of people that are like – oh you just need to be strong through it, or you need to fight it. Some people are like, you know, quality of life, I'm not going to do Chemo, I'm going to let myself die, and that's my choice. That is the person's choice and we need to honor however they choose to deal with it. (mby005252)

It is also important to recognize that some of the most personalized approaches to care are right within our reach. It might be something we can change about the environment, someone we can help get to the hospital, or a specific topic of discussion. Small gestures of kindness and consideration for someone's needs can go a long way. Conversely, when something very simple is withheld from the patient, it can have a negative effect not only on the patient, but on the family as well. One wife describes the horrible experience her husband had the morning before she came in.

The night nurses heard the showers running and they asked, who is down there, and it was Mike taking a shower. He wasn't supposed to be out of the bed. When I came to the hospital in the morning, they had him tied to the bed. I thought, enough of this. The doctor said that he probably only had a couple of days and I said I don't care, my husband told me he wanted to be at home. (mby007007)

To experience laughter. Finding the right moment to make light of a situation and to share in a positive exchange is an important reflection of the state of a relationship. Laughing feels good, and in an appropriate context, laughter can calm someone's nerves, bring groups together, and create a calming energy in the environment. Chuck, a caregiver for families who have loved ones in the hospital, was being interviewed by a

friend about his experiences over the years. A distinguishing feature of Chuck's work is his approach. Here, his friend says:

And you know Chuck, being a person with disabilities myself I've learned a lot from you about kindness and fun and laughter. Because, as you know, I was diagnosed myself as mentally retarded and as you know my diagnosis is severe dyslexia. It would have been great to have someone like you or programs like the Hospitality House when I was growing up. (atd000345)

This speaks to laughter being an important part of taking care of people with more complex needs. People need to be lifted up, and it is often the case that laughter can be very effective in achieving this result. Sometimes, the person in need can use laughter themselves, they do not always need to be the recipients of laughter. Carrie's mom was a terminally ill patient in a facility she did not like being in. She was not connecting well with the staff, and was looking to turn a negative situation into a light-hearted, positive one. Carrie explains:

She would tease the nurses. She was so hard to get along with in the hospital, she would make up these things and be paranoid about that the nurse thought this or did that and she would go through like of ten of them until she could find one that she could stand. The rest of us would roll our eyes and be sympathetic; she just couldn't get along with anybody. Someone had sent her this card, one of the singing cards; it sang the song A Spoon Full of Sugar. She was at a facility that she absolutely hated. When she would ring for help no one would answer and she didn't get treated very well so she rigged the card up so it was hanging on the wall and whenever one of the nurses would walk out it would open it up and it would start singing and it would freak them out and she would just laugh and laugh about pulling this prank on them. (dde000600)

Steve, Dov's dad, talk about a similar prank that he and his son shared:

I think one of the most fun days I've had in my life was shopping with Dov and his mom for a ladies secret thong from Victoria Secret. He wanted to go into his last day of radiation wearing that. (mby005252)

Laughter is often associated with happiness, good memories, and joy. Leon spoke about his friend, Tammy, who was dying in the hospital. Here he is referencing a dream he had and peacefulness he shares is powerful:

Then I had a dream, and, in that dream, she was happy, and she had her weight back and she was laughing, and she was running and there were flowers, I remember, and I knew she was going to die. (mby006899)

Needs 2: Shared Needs between Patient and Family

To engage in honest communication. Fostering honesty and delivering honest communication part and parcel of social culture outside the health care setting.

Dishonesty has very negative connotations and provokes unsettled feelings. Interestingly, some people think that the concept of honesty has different rules in the health care environment. Here, Carrie talks about a communication with the doctor she had:

I think the doctor only told me at the time and I was grateful that he was honest because doctors don't want to tell you what is wrong because they can get in trouble for that, but I was lucky that the doctor she had did take me aside and told me how sick she was and told me it was probably pancreatic cancer. (dde000600)

Honesty does not just have to be about the prognosis. It is easy to instill a sense of honest communication during day-to-day conversations. Addressing the situation at hand, and not being hesitant about bringing up something glaringly obvious, can also encourage honesty. One patient spoke about something as simple as hair loss:

I'd rather someone say like wow you lost all of your hair, how much does that suck? Even joking about it, whatever, I think, for me dealing with it and realizing that it is huge factor in their life. (mby0005252)

Needs 3: Shared Needs between Patient and Provider

To be treated kindly and to treat people kindly. Kindness is the care and concern one feels and gives in exchanges with another person. Generally speaking,

everyone wishes to be treated kindly. Caring providers hope to be kind, but it is important to remember that kind intentions are not the same thing as kind behavior. Chuck, the caregiver introduced earlier, described an essential part of what he does:

I really think that the biggest thing you can do in any situation that we are in is to let the people know that we care. (atd000345)

There were no direct statements from patients regarding their need for kindness, but this patient related need was expressed from family. Yvette and Cy spoke about their loved one's experience of dying in the hospital, and how nice it was to see her being treated kindly.

It seemed like the nurses and the doctors that worked with her became friends almost. I mean, they knew us. When we would come in on the floor, they were always very warm. I was always impressed with the kind of treatment that she got. (dde000137)

Needs 4: Shared Needs between Family and Provider

To be at peace. Family members desire their loved one be at peace. This is an important piece in the big picture of dying. When someone is not at peace, they are distressed, restless, or scared. Families often advocate for an environment conducive toward peacefulness. Here, Leon described her experience of telling her husband about Tammy's death:

I went out to the shed and told him that she had passed away. I just felt relief. She was totally prepared to die and at peace with it. She had such a strong faith and such a belief in a God in heaven and she wasn't afraid at all. (mby006899).

