TRANSITIONING FROM CURATIVE CARE TO END-OF-LIFE CARE IN THE ACUTE CARE HOSPITAL:
A HERMENEUTICAL PHENOMENOLOGICAL STUDY

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Amanda Lynn Hahn, candidate for the degree of Master of Social Work, has presented a thesis titled, *Transitioning From Curative Care To End-Of-Life Care In The Acute Care Hospital: A Hermeneutical Phenomenological Study*, in an oral examination held on March 13, 2020. The following committee members have found the thesis acceptable in form and content, and that the candidate demonstrated satisfactory knowledge of the subject material.

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Abstract

This study examined the experiences of members of multidisciplinary teams in two urban acute hospitals when transitioning from curative care to end-of-life care with a patient. With so many people continuing to die in acute care hospital wards (Canadian Hospice Palliative Care Association, 2016; Cavaye & Watts, 2012; Grande, 2009), it is important to understand how the members of the multidisciplinary team in hospitals experience this transition, and to recognize what is being done well and what needs to be improved upon in this transition. The study was undertaken with a hermeneutical phenomenological research approach. Participants interviewed in the study were physicians, social workers, nurses, occupational therapists, physical therapists, and speech-language pathologists. Participants identified the acute care system as a barrier to end-of-life care. Participants also identified that patients’ and families’ difficulty with accepting end-of-life prognoses as a delay to the provision of good end-of-life care. Participants contradicted the existing literature which suggested that health care providers, as a population, were uncomfortable with dying patients and in denial of death. Ultimately, the study revealed that these healthcare providers were interested and invested in providing good end-of-life care to their patients, but could benefit from better support from the acute care system they work in, as well as more access to, and opportunity for, training and education in this area.
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Dedication

I would like to extend my gratitude to the many family members, friends, and work colleagues who supported me throughout this journey; without your support, this project could have never come to fruition. I wish to especially express my appreciation to my friend and colleague Danielle, who refused to let me give up and always had words of encouragement when I needed them the most. I would like to acknowledge the assistance I received from my sister, who helped set me up to complete my interview transcripts so much more efficiently than I ever could have without her help. Finally, I would like to thank my mom who was always available to listen to my frustrations and offer encouragement.
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Chapter One: Introduction

While more people are dying in their own home or their preferred location of care (Scanlan, 2016), most people continue to die in the acute hospital setting (Canadian Hospice Palliative Care Association, 2016; Cavaye & Watts, 2012; Grande, 2009). However, the need for end-of-life care is not always recognized nor provided in acute hospital wards (Fitch et al., 2016; Grande, 2009; Walling et al., 2010). The multidisciplinary healthcare team is integral in the provision of end-of-life care in acute care; this team is influenced by a number of factors which affect how end-of-life care is delivered.

The purpose of this study is to understand how members of the multidisciplinary team experience the transitions to providing end-of-life care in an acute care setting. A hermeneutical phenomenological research design was used to achieve this. Data was collected via in-depth interviews with members of acute multidisciplinary healthcare teams who work in hospitals located in urban centres in Saskatchewan: physicians, nurses, physical therapists, occupational therapists, speech-language pathologists, and social workers. The primary goal of this study is to describe the lived experiences of the members of the multidisciplinary team in caring for dying patients on acute care wards. Findings of this research study provide insight on the barriers and delays to, end-of-life care, as well as the promotion of adequate end-of-life care as it is delivered in the acute care setting by the multidisciplinary team, and how the multidisciplinary team can work together effectively to provide adequate end-of-life care on an acute care ward.

Before examining the relevant literature about multidisciplinary teams and end-of-life care in hospital, a discussion of background information and the conceptual
framework will be provided. Following, key concepts related to this research will be defined. Finally, a reflection on how I became interested in this research topic will be presented.

**Background and Rationale**

The majority of people die in acute care, not at home or in hospice (Cavaye & Watts, 2012; Grande, 2009). In Canada, more than 150,000 deaths occur annually in hospitals (Canadian Institute for Health Information, 2017b). The leading cause of deaths in hospital are stroke, chronic obstructive pulmonary disease, sepsis, heart attack, pneumonia, and heart failure (Canadian Institute for Health Information, 2017b). Generally, for those in hospital, end-of-life care interventions are being started too late (Le & Ashby, 2007; O'Callaghan et al., 2014; Usatine et al., 2013). Initiation of end-of-life care is dependent upon the health care team’s ability to recognize this need, as well as having the capacity to carry out the interventions needed. The delay in referrals to appropriate end-of-life resources, such as palliative or hospice care, have resulted in many individuals attending the hospital emergency departments during the last month of life (Zalenski & Zimny, 2016). Further, of those individuals who attend the emergency department, many are admitted to hospital and die on an acute care ward (Zalenski & Zimny, 2016).

Unfortunately, many Canadian families report dissatisfaction with the provision of end-of-life care in acute hospital wards (Heyland et al., 2005). This dissatisfaction relates to communication (Anselm et al., 2005; Carline et al., 2003; Cipolletta & Oprandi, 2014), health care professionals’ lack of knowledge about end-of-life care (Bradley et al., 2002; Cipolletta & Oprandi, 2014), health care professionals’ belief that
acute care is the wrong location for end-of-life care to occur (Calnan et al., 2013), and health care professionals’ discomfort with dying and death (Carline et al., 2003; Cipolletta & Oprandi, 2014). Many of the factors related to poor end-of-life care result in compromising a patient’s dignity and quality of life at the end-of-life and could be avoided if the health care team could more promptly recognize the need to transition to end-of-life care and be supported in providing end-of-life care.

While dignity and quality of life at end-of-life are subjective concepts and vary from one individual to another, they can be universally supported by health care professionals who value autonomy, diversity, truth, and responsibility in the patient-caregiver relationship (Coventry, 2006). Improved health status and patient/family satisfaction is related to good management of physical and emotional symptoms, inclusive decision-making, communication, and avoidance of inappropriate medical interventions that prolong dying (Heyland et al., 2005; Tilden et al., 2002). Quality of life at end-of-life can be determined by measuring patient happiness, satisfaction, and morale (Kaasa & Loge, 2003). When the health care team is unable to recognize, initiate, or provide end-of-life care to a dying patient, the patient’s experience is even more compromised. Sadly, some of the most basic activities of daily living, such as getting to a toilet to urinate or having a bath, do not occur when patients are at end-of-life; this damages their self-worth, dignity, and quality of life (São José, 2016). As a patient deteriorates during the end-of-life process, they experience several losses: control of bodily functions, ability to participate in activities, social contacts, and power (São José, 2016). These losses are even more pronounced when the attending health care team overlooks tasks related to maintaining the patient’s hygiene, supporting social
interaction, and including the patient in decision making to lessen a power imbalance; this oversight can contribute to diminished self-respect and dignity (São José, 2016). With the loss of dignity, patients are at risk of feeling they are not worthy of respect (Cipolletta & Oprandi, 2014). Good end-of-life care and maintenance of personal dignity is directly related to a patient’s quality of life at end-of-life; therefore, how health care professionals transition from curative care to end-of-life care is important, especially given the number of patients who die in hospital each year.

**Conceptual Framework: General Systems Theory**

Systems make up the world around us. Our bodies are systems, our families are systems, and our schools and workplaces are systems. If we commit a crime, we become part of the legal system, and if we are admitted to the hospital, we become part of the health care system. A system can be defined as “a regularly interacting or interdependent group of items forming a unified whole” (Oxford Living Dictionary, n.d.), “a form of social, economic, or political organization or practice” (Oxford Living Dictionary, n.d.), or “a set of things working together as parts of a mechanism or an interconnecting network; a complex whole” (Merriam-Webster, n.d.)

If one looks at the world as made up of an infinite number of systems, it is hardly surprising that from the work of many theorists, systems theory was developed. The roots of systems theory date back to Aristotle and Descartes and over time have evolved into many types of systems theories (Cordon, 2013). For the purposes of this research study, general systems theory will be the framework applied.

Von Bertalanffy (1968) is credited with developing general systems theory; he claimed that systems should be looked at as a whole entity, with all the pieces of the
entity interacting and influencing each other. A system can be either closed and cut off from its environment, or open and connecting with its environment (Von Bertalanffy, 1968). General systems theory can be applied to any system (Von Bertalanffy, 1968). When applied to a social circumstance, Schafer (1969) attests that behaviour should be considered the consequence of the social situation a person finds him/herself in. Systems are composed of hierarchies, and the social units within the system may change position within the hierarchy (Schafer, 1969). Finally, Schafer (1969) states that a person’s past must be considered to determine how they have evolved into the person they are in the present. General systems theory can certainly be applied to health care, it is made up of the patient and family, the health care providers, and the health care organization these individuals exist within (Wallace, 2016). Indeed, all of these pieces make up an open system that influences, and is influenced by, one another (Wallace, 2016). How readily a patient accepts an end-of-life prognosis, for example, can influence when the health care team is able to start providing end-of-life care. Alternatively, if a health care provider is unable to accept that a patient is at a point of medical futility, the patient is influenced by this and less likely to have end-of-life care measures offered. Finally, if the system is unable to provide appropriate staffing or appropriate care locations (for example, palliative care unit beds), then both the health care team and the patient are influenced by this and will need to provide and receive end-of-life care in the current location.

**Key Terms**

The following terms are commonly used in both the literature and by the participants of this study. They also provide some context for how end-of-life care is carried out in acute care settings. The first group of terms are theoretical based, and the
second group of terms are related to the specific system and participants this study focuses on.

Theoretical Terms

Acute Care.

Acute care in Canada is considered to be hospital based, and provides “necessary treatment for a disease or severe episode of illness” with a goal of “discharging patients as soon as they are healthy and stable” (Canadian Institute for Health Information, 2017a, para.1). For the purposes of this study, this definition will be used and will also encompass wards with patients who may be admitted to hospital for surgery, or alternate level of care services which include social reasons (such as addictions or housing concerns).

End-of-Life Care.

End-of-life care is the care an individual receives when their health is in decline, and who is considered terminal, with an expectation of death in the near and foreseeable future (Canadian Institute for Health Information, 2011). End-of-life care and palliative care are terms that are often used interchangeably (Canadian Institute for Health Information, 2011), however end-of-life care is more accurately described as the final phase in the continuum of palliative care (Canadian Partnership Against Cancer, 2017). Therefore, in this study, end-of-life care will be defined as any care that a patient receives when death is imminent (predicted to occur in the near future) and can be exclusive or inclusive of palliative care services. The delivery of end-of-life care can be complicated by the continuation of curative treatments, unpredictable illness trajectories, and unknown patient preferences (Willard & Luker, 2006).
Palliative Care.

Palliative care should be viewed as a continuum that begins at the time of diagnosis of a serious or life threatening illness, and continues through end-of-life care (Canadian Partnership Against Cancer, 2017). Palliative care refers to a multidisciplinary approach (Cagle & Widera, 2014; Yeh & Bernacki, 2017) that is patient and family centered rather than disease or illness focused (Zalenski & Zimny, 2016). Palliative care can be delivered in a variety of settings, including the home/community, in-patient acute care, in-patient palliative care, and hospice (Hui & Bruera, 2016). Inclusion of palliative care early on in a terminal illness has been shown to decrease hospital visits and admissions (Jain & Smith, 2016), and to create an increased quality of life which includes the patient’s end-of-life goals being achieved (Hall et al., 2015). Palliative care is defined by the World Health Organization (2017) as “an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (para. 1).

In best practice, a patient with a diagnosed life-threatening illness or disease should be connected to palliative care early on in the course of the illness (Canadian Partnership Against Cancer, 2017; Dharmasena & Forbes, 2001; Hall et al., 2015; Hui & Bruera, 2016; Jain & Smith, 2016; Yeh & Bernacki, 2017). This means that an individual could be receiving palliative care services before the imminent end-of-life phase begins and before death is predicted to occur in the near future (Dharmasena & Forbes, 2001; Dunkle et al., 2016; Yeh & Bernacki, 2017). Early palliative care intervention results in a
better continuum of care, with a trajectory of increased involvement from the care team as the illness progresses (Canadian Partnership Against Cancer, 2017). Additionally, palliative care can support the patient’s family beyond the patient’s death with continued support and access to bereavement counselling (Canadian Partnership Against Cancer, 2017; Dunkle et al., 2016).

**Hospice Care.**

In Canada, hospice care and palliative care are terms that are often used synonymously (Canadian Hospice Palliative Care Association, 2017). However, hospice care is considered to be a specialized area of palliative care that occurs when curative treatments are no longer being prescribed (Miller & Ryndes, 2005) and therefore occurs during the end-of-life phase of palliative care. As a specialized area of palliative care, hospice care is delivered by a multidisciplinary team that is concerned with relieving suffering and improving quality of living and dying for patients while simultaneously addressing psychosocial, physical, spiritual and practical issues faced by patients and families at end-of-life (Canadian Hospice Palliative Care Association, 2017).

**Thesis Specific Terms**

**Do Not Resuscitate (DNR).**

Generally used to express that the individual does not want cardiopulmonary resuscitation performed in the event of a medical emergency and that natural death should be allowed to occur.

**Goals of Care.**

This is the terminology used within the Saskatchewan Health Authority-Regina Area when completing an advance care plan with patients (Saskatchewan Health
Authority, 2019). Below are the four goals used within the Saskatchewan Health Authority-Regina Area, including the accepted definition of the goal of care. Patients are encouraged to choose a goal of care to direct the medical team so that in the absence of patient capacity, the patient’s wishes can still be followed. Best practice in acute care encourages all patients to have this conversation with a member of the multidisciplinary health care team.