Bob, whose mother Doris was dying, recounts his experience of appreciating his mother being at peace. This description is illuminating because Bob also articulates what he does not consider to be *being at peace*.

The scene was really very calm, peaceful and serene very unlike the scene in the ICU with all the tubes machines, buzzers and the lights. There was quiet music playing and mom seemed to be at peace. (mby008342)

For care providers, it is also important that one is internally at peace. There is often a burden placed on care providers regarding the management of the dying process. With this comes an internal challenge to ensure you have done everything in the patient's best interest. Care providers can feel unsettled at times, but very much desire to be at peace themselves. Here, Lynn, a palliative care nurse practitioner, describes her personal journey:

I feel that in our work that we are doing with the people in the hospital that are so emaciated from cancer or from their pain or at the end of their life. I feel that I have been given a blessing and opportunity to be able to do the work that she did too. Part of the question about the work we do and what we get out of it and how we can continue to do it. I know that when I'm with a person, I do pray inside all the time inside for peace for myself and for them that ... and I try to give off that peace from me to them from my body, through my hands, opening my heart to them. To think that I get paid to do that is a wonderful thing. (mby007797)

To not be sad. Not being sad is an important need for both care providers and family. It may be a need for patients as well, but this theme did not emerge from the sample that was interviewed. Words, such as *gloomy* and *grim* were used to describe feelings associated with the process of family's loved one dying. Family members telling their stories did not explicitly say, "I need to not be sad," but the implied negative connotation was noted. This negative nature is associated with the outcome of the dying process, which is death. Eloise, a mother of a woman who spent a week in the hospital after injuries suffered from the 9/11 terrorist attacks described her feelings:

She was one of the eight people who were medevaced to the Washington Hospital Center. She lived for exactly one week. Then she died. That was a very gloomy day for me and for my family (dda000469)

In this next excerpt, Joanna talks with her mom Emily about their father's experience of dying in the hospital:

We were told to go in and say our last goodbye. Things looked very grim. The chaplain said this was something we need to do, so the nurses were kind enough to let us in just for a few moments. (dde000090)

The sense of sadness is felt by care providers as well. There is a constant fight for life.

When someone is dying, it feels like a loss. Steve, a nurse, described a dying patient he was caring for, using negative words when talking about the outcome of his patient's terminal illness:

He had a terminal illness; he had cancer of the abdomen and at that point, the outcome was quite grim. (dde000108)

In this next story, between Lynn and Emily, palliative care nurse practitioners, Emily describes a sad moment she experienced when caring for one of her patients. Not only does she describe sadness, but she also described feeling that it is wrong for her to feel this way:

And do you remember that time I called you from work when I had to sequester myself in a supply room and just sobbed on the phone to you about this very sad situation of a women in her late 30 or around 40 who was dying, and her mother came to me and was crying. So, so sad and so beautiful and I was on overwhelm. That is unusual for me at work, I can always handle it, I may break down later at home, but that day I just had to talk to someone and you were great to talk to on the phone and you gave me the strength to go on because sometimes it just affects you so bad. (mby007797)

Needs 5: Patient Specific Needs

Only two of the 19 interviews in this study were with patients who experienced dying in the hospital. Each provided an interesting perspective. Edward was a patient in the intensive care unit after a sudden illness. His providers told him and his wife Emily

that he was not going to make it. Edward's death was imminent; nonetheless, he shares that hope and faith were crucial needs at this time:

It's like a leap of faith. Basically, like saying ok I'm going to give up doing this on my own and just hope for the best. Hope that when I'll let go knowing and feeling that I was going to pass out and hoping that I would revive. But at the time I wasn't really concerned about the alternatives, I wasn't really afraid. I just went with it. (mby005376)

Dov, who shared his experience of being terminal in the acute care setting, spoke about not only his experience, but the experience of others who were terminal. There is a need to tell their story and to make the bigger picture known to people who will listen:

I would bring candy and talk to people and hear their stories. People have a real need to tell their story and be heard and to be able to do that even it is just to go over and say, "what kind of cancer do you have", and how is it going for you? To hear that from someone who also has cancer. I know it means a lot for me to be able to do that and for a lot of people there it seemed to mean a lot. (mby005252)

Needs 6: Family Specific Needs

Needs that are specific to family were the most plentiful. Fourteen of the 19 stories were told by family members. Needs that fall into this group include the need for physical presence, the need to not suffer, and the need for holistic health.

The need for physical presence. Kathy, a nurse at Florida Hospital, described her experience with her dying father. Physical presence felt like support for Kathy. It was a crucial need in her process.

And during all of his treatment, here at Florida Hospital, there was great support next to me, physically, like people coming by to see my family, whatever need that I had you might be a nurse, but all of a sudden you are the family member and you might need to be talked to differently because you need to hear things differently. (ddc000503)

Joana and Emily also spoke about the physical presence of the chaplain.

What was so nice was that when we arrived at the emergency room we had a pastor assigned to us and she never left our side. She would turn and pray for us every time we asked. (dde000090)

Jody, a woman whose father died in the hospital, spoke about how she felt she needed to be with her father physically when he passed, and still felt horrible for not being there.

Her need stemmed from her perception of her father needed to have his family with him.