**Full Treatment (FT).** This is one of four goals of care within the Saskatchewan Health Authority-Regina Area, and is defined as: “I want to have life support with all necessary medical interventions, such as CPR, a ventilator (breathing machine), feeding tube, intravenous fluids, or kidney dialysis. This includes all resuscitative measures as medically necessary. Includes intensive care.” (Saskatchewan Health Authority, 2019, p. 23)

**Full Treatment Conditional (FTC).** This is one of four goals of care within the Saskatchewan Health Authority-Regina Area, and is defined as:

I want a trial period of life support with all necessary medical interventions. This includes all the medical care listed in Full treatment, including CPR and intensive care. If the trial period does not help me recover to an acceptable state of health known to myself/Proxy, then I want these interventions stopped to allow natural death to occur. The trial period will be defined through discussions by myself/Proxy and the Health Care Team. (Saskatchewan Health Authority, 2019, p. 23)

**Limited Additional Interventions (LAI).** This is one of four goals of care within the Saskatchewan Health Authority-Regina Area, and is defined as: “I want conservative
management of my medical condition. I do not want CPR or a ventilator (breathing machine). Use medical interventions to relieve my pain and suffering, such as medication, positioning, wound care, antibiotics, and [intravenous] fluids” (Saskatchewan Health Authority, 2019, p. 23).

*Comfort Measures Only (CMO).* This is one of four goals of care within the Saskatchewan Health Authority-Regina Area, and is defined as:

I do not want CPR, a ventilator (breathing machine), or other medical interventions, such as a feeding tube, IV fluids or kidney dialysis. If any of these interventions have been started, I want them stopped to allow natural death to occur. This does not include an intensive care setting. (Saskatchewan Health Authority, 2019, p. 23)

**Origin of the Study**

Until very recently, I had been employed as a social worker on an acute care unit in an urban hospital. During this time I observed that, as a health care team, we were failing at providing good end-of-life care to our patients. Through the completion of my course work toward my Master of Social Work degree, a passion to improve the end-of-life experiences for patients that I worked with was instilled in me. Through my education, I gained confidence in my ability to advocate for good end-of-life care for patients. However, I found myself being challenged by other members of the multidisciplinary team with whom I worked who did not seem to recognize the importance of identifying when someone was at end-of-life and changing the care plan to reflect this. I often wondered where the resistance came from, and how these attitudes affected the end-of-life experience the patient had.
Generally speaking, it seems to me that I live in a culture, and previously worked in a system, that is uncomfortable with death. I observe this with my own family and their discomfort in talking about death and realizing their own mortality. I observed it with the family members of patients who were doing very poorly, but who remained hopeful that their loved one would “take a turn for the better” regardless of the prognosis that had been provided. I found it so interesting that as a society we were so afraid of and uncomfortable with such a normal phenomenon. My passion for end-of-life care was fully ignited when I watched the CBC’s documentary series *Keeping Canada Alive* (Greschuk, 2015). In the third episode a palliative care physician, Dr. Sugar, explains that “we measure our life with weddings and births, but dying is really important. It’s really important. I mean, you only get to do it once. You can get married lots of times” (Greschuk, 2015). This remains one of the truest statements I have heard in my life. If there is anything I can accomplish on a professional level, related to my recent employment, it is to get people talking about and comfortable with dying for exactly the reason Dr. Sugar stated. It is because of my own experiences working in healthcare that I endeavored to complete this research study which I hope will provide insight into the importance of providing quality and relevant end-of-life care in an acute care hospital setting.

**Purpose**

My observation that health care professionals have difficulty with recognizing when someone is dying and transitioning to end-of-life care from curative care has been echoed in the literature (Ansell et al., 2007; Fitch et al., 2016; Nouvet et al., 2016; Scanlan, 2016; Sheward et al., 2011; Willard & Luker, 2006). This is particularly
troubling because upwards of 70% of the population will spend their final days in the hospital (Canadian Hospice Palliative Care Association, 2016; Cipolletta & Oprandi, 2014; Grande, 2009; Heyland et al., 2000), yet research suggests that the worst end-of-life care may occur in hospital (Grande, 2009). Over the last several years the importance of quality end-of-life care and the dialogue about death and dying has garnered much interest (Cipolletta & Oprandi, 2014; George, 2002; Scanlan, 2016; Tilden et al., 2002), which is fortunate since death is one thing we are all guaranteed in life.

The purpose of this phenomenological research study is to understand how the members of a multidisciplinary health care team experience the transition from providing curative care to end-of-life care in the acute care hospital setting. In-depth, semi-structured interviews with different members of acute multidisciplinary health care teams were conducted in an effort to obtain data to help describe the lived experiences of the health care team. This research study provides insight into the provision of end-of-life care in the acute care setting and what types of interventions are needed to improve this experience for patients and their families.

**Research Question**

How do members of the multidisciplinary health care team experience the transition from providing curative care to end-of-life care in the acute hospital setting?

**Research Sub-Questions**

1. How do multidisciplinary health care team members define and understand end-of-life care?

2. What do multidisciplinary health care team members feel is important when providing end-of-life care?
3. How do multidisciplinary health care team members’ attitudes about death and dying affect the transition from curative care to end-of-life care in the acute hospital setting?

4. How does communication amongst the multidisciplinary health care team affect the transition from curative care to end-of-life care in the acute hospital setting?

**Thesis Overview**

Moving forward, a comprehensive literature review will be presented in chapter two of this document. Following the review of the literature, the methodology and process used to conduct the research for this project is provided in chapter three. Chapter four is a summary of the findings of the research, presented thematically. Chapter five includes further discussion and analysis of the research findings. Finally, chapter six concludes this document by providing recommendations for future research areas.
Chapter Two: Literature Review

This chapter explores how members of the multidisciplinary team in acute care work together in providing patient care. I consider the barriers in communication and how this affects collaboration of the multidisciplinary team. The roles of social work, nursing, physical therapy, occupational therapy, speech-language pathology, and medicine (physicians) in providing end-of-life care are discussed. An examination of the influences on health care professionals’ attitudes and comfort with death and dying is undertaken. Finally, an overview of the literature as it relates to general systems theory is presented.

The Multidisciplinary Team

Health care is a complex system, made up of many levels, organizations, institutions, agencies, disciplines, decision makers, and policy makers (Cordon, 2013). The different disciplines that make up the health care system exist in individual silos, including for example: social work, nursing, physical therapy, occupational therapy, medicine, and pharmacy (Cordon, 2013). Cordon (2013) proposes that the silos and perspectives of each discipline are what ensure that the patient’s holistic care needs are met. However, when team members fail to understand each other’s perspectives, communication breakdown can occur (Cordon, 2013). Cordon (2013) further asserts that the hierarchies that exist in health care contribute to barriers for the team working together, and that doctors often dominate the plan of care, reinforcing the team members to continue to work within their silos rather than as a single entity. Cordon (2013) suggests that in order to enhance patient care, team members must break down the silos by suspending their power beliefs and identifying a single overall clinical goal.
Barriers to communication and collaboration exist in several systems in the acute health care setting including amongst members of the multidisciplinary team and between the multidisciplinary team and the patient and family (Anselm et al., 2005). Poor communication within the health care team often leads to poor and contradictory communication to the patient and family (Cipolletta & Oprandi, 2014). In particular, health care professionals do not always agree on which discipline is responsible to discuss end-of-life care with the patient and family (Anselm et al., 2005; Cipolletta & Oprandi, 2014). Additionally, patients and families do not always have the capacity to understand what the healthcare team is explaining to them (Anselm et al., 2005). The lack of effective communication in the acute care setting can create dissention amongst the multidisciplinary team, the patient and their family (Carline et al., 2003; Kaufman, 2002; Stoneberg et al., 2016). Communication and respect amongst the multidisciplinary team are the pillars of good patient care (Carline et al., 2003). Having a good multidisciplinary team is essential to providing good end-of-life care, especially in the acute care setting (Booth et al., 2010).