Dad I'm truly sorry that I wasn't there holding you when you passed away because I know that's what you feared the most. He went through that with his mother, he walked out of the room to make a phone call to his sister and my grandmother passed away and he never got over that, so that's why he had the fear. So, if I could change anything in life, turn back the clock, that's what I would tell him, I'm truly sorry, because I should have been there. That's what I would say. (sfd000071)

The need to not to suffer. Anna and Raquel, two women whose father died in the hospital, describe suffering in terms of them both and their fathers not needing to suffer:

Thank God we had him for the rest of the year, but he went quickly, and I thank God that he didn't suffer a lot. If it had prolonged, it would have been harder for him and for us. (ddc000509)

The need for holistic health. Multiple interviews with family members led to several aspects of holistic health being mentioned. Considering all the small pieces that constitute a patient's identity, as well as how these pieces combine to form the whole person as an entity was seen as significant. Regina spoke about the way her husband was cared for when he was dying:

Total health would be actually viewing the patient or member in their entirety. So, we just don't treat the symptoms of a disease or disorder, we treat their entire body. Not just the body, the mind, and the soul as well. We view a person in their entirety and then figure out ways that we can help them with all their aspects. (ddb000893)

Similarly, Emily spoke about attending to the total health of her father.

Even the nurses would ask us if we knew what he would like to watch today, keeping the whole patient in mind. (dde000090)

Dignity and privacy also fall under the umbrella of holistic health. Although these important aspects of care are not elaborated upon in this story told by Cy, he clearly thought that his wife, who was dying in the hospital, was in dire need of both.

Yes. It made us feel at home. There were so many little incidents, many of which you can no longer recall in detail. Almost insignificant incidents, but significant at the time. So small that you could gloss them over, but really meaningful to her sensitivities for her sense of privacy, for the dignity of who she was. Because illness has a way of stripping you almost like the death of a thousand cuts. One little bit at a time, just robbing you of your humanity, robbing you of your dignity. (dde000137)

Needs 7: Care Provider Specific Needs

Two out of the three care giver stories touched upon the need to heal. Although this need is specific to the care provider group, it is based off the perception that patients need healing. Steve, a nurse, tells his wife about the healing he engages in. His healing is both faith based and embraces caring in the most simple form of the word.

(Steve's wife Emily) So sometimes the healing ministry of Christ isn't necessarily medical intervention but human personal intervention?

(Steve) Yes, I think so. I think the healing ministry is just extending a hand in friendship or love or seeing a need and trying to meet that need. (dde000108)

Lynn and Emily, the palliative care nurse practitioners mentioned earlier, spoke about healing in their conversation about the patient being at peace. Healing is the process by which peace comes. Healing in this sense does not mean curing, but rather soothing.

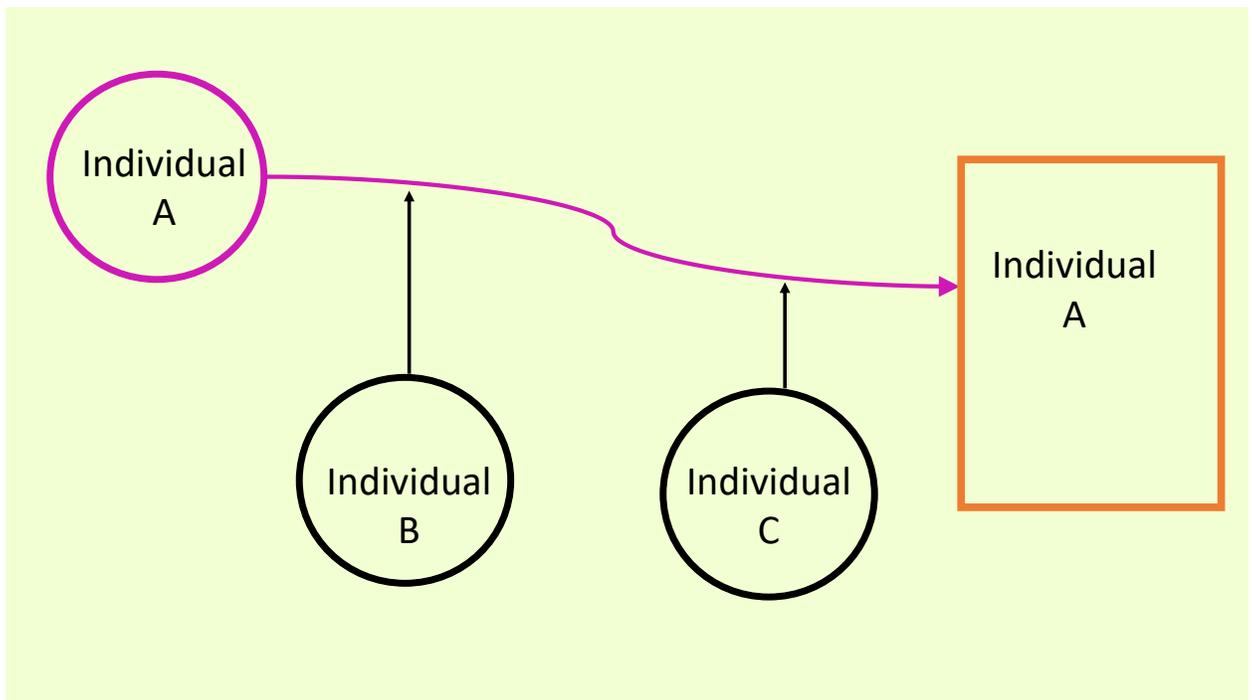
...for them that they can be healed even if that means healing into dying. (mby007797)

Social Process

The third piece of the Theory of Hospitalization at End-of-Life pertains to the social process that occurs at the individual level over time. Each individual engages with

their surroundings and forms their own perspective based on the process they go through. The outcome of this social process, according to grounded theory, is an experience with meaning (Charmaz, 2006).