For the purposes of this paper, the multidisciplinary team will include physicians, social workers, occupational therapists, nurses, speech-language pathologists and physical therapists. These disciplines have been chosen because the motivation to complete this study is born from my own experiences working in the acute health care setting, and these are the disciplines with whom I worked most closely on a daily basis.

Social Workers

Social work is a profession dedicated to helping individuals, families, groups, and communities increase their well-being (Saskatchewan Association of Social Workers,
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n.d.-a). This is done through assisting people to problem solve through the use of their own skills and resources, along with community resources (Saskatchewan Association of Social Workers, n.d.-a). Social workers are concerned with both issues that impact a person individually, as well as with those issues that are broader such as poverty and domestic violence (Saskatchewan Association of Social Workers, n.d.-a). Social workers are commonly employed in hospitals, health centres, schools, advocacy organizations, correctional facilities, housing organizations, private counselling agencies, family courts, child welfare systems, social services agencies, government agencies, First Nations agencies, and consulting agencies (Saskatchewan Association of Social Workers, n.d.-a). This research study is most concerned with those social workers employed in the acute care hospital setting.

In Saskatchewan, social workers are university educated professionals who hold, at minimum, a Bachelor of Social Work degree (Saskatchewan Association of Social Workers, n.d.-a). According to the Canadian Association of Social Workers (2005), a Social Worker is “a person who is duly registered to practice social work in a province or territory” (p.11). In Saskatchewan, the Saskatchewan Association of Social Workers (SASW) is responsible for the regulation of professional conduct of social workers (Saskatchewan Association of Social Workers, n.d.-b). Social workers registered with the SASW are required to adhere to the Canadian Association of Social Workers (CASW) Code of Ethics (2005) (Saskatchewan Association of Social Workers, n.d.-b). Additionally the SASW has published Standards of Practice for Registered Social Workers in Saskatchewan (Saskatchewan Association of Social Workers, 2017) to guide social workers in their practice. Based on the Code of Ethics (Canadian Association of
Social Workers, 2005) and Standards of Practice for Registered Social Workers in Saskatchewan (Saskatchewan Association of Social Workers, 2017), social workers in Saskatchewan are bound by six core social work values and principles. These values are:

- Respect for the inherent dignity and worth of persons
- Pursuit of social justice
- Service to humanity
- Integrity in professional practice
- Confidentiality in professional practice
- Competence in professional practice (Canadian Association of Social Workers, 2005)

Social workers, because of their education and training, should be considered invaluable members of the team when it comes to supporting communication between the multidisciplinary team and the patient and their family (Cadell et al., 2010; Craig & Muskat, 2013; Dunkle et al., 2016; Hebert et al., 2008). One of the main barriers to social workers being able to support communication in the acute care environment is that their roles have largely changed from clinical and psychosocial to facilitating and supporting patient discharge from acute care (Craig & Muskat, 2013; Holliman et al., 2001; Judd & Sheffield, 2010). This means that currently there is generally limited psychosocial support available in the acute care setting (Booth et al., 2010). The push for social workers to assist with discharge planning, combined with increasing caseloads, has resulted in social workers not having the time to complete many psychosocial interventions within the acute care setting (Craig & Muskat, 2013; Hebert et al., 2008).
Discharge planning completed by social workers in a hospital encompasses a number of tasks. In order to create an effective discharge plan, social workers often need to review medical charts, communicate with patients, families, members of the multidisciplinary team, and outside agencies, as well as evaluate discharge locations and the availability of informal supports (Holliman et al., 2001). While their focus may be largely consumed by discharge planning, social workers are still in an ideal position to be able to recognize the comprehensive needs of the patient based on the extensive and in-depth assessments they complete, which can be valuable in implementing a treatment plan (Kitchen & Brook, 2005).

The skills social workers possess can also be applied to end-of-life care. To clarify the role of social workers in end-of-life care, particularly in hospice palliative care, a national task group of social workers and educators in Canada identified competencies social workers should possess when working in hospice palliative care (Bosma et al., 2008). Bosma and colleagues (2008) identify the following social work competencies for social workers in Canada working in hospice palliative care:

- Advocacy
- Assessment
- Care delivery
- Care planning
- Community capacity building
- Evaluation
- Decision-making
- Education and research
• Information sharing
• Interdisciplinary team
• Self-reflective practice

These competencies are meant to be used by social workers as a framework whenever the social worker finds themselves practicing in an end-of-life scenario (Bosma et al., 2008). At end-of-life, the social worker is an important member of the multidisciplinary team as they can provide psychosocial support, referrals to resources, assist in the transition between settings, help patients and families cope with loss, and assist with communication and decision making (Dunkle et al., 2016). Therefore, while social workers arguably possess the skills and abilities to support patients through to end-of-life, the barrier to completing this work is the required focus on discharge planning that social workers are currently expected to have in acute care settings.

Nurses

Nurses are known to work in a variety of settings including nursing homes, hospitals, schools, and within public health services. For the purpose of this study, the term nurse will include registered nurses and licensed practical nurses responsible for the delivery of care in the acute hospital setting.

While in hospital, patients and their families are in contact with nurses more than any other team member (Northcott & Wilson, 2014). Because of the high level of interaction between nurses and the patients and their families, it is not unreasonable to expect that nurses should be proficient in communication with patients and their families. However, because of the number of tasks nurses are responsible to carry out in a day, it can be difficult for nurses to find and allocate an adequate amount of time to
communicating with their patients (Clayton, 2006). Adequate communication between the nurse and the patient is important though, because it can lead to better patient outcomes and better patient understanding of medical treatments (Clayton, 2006). A group of oncology nurses reported that, of all nursing competencies, they would benefit from more education about discussing the dying process with patients and their families (White et al., 2001). Nurses have found it easier to provide end-of-life care and have end-of-life care conversations with patients and families when it is apparent or well established that the patient is experiencing end-of-life (Thompson et al., 2006). While typically nurses are proficient in communication with each other, they may struggle when communicating with other members of the multidisciplinary team (André et al., 2017). Nurses have identified difficulty in working collaboratively with physicians to get appropriate orders, and this can be a barrier to providing good end-of-life care (Thompson et al., 2006). Clayton, (2006) asserts that, in general, nurses would benefit from further training or education to develop more effective communication skills. Indeed, many nurses identify that further education or training opportunities to develop communication skills, especially as it pertains to end-of-life care, are needed (Parish et al., 2006; Peterson et al., 2013).