Figure 3 Social Process Model: Being Out of Control



Data analysis revealed the basic social process of *being out of control*. Individual A is either a patient, a family member, or a health care provider who is experiencing hospitalization at end-of-life. This individual starts their journey, developing their own social process, with the previously assumptions, as well as the subsequent needs and expectations that come from those assumptions. The line that connects circled individual A to squared individual A represents the social process that individuals goes through. Individuals B and C are the other two groups, respectively. These other two groups influence the social process and steer the path of perspective. The outcome represented

by the orange square is the meaningful experience that individual develops as a result of the social process they undergo.

It is clearly understood that each of the three interest groups—patient, family, and care provider—experience hospitalization at end-of-life differently. Their roles are very different; as such, their personal journeys will invariably differ. Although teasing out references to a social process from interviews that were not strictly about such social processes was challenging, a number of quotes could be identified that suggesting a journey that is out of the individual’s control. This is represented in the model in terms of influencing factors.

Family members Meena and Srini described a scene in the hospital where their loved one had been admitted. In this excerpt, Meena reiterates multiple times: “They brought him out of it.” For these family members, their experience was influenced by the providers, thus suggesting an external locus of control:

He was in the hospital for about two days and there were multiple crises and it just got worse and worse. Shortly after we got there he went into congestive heart failure and they brought him out of it, then there was another crisis the next day and they brought him out of it. (mby006095)

Rita, a wife whose husband was hospitalized, felt everything was out of her control. Not just the outcome of events, but the actual decision-making process. Rita and her daughter spoke about their experience at the hospital, and their strong sense of not having any control, particularly when Rita says, “Everything was taken from our hands”:

I remember the doctor pointed at his wrist and he asked Mike what the name of that was. When Mike didn’t know the name, that’s when the doctor knew he had to go to someone else, a specialist. So, he made an appointment the next day and I went with him. From that, everything was taken from our hands. All decisions, although they say it is your decision, they make the calls. (mby007007)

The feeling of being out of control also featured prominently in Edward's recounting of his experience of being in the hospital during end-of-life:

It's like a leap of faith. Basically, like saying ok I'm going to give up doing this on my own and just hope for the best. Hope that when I'll let go knowing and feeling that I was going to pass out and hoping that I would revive. But at the time I wasn't really concerned about the alternatives, I wasn't really afraid. I just went with it. (mby005376)

Bert, whose wife was dying in the hospital, described feeling that neither he nor his wife were in control of their care trajectory. This negative experience impacted Bert deeply and instilled a misconception about the intentions and organization of the hospital environment:

But once we she was not a prime candidate for chemotherapy any longer; they kicked us out of the hospital because she was not a money generator for them. (mby005833)

In an interesting statement made by Lynn and Emily, the two palliative care nurse practitioners, reveal their sense of burden. The phrase *have to deal* has a negative connotation and touches upon that feeling of being out of control that family members, like Bert, describe:

But when you have to deal with these families that are losing someone, that can be very heartbreaking and a lot of our work over the years has involved that kind of thing. (mby007797)

The way Lynn and Emily describe *having to deal* highlights that, for health care providers, the social process—from needs and expectations, to the final outcome—can also feel out of their control, and is influenced by the two other main groups engaging in the overall experience of hospitalization.

Summary

Hospitalization at end-of-life is a complex process involving the patient, the family, and care providers. Assumptions are pre-conceived notions agreed upon by each of the three groups. These assumptions have emerged from the literature and are general social standards that encompass quality end-of-life care in the hospital. They are applicable whether one is receiving care, supporting someone who is receiving care, or are the one providing care.

This theory describes needs stems from the physical presence of being in a hospital and having a role in the end-of-life process. Moreover, these needs arise the instant one becomes a recipient of, supporter of, or provider of care. These needs come in a variety of forms—emotional, physical, and spiritual—and are dependent on each individual's current state. Some needs are shared by all, while others are shared just between two groups, and some are purely individual.

These needs directly translate into expectations. As such, if you need something, there is no reason to not expect it. Once the individual has established a set of needs and expectations, the next major step in the theoretical process begins. This social process, therefore, is the psychological process an individual goes through, over time, within the social construct of the care setting. Therefore, this process should form a meaningful experience for the individual experiencing it.

Each individual begins the social process with their own needs and expectations. As they move along the time continuum, engaging with the two other interest groups, they form meaningful experiences. A key piece of this theory, however, is that the social process is not just a product of the individual's journey, it is heavily influenced by the

two other interest groups. These influences ultimately shape the outcome of the social process, and play a key role in the final meaningful experience of the individual.

CHAPTER 5

REFLECTIONS ON THE FINDINGS

Introduction

The major goal of this study was to understand the meaning associated with the end-of-life process in a hospital. This process is centered in the patient experience, but it also involves perspectives of the family and care providers. A preliminary conceptual model of hospitalization at the end of life emerged as a result of data analysis.

The model is founded in a state of unified assumptions all three perspectives have regarding EoLC in the hospital: it should be dignity preserving, individualized, and cohesive. From these assumptions comes the social process. Social processes are grounded in psychological behaviors that construct our reality.

The social process in the hospital at end of life occurs over time, and it has been identified as *being out of control*. Needs and expectations of each individual (patient, family, and care provider) frame the construct for interpreting the experience. As the individual interacts with the surroundings, that person is influenced by the perspectives of the family and care provider as well as the person's own perspective to ultimately create a meaningful experience.

Discussion on Findings and Relevant Literature

The needs associated with hospitalization at end-of-life are both individualized and shared. Data analysis revealed many different need groups and elucidated a model that reflects a population with varying demands. Although each perspective begins the experience in the hospital with unified assumptions, each group diverges and redefines needs based on its role in the hospitalization experience. Shared needs centered on

communication, patient-focused care, kindness, and humor. Individual needs of the patient, family, and care providers, respectively, focused on positivity, physical presence, and healing.

These personalized necessities are then transformed into differing experiences based on the influence of others around them. The essentially *out-of-control* course of action was expressed by each perspective group and served as the pathway for constructing meaning. Data on the social process piece was very limited and requires further exploration, though on initial interpretation it appears there is a strongly external locus of control as evidenced by stories that are more about the peripheral factors that made each group vulnerable to the impact of others. The central components of this model must now be explored in the context of the relevant literature.

The Link Between Social Processes and Needs

The goal of this grounded theory study was to identify the basic social process associated with end-of-life experiences in the hospital. What the data overwhelmingly revealed was a social process rooted in the needs of the individuals living the experience. Looking into the current state of literature surrounding social processes during end of life uncovered multiple grounded theory studies with subsequent theories constructed on the basis of needs.

Three studies with comparable findings helped strengthen the link between social processes and needs during end of life. Table 5 below illustrates the different social process theories identified in the literature and their accompanying needs.

Table 5 Social Process Theories and Accompanying Needs

Social process	Needs	Citation
<i>Rediscovering</i>	The need to be at peace The need for laughter The need for escape	Lewis (2015)
<i>Experiencing end of life</i>	The need for adherence to patient preferences The need to not be left alone The need to be bathed and toileted	Sessanna (2010)
<i>Creating a haven for safe passage</i>	The need for patient-centered care The need for detailed communication The need to provide good care	Thompson, McClement, & Daeninck (2006)

All three studies above provide context for interpreting the theory of *being out of control*. In addition, two studies shed light on additional needs.

Lewis (2015) describes a basic social process of caregivers of persons with dementia at end-of-life as *rediscovering*. Rediscovering is the process by which these caregivers go through in an attempt to solve the basic social problem of *role entrapment* (Lewis 2015). Caregivers' needs of *being at peace* and *laughter* were consistent with needs identified in the stories (data) in this study. The need for escape was a new concept that emerged from Lewis's (2015) study. Future research should involve validating this concept and understanding how it fits with the model of hospitalization at end-of-life.

Sessanna (2010) developed a basic social process theory of *experiencing end-of-life* as described by older adults. The model consists of three categories; fearing, preparing, and caring. Fundamental to each category are individuals' EoLC needs and preferences. Looking at the EoLC experience in the hospital through the lens of Sessanna's (2010) social process theory and the conceptual model of hospitalization at end-of-life that emerged in this study could provide expansive understanding of the care provider's and family's needs as well as guidance for attending to some of the more objective needs such as planning and advanced directive.

Thompson, McClement, and Daeninck (2006) describe a basic social process theory of *creating a safe passage* portrayed by nurses in acute care settings who provided EoLC. Needs of these nurses were to provide an environment that promoted patient-centered care and established relationships that were grounded in through communication with the goal of explaining and reassuring (Thompson et al., 2006). Consistent with the *model of hospitalization at end-of-life*, nurses in Thompson et al.'s (2006) study discuss barriers related to *not getting what is needed* and present the important concept of *being there* that was found in this study as well. The physical presence of all three groups—patient, family, and care provider—is an essential component in developing a preferred, meaningful experience of EoLC.

End-of-life and Hospitalization Models

Unitary Caring Model

Reed's (2010) unitary caring model was derived as a method to guide advanced practice nurses (APN) in palliative care. The concepts of pattern, wholeness, consciousness, caring, transformation, relationship, and meaning direct the APN to

healing. Healing is rooted in the spiritual, physical, cultural, and psychosocial needs of the patient (Reed, 2010). The model takes into consideration the unique role of the APN and sets the stage for comprehensive palliative care.

Both palliative care nurse practitioners in the current study expressed a need to heal. The process for achieving healing is the premise of the Unitary Caring Model (UCM) and could provide a framework for enhancing EoLC in this population. Also, the concepts of *meaning* and *pattern* in the UCM are consistent with the appreciation for a meaningful experience during hospitalization found in this study. Another finding from this study was that the experience of each perspective group is influenced by others and results in a process of *being out of control*. Taking into consideration the principles of the UCM could assist those involved in the experience of EoLC and tighten the gaps between need groups, providing a more collaborative approach to a unified outcome.

The Integrity of the Human Person Framework

Factors influencing the integrity of the human person is a conceptual framework for providing EoLC (Nolan & Mock, 2004). The process for interacting within the experience of EoLC is influenced by the nature of all the dying individual and takes into consideration both the external and internal factors that impact the integrity of that individual. Meaningful outcomes are grounded in the spiritual, functional, psychological, and physical nature of the person (Nolan & Mock, 2004).