**Occupational Therapists**

Occupational therapists in Saskatchewan are university educated (Saskatchewan Society of Occupational Therapists, 2017b), and are registered with the Saskatchewan Society of Occupational Therapists (Saskatchewan Society of Occupational Therapists, 2017a). Occupational therapists are concerned with helping people participate in the many activities and tasks of daily living such as getting dressed, mobility, and
completing household chores (Saskatchewan Society of Occupational Therapists, 2017b). Occupational therapists work with people whose ability to participate in these activities may have been affected by illness, disease, or circumstance (Saskatchewan Society of Occupational Therapists, 2017b). This study includes those occupational therapists employed in the acute hospital setting.

Occupational therapists should also be considered valuable members of the acute multidisciplinary team when providing end-of-life care (Anonymous, 2005). Unfortunately, the services and support occupational therapists can provide at end-of-life has been overlooked (Keesing & Rosenwax, 2013) and the profession is generally poorly represented when it comes to providing services to those at end-of-life (Anonymous, 2005). In one study, occupational therapists identified that their main role was in aiding with activities of daily living and that supporting end-of-life care was not recognized (Kinn & Aas, 2009). This lends support to the notion that occupational therapists are not accepted nor utilized regularly in providing end-of-life care. This oversight of including occupational therapists consistently in end-of-life care is not so much the result of a barrier as it is simply an absence of communication and collaboration amongst the health care team entirely.

**Physical Therapists**

Physical therapists are university educated health professionals who specialize in assessing, diagnosing, and treating muscle and joint problems (Saskatchewan College of Physical Therapists, n.d.). Physical therapists are also trained to treat and assist in the management of breathing, heart, nerve, and circulatory conditions (Saskatchewan College of Physical Therapists, n.d.). In order to practice as a physical therapist in
Saskatchewan, an individual must be licensed by the Saskatchewan College of Physical Therapists (Saskatchewan College of Physical Therapists, n.d.). This study is interested in physical therapists that work in the acute hospital setting.

Similar to occupational therapists, physical therapists are not often involved in end-of-life care within an acute care setting. The lack of involvement of physical therapists at end-of-life begins right from the beginning of their education, as it is a topic that they are not well educated in (Kugler, 2014; Ogiwara & Matsubara, 2007). In fact, even at a hospice level physical therapists are often overlooked regardless of their ability to contribute to symptom relief and fall prevention (Fellows, 2014). Physical therapy needs to be recognized for its capacity to provide supportive care aimed at improving quality of life rather than increased function (Briggs, 2011). Additionally, physical therapists are able to assist caregivers in learning to safely move patients at end-of-life (Briggs, 2011) and therefore, members of the acute multidisciplinary team can benefit from working with physical therapists when caring for dying patients.

**Speech-Language Pathologists**

Speech-language pathologists in Saskatchewan are university educated professionals who specialize in the assessment and treatment of language, speech, voice, fluency, cognition, communication disorders and swallowing difficulties (Saskatchewan Association of Speech-Language Pathologists and Audiologists, 2017a). Speech-language pathologists are required to maintain registration with the Saskatchewan Association of Speech-Language Pathologists and Audiologists in order to practice in Saskatchewan (Saskatchewan Association of Speech-Language Pathologists and
Audiologists, 2017b). This study includes those speech-language pathologists employed in the acute hospital setting.

Speech-language pathologists may be consulted to assess the swallowing abilities of an individual at end-of-life while in hospital. However, from a palliative care approach or in a hospice care setting, speech-language pathologists are noted to be uninvolved in care activities (Irwin, 2006). When a speech-language pathologist is involved with a patient at end-of-life, the speech-language pathologist is required to follow the advance care directives of the patient. However, in the absence of a directive they are ethically obligated to continue to act within the best interest of the patient (Irwin, 2006). This requires that the speech-language pathologist provide education and information so that the substitute decision maker (often family) can make an informed decision regarding feeding options, such as tube-feeding or to continue swallowing and eating at risk (Irwin, 2006; Pollens, 2004). Ultimately, the speech-language pathologist should be working toward meeting the goals of palliative care within a feeding capacity once a patient has been deemed palliative (Irwin, 2006). Overall, the literature available regarding speech-language pathologists and end-of-life care is scarce (Pollens, 2004), but appears to be somewhat more prevalent than that of occupational and physical therapies. Certainly, speech-language pathologists are more recognized as having a role with patients at end-of-life.

**Physicians**

For the purpose of this study, the term physician will be used to describe the most responsible physician (the physician under whom the patient is admitted to hospital) as well as consulted physicians (those physicians who have been consulted by the most
responsible physician for care related to their specialty). Health care professionals in acute care identify that it is important for physicians to recognize the contributions that all members of the healthcare team can make in the provision of care to patients (Carline et al., 2003). Nurses have identified that physicians often delegate the task of discussing end-of-life care to them although disclosing imminent death remains the responsibility of the physician (Cipolletta & Oprandi, 2014). While some physicians recognize the importance and value of nurses as a member of the healthcare team, other physicians have a hierarchical stance and affirm that nurses exist to carry out physicians’ orders and are not in a position to contribute to the diagnostic and treatment processes (Liberati et al., 2016). In terms of a possible hierarchy in the multidisciplinary team, the lack of literature available regarding physician interactions with members of the team besides nursing is suggestive that, outside of nurses, physicians place little value on other health care professionals’ contributions to patient care.

Patients and families have identified that one of the most important pieces at end-of-life is to have clear and regular communication with their physician (Heyland et al., 2010; Parker et al., 2007). This aids patients and families in being able to participate in decision-making (Thompson et al., 2006). However, physicians often use ambiguous language and medical jargon which does not appropriately inform patients and their families, and often leaves them in a state of confusion and unknowing (Anselm et al., 2005; Sorensen & Iedema, 2011; Stoneberg et al., 2016; Walling et al., 2010). Physicians have also been known to not listen to the patient (Taylor & Chadwick, 2015), or not fully explain the intervention they are planning, thus preventing the patient and family from being able to fully participate in care planning and decision making (Anselm et al., 2005;
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Sorensen & Iedema, 2011; Walling et al., 2010). This can result in the patient receiving unwarranted medical interventions that are not consistent with their end-of-life wishes (Walling et al., 2010). In fact, some research suggests that the inability of physicians to initiate end-of-life care discussions, combined with patients’ unwillingness to accept a terminal prognosis, is the biggest barrier to patients accessing hospice services (Steinhauser et al., 2000)

Physicians identify that one difficulty in communicating with patients and their families is determining an accurate prognosis, which can be influenced by the unpredictable nature of a disease or the unknown efficacy of a treatment (Anselm et al., 2005; Dharmasena & Forbes, 2001; Kaufman, 2002). Time management has also been identified as a factor that prevents physicians from having appropriate conversations with patients and their families (Carline et al., 2003; Luthy et al., 2009). Not understanding the patient’s needs and knowledge also impacts how physicians communicate with their patients (Luthy et al., 2009). Overall, the literature demonstrates that as a profession, acute care physicians are not completely competent in discussing end-of-life care with their patients and patients’ families.