Similar to the conceptual model of hospitalization at end-of-life developed in this study, the Integrity of the Human Person Framework involves external influencing factors that impact the patient experience. Both the external and internal factors influencing the integrity of the human person are substantial additions to the model

identified in this study and could guide future testing of the model. Both models recognize the care provider as a key component contributing to the experience of the patient and the outcome of care. In the Integrity of the Human Person Framework, family is seen as part of the spiritual domain of the patient (Nolan & Mock, 2004). Appreciating the findings of the current study could elevate the understanding of the family involvement in Nolan and Mock's framework and push the boundaries of achieving a meaningful experience for all persons involved.

Model of Perceived Uncertainty in Illness

The Model of Perceived Uncertainty in Illness is a renowned framework in nursing that focuses on understanding the patient experience during illness and treatment in hospitalization (Mishel, 1981). This conceptual framework led to the development of an uncertainty scale has been used widely in nursing research to explore relationships in theory. The Mishel Uncertainty in Illness Scale (MUIS) is an instrument that could be used to explore uncertainty of patients described in this study. The data here revealed a network of needs but did not uncover any information about the uncertainty related to the experience. With a better understanding of uncertainty in terminal illness, we could broaden the model of needs, better appreciate the patient's perspective, and move toward a framework for EoLC that is not just based on what we know patients need but also what patients are unsure they need.

Significance of Findings

Although preliminary in nature, the findings of this study add to the body of knowledge in the experience of EoLC in some important ways. The premise that the experience of EoLC in the hospital is constructed by first understanding the needs of

those involved was found in this study as well as in several other studies that looked at social processes at end-of-life. This common theme has not yet translated to nursing practice but with the addition of this research, it is my hope that the transition from research evidence to practice can begin.

An additional contribution is the development of the social process of *being out of control*. This process was found to be related to not only the patient but the family and care providers as well. This is new finding with the end of life literature and helps add to the understanding of dying in the hospital. With this psychological aspect of self being the same across perspective groups, conversations about *being out of control* can begin to happen. Understanding how others we interact with are interpreting reality will enhance relationships, promote communication in practice settings, and launch future research endeavors looking to uncover additional psychological perspectives surrounding the complexity of EoLC in the hospital.

Findings of this study also helped to fill the gap in our understanding of the patient perspective in ELOC. Opportunities for further research regarding the patients' need to tell their story along with investigation into needs of patients at end-of-life were identified.

Limitations of this Study

Limitations of this study pertained mostly to the use of secondary analysis and the implications it had on the findings. The stories that were used were collected as part of an initiative to preserve and share narratives of peoples' lives. The process was not manipulated, guided, or directed in such a way that could focus the stories. Although each story used in this study involved discussions regarding the experience of end-of-life

care in the hospital setting, most often the dialogue was short. Stories included many other details, tangential thoughts that were not necessarily relevant to this study and therefore were not included.

If the stories used in this study were collected in real time with patients I recruited, I would have been able to follow the experience from assumptions through needs and social process to determine the outcome of a meaningful experience. It was clear that the needs identified were true to each person's experience, but I would have liked to confirm the social process of *being out of control* with the participants. If I had been able to follow the specific experience of each group through the conceptual model of *hospitalization at end-of-life* my findings would have been strengthened.

Also, the patient and provider group perspectives were only derived from two stories each; the bulk of the data was from the family perspective. If this study had been conducted in real time, I would have been able to engage with patients while they were in the hospital and experiencing end-of-life. I would have asked about each of their needs and determined if they were met. Understanding whether each perspective group had needs that were met would allow me to expand on the social process of *being out of control* and start making connections between that process, the needs that feed it, and the outcome of the process.

Implications for Nursing

Education

The potential impact this study could have on nursing education is significant. Teaching nurses about the varying needs of different perspective groups could not only improve the patient experience but could spark the change we need in nursing practice.

We are moving towards nursing models that are focused on aging, inclusivity of multi-disciplinary approaches, and care that is holistic at every level from birth to death.

Recognition of the current social process behavior identified in this study as *being out of control* would shed light on the contrasting needs of key stakeholders and possibly shift the paradigm of EoLC.

Nursing care is founded in nursing education. Knowledge is a key concept in practitioner advancement and plays an important role in the development of both the breadth and depth of nursing perspective. As the population continues to age and become increasingly resistant to illness and disease, the need for end-of-life care education is only going to escalate. Being able to provide quality care to dying patients and their families will only come as EoLC education improves. My hope is that this study adds to the body of knowledge surrounding end of life, sparks future education, and allows for a true paradigm shift in the practice of EoLC.

One practical approach to incorporating this important piece of nursing care into education is to develop simulation activities in the academic setting that pertain to conversations about death and dying, constructing care plans that are holistic and comprehensive, as well as learning how to engage with family, other care providers, and the patient themselves.

Practice

EoLC in the hospital can be improved by thoroughly assessing the needs of the patient, family, and health care providers. The healthcare team needs to implement methods that would engage care providers in activities that allow for adequate reflection of their own needs and how they influence the experience for the patient and family.

Being cognizant of the social process identified in this study as *being out of control* could change the culture of the EoLC experience in the hospital and open the door for deeper conversations as well as enhanced philosophical understanding of our current actions, our intended behaviors, and the power our behavior has on the influencing of others, regardless of our role.

As discussed earlier in assumptions, the family is often seen as the voice of the patient. Findings in this study challenge that thinking. This needs to be addressed in the forefront of nursing practice. We cannot assume the dynamics of the patient or their family. Clear, articulate discussions must occur.