Discomfort and Fear of Death and Dying

When someone attends to the emergency department, or is admitted to hospital following surgery, the intent is generally focused on curative measures and avoidance of death. As a society, we do not accept death as a natural and acceptable occurrence in life (Anselm et al., 2005). This is consistent with the model of health care that exists in Canada, which focuses on curative and life-saving interventions (Northcott & Wilson, 2014; Taylor & Chadwick, 2015). Physicians and nurses are among the health care
professionals who are most likely to provide care to people who are dying (Northcott & Wilson, 2014). However, physicians are very likely to view death as a medical failure (Cipolletta & Oprandi, 2014; Luthy et al., 2009; Northcott & Wilson, 2014; Stoneberg et al., 2016; Taylor & Chadwick, 2015). Combined with this view is the complicating fact that many physicians are uncomfortable with dying and death (Sorensen & Iedema, 2011; Wallerstedt & Andershed, 2007). Physicians do not want to have conversations about end-of-life, nor make the determination that a person is at end-of-life (Dharmasena & Forbes, 2001; Nouvet et al., 2016; Sorensen & Iedema, 2011). This can be because of difficulty with prognostication (Dharmasena & Forbes, 2001; Nouvet et al., 2016) or the tendency to try every intervention available in order to avoid death (Nouvet et al., 2016).

The discomfort physicians have in caring for dying patients has been argued to be connected to their exposure to dying and death during their training (Anderson et al., 2008; Thompson et al., 2006). In fact, when medical students were presented with the topic of dying and death during their education and training, they were not only more comfortable in their interactions and treatment of dying patients, but actually had an increased level of knowledge about end-of-life care (Anderson et al., 2008). Interactions with, and education about, dying and death also leads to better emotional coping abilities amongst physicians (Anderson et al., 2008; Schneider et al., 2006), and health care professionals in general (Barrere et al., 2008). This sentiment is echoed by nurses and nursing students who indicate that they would benefit from additional education about, and opportunities to participate in, end-of-life care (Cavaye & Watts, 2014; Parish et al., 2006; Peterson et al., 2013). Further, Lange et al. (2008) found that more experienced nurses had a more positive attitude about providing care to dying patients. Nurses also
acknowledged that it was easier to transition to end-of-life care when there was
compelling evidence that the patient was dying (Thompson et al., 2006), was a
participant in decision making (Thompson et al., 2006), and when the nurse agreed that
end-of-life care was appropriate (Northcott & Wilson, 2014).

Allied health care professionals, such as occupational therapists and physical
therapists, are not often included in the provision of end-of-life care in an acute care
setting, as was previously discussed (see pages 21 and 22 of this thesis). In addition to
this gap in practice, the literature available regarding occupational and physical
therapists is limited to suggesting that these disciplines should be more included in the
provision of end-of-life care, and that often an inadequate amount of education on this
topic is provided to these professionals. In contrast, social workers are noted to have a
variety of roles during the provision of end-of-life care (Dunkle et al., 2016) and are
well-suited in supporting the provision of end-of-life care (National Association of
Social Workers, 2004). However, there is some need for training in end-of-life care
competencies, as laid out by Bosma et al. (2008), to be integrated into both
undergraduate and graduate social work education programs to increase the number of
competent end-of-life care social work practitioners. This is suggestive that newly
graduated social workers may not be well educated or exposed to the topics of death and
end-of-life care.

Unfortunately, the literature is highly suggestive that, in general, health care
professionals avoid those patients who are at end-of-life (Cipolletta & Oprandi, 2014).
There is some evidence that an awareness or availability of palliative care increases the
chance of the health care team requesting palliative care involvement (Bailey et al.,
2005; Cohen et al., 2011). However, referrals to palliative care were also influenced by the health care professional’s own attitude about palliative care (Bradley et al., 2002) which means that those professionals who do not appreciate palliative care are more likely to not make a referral for such services (Fitch et al., 2016; Willard & Luker, 2006).

**General Systems Theory**

In approaching the topic of how members of the multidisciplinary health care team transition from curative care to end-of-life care, a general systems theory approach will be taken. General systems theory has been a popular theory amongst social work practitioners for many years (Hudson, 2000). Social workers have been drawn to this theory as it coincides with the approach of looking at the entire situation of a client (Hudson, 2000). Its’ introduction to social work occurred in the 1950s, and it gained immense popularity amongst practitioners through the 1960s (Hudson, 2000). While widely used, general systems theory is not without its criticisms.

One criticism of general systems theory is that it is too general to be used effectively (Drover & Schragge, 1977; Hudson, 2000). Further criticisms are related to its emphasis on hierarchies within systems without identifying a process to address the hierarchies (Drover & Schragge, 1977). Hudson (2000) attests that this theory is outdated and leads to negative consequences in social work practice as it does not allow practitioners to promote growth and change with their clients. Despite these criticisms, this theory remains appropriate for this research study as the goal of this study is to describe and understand the experiences of the participants. This study highlights areas within the healthcare system that could be further researched and improved upon for the overall well-being of both healthcare providers and the patients they care for. The
purpose of this study does not include an over all plan to improve the system the
participants work within.

Fitch (2004) argues that general systems theory is relevant from an organizational
and information system perspective. He provides the following example about a mom
and her child who are accessing different resources in the community:

[T]he elements of the system would consist of Carl and his mother, the physician,
the medical center, the early intervention program, and the counselling agency.
Whereas each element may have an opinion about its inherent relevancy, they
were relevant to Carl’s mother in this situation as a means to get the services she
needed for her child. In that regard, they were functioning as a system…Without
the exchange of information, the interrelations and system would not exist. In
[this] example, Carl would not get the services he needed (p. 498).

An application of general systems theory in this regard is appropriate for this research
study, which examines a number of resources within the hospital setting, and how that
system is organized and exchanges information, with the end goal of providing the
patient and family with the appropriate services.