Research

Further research needs is needed to confirm the findings of this preliminary grounded theory study. Enrolling patients, family, and providers into a research protocol aimed at verifying this social process and the associated need structure would be beneficial to all three groups. Many of the statements taken from the stories used in this study could have been elaborated on if subjects were actively enrolled in a study. It would be enlightening to know what the meaningful experience entailed and whether we could draw direct conclusions from understanding the needs and the social process of *being out of control*. Additionally, are there variables that could alter the social process and therefore reshape the meaningful experience?

During the process of creating reflective memos, I stumbled across many different ideas regarding EoLC experiences that could be explored in future research studies. Some reflections are included here:

Maybe the family is *not* an extension of the patient but rather *another* patient who needs to be cared for separately because of different goals, different communication tactics, and

so on. Is double our patient loads in order to take care of family actually achievable? Taking care of family is very taxing. They aren't physically sick, so you are taking care of their emotional needs, which can be emotionally exhausting for the care providers. (memo.12.1.2018)

Could people tell these stories before they die so the people in the hospital knew more about them and could provide care they wanted? It's *so* important to know a great deal more about a patient in order to care for them holistically. What would these things be? Where they were born? What did they do for work? Who are the important people in their life? What is their communication style? Are they more passive or more outspoken? What role do you want your family to play? We just assume family is an extension of the patient but that shouldn't be default. (memo.12.15.18)

Data showed patients need to tell their story, so should care providers tell their story? Would it make people feel better if I told them I had a husband and a daughter and parents and a dog and go through challenges myself? If we were more open about how we are processing, would it make it a better experience? Can we just tell people what they should expect? (memo.01.05.19)

Summary

The conceptual model of *hospitalization at end-of-life* as well as subsequent model of needs and social process model of *being out of control* have been discussed. Many components of these models are consistent with current literature surrounding EoLC. A noteworthy finding was the link between social process and needs. Many other studies related to end-of-life care developed social process models founded in needs. These types of models are consistent with the findings of this study, so the study is ready for empirical testing.

Because of the preliminary nature of this study, there are many opportunities for future validation of findings and deeper understanding of the conceptual components. Implications for research, practice, and education have been presented along with limitations and significance of findings.

APPENDICES

APPENDIX A

ROL Matrix

Citation	Aim/Methods	Sample/Setting	Findings
Ando, Morita, Lee & Okamoto, (2008)	<p>Mixed methods</p> <p>To investigate what kind of meanings terminally ill cancer patients attribute to their illness and if positive meaning attributed to higher spiritual well being</p>	Ten patients with advanced-stage cancer from palliative care units at two acute care hospitals	<p>Meanings associated with illness were positive, natural acceptance, negative acceptance, search for meaning, and regret and sorrow. Positive meaning was associated with higher spiritual well-being.</p>
Boyd, Merkh, Rutledge, & Randall (2011)	<p>Descriptive correlational survey study</p> <p>To characterize oncology nurses' attitudes toward care at end of life and their experiences in caring for terminally ill patients.</p>	Thirty-one oncology nurses with experience caring for terminally ill at a large acute care hospital	Nurses have positive attitudes about caring for terminally ill patients, but they report missed opportunities in regard to thorough discussions and referrals to hospice
Calvin, Kite-Powell, & Hickey (2007)	<p>Descriptive qualitative</p> <p>To describe neuroscience intensive care unit nurses' perceptions regarding their roles and responsibilities in the decision-making process during the change in intensity of care</p>	Twelve Neuroscience ICU nurses who volunteered to participate at large acute care hospitals	Nurses felt their roles and responsibilities were categorized as providing guidance, being positioned in the middle of the communication process, and feeling the emotions of patients and families

	and end-of-life care for patients		
Hinderer (2012)	Phenomenology To explore critical care nurses' experience with patient death	Six nurses who worked in a critical care unit together and had experienced multiple deaths	Experiences were described as coping, personal distress, emotional disconnect, and inevitable death.
Johnson & Gray (2013)	Hermeneutic phenomenology To explore nurses' perspectives on the phenomenon of end-of-life care in the hospital setting	Thirteen nurses who worked at either a large academic medical center or community hospital	Experiences were described as confronting challenges, coming to understand end-of-life care, and transforming end-of-life care
Jones et al. (2011)	Descriptive quantitative To assess agreement between patient's quality of life and quality of life assessed by family and physician	197 patients, 197 family, 197 physicians from one large acute care hospitals palliative care unit	Statistically significant differences between patient's quality of life and assessed quality of life by family and physician. Family tended to underestimate quality of life. Accuracy did improve as time went on.
Knauft, Nielsen, Engelberg, Patrick, and Curtis (2004)	Cross sectional analysis of prospective data To identify barriers and facilitators to communication about end-of-life care	115 patients and 115 physicians from a large teaching hospital	Only 32% of patients reported having a conversation with their physician about end-of-life care. Barriers to this communication included wanted to talk about being alive as opposed to dying, not being sure who to have the conversation with, and ambiguity