Summary

To summarize, a majority of people in Canada are admitted to hospital and die in
acute care wards in hospital each year (Canadian Hospice Palliative Care Association,
2016; Cipolletta & Oprandi, 2014; Grande, 2009; Heyland et al., 2000). However,
members of the multidisciplinary health care team in the hospital are either not being
utilized to their full capacity in providing care at end-of-life (Craig & Muskat, 2013;
Fellows, 2014; Hebert et al., 2008; Keesing & Rosenwax, 2013), are not well-educated
in the provision of end-of-life care (Cavaye & Watts, 2014; Parish et al., 2006; Peterson et al., 2013), or avoid patients who are dying all together (Carline et al., 2003). While there is some information available about what leads to the difficulty in transitioning to and providing end-of-life care in the hospital, an in-depth study examining how the multidisciplinary health care team in a hospital acute care setting makes the transition as a system has not been completed. This research study aims to provide an understanding of how members of multidisciplinary teams in an acute care hospital recognize and transition from curative care to end of life care. In order to obtain this data, a hermeneutic phenomenology research approach was used.
Chapter Three: Methodology

This study was undertaken using a qualitative research approach as the objective of this study was to understand how members of acute hospital multidisciplinary health care teams experience the transition from curative care to end-of-life care. A qualitative approach is generally used when a phenomenon needs to be explored (Creswell, 2013) because the present knowledge and theories are suspected to be biased, or the researcher seeks to understand or describe a specific phenomenon that has not been researched thoroughly (Morse & Field, 1995). Qualitative research usually seeks to describe the phenomenon from the perspective of the participants (the *emic* perspective) and occurs in the setting where the phenomenon occurs if possible (Creswell, 2013; Morse & Field, 1995). A qualitative research approach was chosen for this study because I sought to understand how the members of the multidisciplinary health care team experience the transition from curative care to end-of-life care; I wanted to understand their perspectives and hear about their experiences. This chapter will discuss philosophical assumptions and interpretive frameworks relevant to qualitative research, as well as the qualitative approach and research design utilized in this study. It will conclude with a discussion on trustworthiness and personal reflexivity.

Philosophical Assumptions

Creswell (2013) identifies four philosophical assumptions that researchers hold when conducting qualitative research: ontological, epistemological, axiological, and methodological.

Ontological assumptions are related to the nature of reality; qualitative researchers believe that reality is different for everyone and therefore different realities
exist (Creswell, 2013; Florczak, 2016). To put it another way, ontology is about how we know what we know (Meyrick, 2006). In qualitative research, this can be achieved when the researcher explores and collects the accounts of different perspectives from the participants in the study. While all of the participants have experienced the same phenomenon, each participant will have a unique perspective of the phenomenon (Creswell, 2013).

Epistemology is concerned with the researcher getting as close to the research participant as possible, in order to better understand the participants’ knowledge (Creswell, 2013). This is because in qualitative research, knowledge is viewed as subjective and the researcher relies on quotes and first hand observation as evidence of the knowledge being shared by the participant (Creswell, 2013).

The third assumption is the axiological assumption. The axiological assumption asks about the values the researcher brings to the study (Creswell, 2013). Qualitative researchers report their values and biases, and remain aware of how their values influence their research (Creswell, 2013). Phenomenological research specifically believes that the researcher already has a relationship with and some understanding of the phenomenon being studied; it is therefore of utmost importance that the researcher be aware and acknowledge their prior beliefs and knowledge (Wijngaarden, et al., 2017). Creswell (2013) referred to this as “positioning” (p. 20).

The final assumption is methodology. This refers to the procedures and how they are characterized by the growth of the research “from the ground up” (Creswell, 2013, p. 22). Rather than beginning with a theory or perspective, the researcher collects data, and through the analysis of the data, a development of detailed knowledge occurs, resulting
in the emergence of a theory (Creswell, 2013). Methodology then is concerned, not just with how the research is being conducted, but also with why the research is being conducted in a certain way (Carter & Little, 2007).

**Interpretative Framework**

Interpretative frameworks refer to the worldview the researcher has when approaching a research study. In approaching this study, I prescribe to the social constructivist, or interpretivist, view. Social constructivists seek to understand the world that they exist in (Creswell, 2013). Experiences have subjective meaning, and research relies on the research participants’ views of the phenomenon being researched (Creswell, 2013). Researchers do not aim to prove a theory, but rather to develop a pattern of meaning based on the interaction with participants (Creswell, 2013). Questions are usually broad and open ended, as the researcher observes and listens to people in their life setting (Creswell, 2013). The research focuses on how people interact with each other as well as the context which the interactions occur within (Creswell, 2013; Williams, 2000). Further, researchers are aware of their own backgrounds and how this influences their interpretation of the experiences (Creswell, 2013; Williams, 2000). Ultimately, the researcher endeavors to interpret the meaning the participants have about the world (Creswell, 2013). Social constructivism is common in phenomenological research studies (Moustakas, 1994) like the one I have undertaken.

**Phenomenology**

The phenomenological perspective questions how the world is experienced, and seeks to understand the world we live in (Van Manen, 1990). To achieve this, a researcher attempts to describe and understand the common meaning of the lived
transitions from curative care to end-of-life care experiences of individuals (Creswell, 2013; Morse & Field, 1995). Upon completion of a phenomenological research study, the researcher will understand the experience of the participants, as if the researcher had experienced it personally (Kumar, 2012).

Phenomenology was born out of the philosophical works of Husserl related to the world of lived experience—“lifeworld” (Van Manen, 1990). Husserl was interested in describing how the world is constituted and experienced (Van Manen, 1990). Phenomenology, therefore, is not interested in producing empirical data or theoretical observations but rather an account of an experience as it was lived (Van Manen, 1990). Phenomenology is interested in understanding the meaning or essence of the lifeworld (Creswell, 2013; Van Manen, 1990).

Phenomenology, though, is not simply an investigation of how or why individuals complete a certain task (the phenomenon), but rather is interested in the experience the individuals had with the phenomenon (Van Manen, 1990). Phenomenology seeks to understand “what it is like” to have the lived experience being researched (Van Manen, 1990, p. 42). Because phenomenology is the study of many individuals’ perspectives of an experience, generalization of a phenomenological study is more concerned with identifying similar meanings, not an identical duplication of the meanings (Morse & Field, 1995).

Bracketing

In conducting a phenomenological research study, it is necessary for the researcher to “bracket” out their own personal experience with the phenomenon (Creswell, 2013; Kumar, 2012; Overgaard, 2015). The process of bracketing is also known as epoche. Epoche is simply reflecting on and recognizing the researcher’s own
experiences and ensuring that those assumptions and attitudes will not be included in the analysis of the data, so as to minimize any bias to the phenomenon the researcher is describing (Creswell, 2013; Overgaard, 2015).

Creswell (2013) acknowledges that bracketing cannot be done entirely. Because the researcher includes bracketing, or self-reflexivity, in the research study, it is left to the reader to determine how successful the researcher was in leaving their biases out. In hermeneutic phenomenology, bracketing is not necessary as the researcher believes it is impossible to eliminate their own experiences and biases in interpreting the experiences of the participants (Kumar, 2012).

**Hermeneutical Phenomenology**

Hermeneutical phenomenology is not only concerned with providing a detailed description of the essence of the lived experience, but is the practice of interpreting the meaning of the essence (Van Manen, 1990). Researchers who prescribe to the hermeneutical phenomenological approach believe that the researcher and reader “belong” to the text, as they cannot be separated from it (Van Manen, 1990). That is, the hermeneutical phenomenological approach requires the researcher to believe that, although they have set out to provide an objective description based on the lived experience of the participant, both researcher and reader cannot learn about the lived experience without interpreting it through their own lens (Van Manen, 1990).