			about preferences surrounding end of life
Lankarani-Fard et al. (2010)	Observational quantitative To determine what values patients consider important regarding end of life care	33 patients from a tertiary care academic hospital	The value of highest importance was to be free from pain. The value of lowest importance was to have close friends near by
Mack et al. (2012)	Prospective cohort study To evaluate incidence of end of life care discussions.	2155 patients whom received care at one of 5 large VA hospital organizations	73% of patients had end of life care discussions. For those who had discussions, the median time of discussion was 33 days before death
Parish et al. (2006)	Retrospective mixed methods To analyze end of life care received by patients in the acute wards of a busy teaching hospital	20 deceased patients and 40 nurses from a large teaching hospital	Nursing care plans were not consistent with the care they explained they provided. Patients were not involved in decision making. Documentation was poor.
Popejoy, Cheyney, Beck, & Antal (2009)	Descriptive qualitative To elucidate nurses' viewpoints of caring for critically ill and dying patients in ICUS.	22 ICU staff nurses from MICU, SICU, and NCCU in a large community hospital	Viewpoints consisted of helping the patient through, telling bad news, grieving as a process, family as the patient, and the dying patient's effect on the nurse.
Riggs, Woodby, Burgio, Bailey, & Williams (2014)	Descriptive qualitative To analyze bereaved next of kin's suggestions for improving end of life care in VA medical centers	78 Bereaved next of kin who died at the VA medical center	Next of kin's suggestions included, compassionate care, good communication, support for family visits, and death preparation

Spichiger (2009)	<p>Interpretative Phenomenology</p> <p>To explore the experiences of family members and terminally ill patients receiving end of life care</p>	10 family members of terminally ill patients at a large medical center	Family described their experiences as personal suffering, the sense of being or not being integrated into the hospital, the primary importance of caring for the patient, and the consequences of accompanying a patient with a terminal illness
Sullivan et al. (2007)	<p>Secondary exploratory analysis</p> <p>To describe whether and when physicians report recognizing and communicating the imminence of death.</p>	196 physicians and 70 associated patients they had cared for.	86% of physicians reported knowing that death was imminent but less than half of patients were told.
Thompson, McClement, & Daeninck (2005)	<p>Grounded theory</p> <p>To develop an understanding of the process nurses, undertake in providing high quality end of life care</p>	10 nurses from two large, affiliated university teaching hospitals	The basic social problem was that nurses were striving to provide quality care but were being pulled in all directions. The subsequent theory "Creating a safe haven" emerged.
Torke, Garas, Sexson, & Branch (2005)	<p>Descriptive qualitative</p> <p>To characterize the views of seriously ill African American patients toward end of life care</p>	23 African American patients at an Urban teaching hospital	Ceasing aggressive care was seen as giving up, end of life care was seen as being in God's hands, and a major goal was to be free from pain and suffering
Virdun, Lockett, Davidson, & Phillips (2015)	Systematic review	8 articles generated data from 1141	The five most important pieces of end of life care in

	To ascertain the five most important elements of inpatient end of life care	patients and 3117 families	the hospital were effective communication, expert care, respectful and compassionate care, trust in clinicians and financial affairs
Willard & Luker (2006)	Grounded theory To discuss the challenges associated with end of life care in the hospital	29 Cancer nurse specialists from 5 acute care hospitals	End of life care in the hospital is driven by preoccupation with treatment, routine practice, and negative perceptions of palliative care
Williams, Lewis, Burgio, & Goode (2012)	Descriptive qualitative To explore perceptions of how hospital nursing staff supported and facilitated family presence during the actively dying phase	78 family members of patient who died at a large VA hospital 3-6 months prior	Nurses effectiveness in optimizing family support required clinical competency in recognizing the actively dying phase of life and engaging in behaviors that facilitated the delivery of end of life care
You at al. (2014)	Cross sectional design To identify which elements of end of life care are most important to patients and families	233 patients and 205 family members from 9 Canadian hospitals	Patients remarked that clinicians addressed individual goals of care infrequently. Most important elements were preferences of care, values, prognosis, fears, and questions about goals of care

APPENDIX B

IRB Waiver



University of Massachusetts Amherst
Human Research Protection Office
Mass Venture Center
100 Venture Way, Suite 116
Hadley, MA 01035

Office of Research Compliance
voice: (413) 545-3428
fax: (413) 577-1728

Memorandum – Not Human Subjects Research Determination

Date: May 2, 2018

To: Alyson Prokop, Nursing

Project Title: The Social Process of Dying in the Hospital: A Grounded Theory Study

IRB Determination Number: 18-100

e-Protocol # 2018-4779

The Human Research Protection Office (HRPO) has evaluated the above named project and has made the following determination based on the information provided to our office:

The proposed project does not involve research that obtains information about living individuals [45 CFR 46.102(f)].

The proposed project does not involve intervention or interaction with individuals OR does not use identifiable private information [45 CFR 46.102(f)(1),(2)].

The proposed project does not meet the definition of human subject research under federal regulations [45 CFR 46.102(d)].

Submission of an Application to UMass Amherst IRB is not required.

Note: This determination applies only to the activities described in the submission. If there are changes to the activities described in this submission, please submit a new determination form to the HRPO prior to initiating any changes.

A project determined as “Not Human Subjects Research”, must still be conducted in accordance with the ethical principles outlined in the Belmont Report: respect for persons, beneficence, and justice. Researchers must also comply with all applicable federal, state and local regulations as well as UMass Amherst Policies and procedures which may include obtaining approval of your activities from other institutions or entities.

Please do not hesitate to call us at 413-545-3428 or email humansubjects@ora.umass.edu if you have any questions.

A handwritten signature in cursive script that reads 'Iris L. Jenkins'.

Iris L. Jenkins, Assistant Director
Human Research Protection Office

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