The goal of this research was to not only describe the experiences of the participants, but to interpret their experiences and find meaning. To achieve this, I needed to design my study so that I could hear and understand the experiences of
different members of the multidisciplinary team who had experience caring for patients who were dying in the acute care hospital.

**Research Design**

To understand the experiences of members of the multidisciplinary health care team in transitioning from curative care to end-of-life care in the acute hospital setting, semi-structured interviews were conducted face to face with the exception of one interview which was completed via telephone. Data was obtained from the interviews and analyzed and organized drawing on the approaches of Van Manen (1990), as well as Morse and Field (1995).

**Research Ethics**

Prior to beginning participant recruitment and participant interviews, ethical approval was obtained from both the University of Regina Research Ethics Board and the Saskatchewan Health Authority Research Ethics Board through reciprocal agreement (see Appendix E). Following ethical approval, operational approval was also obtained from the Saskatchewan Health Authority (see Appendix F).

**Participant Recruitment**

Participants from multidisciplinary teams in acute care in Regina (Regina General Hospital and Pasqua Hospital) were invited to participate in this study. The rationale in choosing these locations is based on convenience sampling. I first contacted managers of different departments and nursing units within the hospitals via e-mail to determine if any staff were interested in and available to participate in the study. Because I was currently employed at the Regina General Hospital, the invitation to participate was not extended to staff employed on the units I worked most closely with. The e-mail
to the managers included a request to post a letter of invitation (Appendix A) as well as an offer to attend units and departments to provide a brief presentation on my research. Unfortunately, this initial plan of recruitment did not garner any results, so I reached out to a senior therapies staff member and a nurse educator and requested that they forward the letter of invitation (Appendix A) to their colleagues at both hospital sites. I also reached out directly to my social work colleagues at both hospital sites and sent them the letter of invitation (Appendix A) directly. As potential participants contacted me following this approach, I used criterion sampling to determine if an individual was appropriate for participation in this study.

Criterion sampling was used to determine appropriate recruitment, due to the nature of needing participants who had experienced the same phenomenon (Creswell, 2013). In this study the phenomenon is working in an acute care unit and experiencing the transition from curative care to end-of-life care. To simplify the determination that a participant had experienced this transition, in the previous 12 months to the interview, they had to have been involved in providing care within the last week of an acute care patient’s life.

Sample

Creswell (2013) states that, in phenomenology, a sample size of 10 to 15 participants is used. Because my study was interested in the perspectives of multiple health care disciplines, I aimed to have at least 10 participants and as many as 15. The final sample included 10 participants: one occupational therapist, one physical therapist, one speech language pathologist, two physicians, three registered nurses, and two social workers. Three participants were employed at the Pasqua Hospital, and seven at the
Regina General Hospital, although some participants did occasionally work at both locations.

**Data Collection**

Data was collected via audio-recorded interviews with participants. Participants were responsible for choosing the location where the interview occurred in order to create an environment where they would be comfortable sharing their thoughts and experiences. Three interviews occurred in office space I provided, three interviews occurred in office space provided by the participants, three interviews occurred in public locations (coffee shops), and one interview was completed via telephone. Informed consent was obtained from all participants prior to the start of the interviews (see Appendix B). A copy of the consent form (Appendix B) as well as information on their Employee and Family Assistance Program (EFAP) was left with each participant following the completed interview.

Semi-structured interviews are used when a researcher knows most of the questions that need to be asked, while still providing participants with the freedom to respond openly (Morse & Field, 1995). A semi-structured interview should reflect a conversational tone between interviewer and interviewee (Morse & Field, 1995). The use of semi-structured interviews in this study allowed for the gathering of more consistent information as the participants in this study came from a variety of disciplines. It was important that the questions were open-ended and not leading (Morse & Field, 1995). As interviews progressed, additional questions surfaced and therefore the interviews were not limited to the prepared interview guide (see Appendix C).
A digital recorder on my personal iPhone was used to audio record the interviews. Interviews lasted approximately 15 to 30 minutes. Following the interview, the digital recording was transferred to my password protected computer and saved as an mp3 file. The recording was then deleted from the iPhone once it had been transferred to the computer.

Each interview was transcribed verbatim by me, using For The Record (2017) transcription software. Transcripts were then provided to each participant via e-mail or via hard copy (as per the participant’s preference) for their review. Participants were encouraged to add to, delete, and clarify their transcripts. Once a participant was done reviewing their transcript, they signed a transcript release form (see Appendix D) giving me permission to use the transcript in my thesis. They were offered a copy of the release form for their own records.

To maximize confidentiality of participants, participant names were removed from transcripts and were not audio-recorded at the time of the interview. Participants were assigned a participant number, and a master list was composed with corresponding participant numbers. Only myself, as the principal researcher, and my thesis supervisor, have access to this participant list. Participants were not identified by discipline throughout the study as much as possible, although some comments may be indicative of a discipline.

**Data Analysis**

The interview transcripts were analyzed thematically. Thematic analysis is common in phenomenology (Morse & Field, 1995). The coding of the data during the
analysis was completed manually. Thematic analysis was completed using Van Manen’s (1990) approach as a guide; data analysis was completed as follows:

1. Transcripts and field notes were read and reflected upon in an effort to grasp the essential meaning of the phenomenon. This is referred to as the “wholistic reading approach” and seeks to identify the main significance of the entire interview (Van Manen, 1990, p. 93).

2. I re-read the transcribed interviews to determine the statements that seemed “essential” to the phenomenon being described (Van Manen, 1990, p. 93). Significant statements were highlighted.

3. I then reviewed the highlighted statements to determine themes and made notes of what theme or subtheme each statement fit best into.

4. The highlighted, significant statements were then organized into a Microsoft Word document by theme and subtheme, allowing for the ease of discussion.

Validity

Qualitative research has been criticized for its subjectivity (Morse & Field, 1995) and the difficulty in validating the research using traditional methods (Creswell, 2013). However, a number of validation strategies have been developed and are used in qualitative research. One of the more popular methods of validation for qualitative research was developed by Lincoln and Guba (1985). To test the validity of a study, this perspective looks at the credibility, transferability, dependability, and confirmability of the research (Lincoln & Guba, 1985).

Credibility is achieved by prolonged time spent in the field and through triangulation (Lincoln & Guba, 1985). Substantial description, they suggest, will
determine that the findings are transferable to another population (Lincoln & Guba, 1985). Dependability and confirmability relate to the methods of research, and are the qualitative equivalents to reliability and objectivity used in quantitative research (Creswell, 2013). Dependability evaluates the extent in which the research study can be replicated whereas confirmability is concerned with the researcher remaining neutral throughout the process (Morse & Field, 1995).

To ensure the validity of my own research, transcripts were confirmed with the participants, sometimes referred to as member checking (Lincoln & Guba, 1985). Triangulation occurred through the corroboration between participants and between participants and the related literature. I was also reflexive in completing this research. Reflexivity requires the researcher to be aware of their biases, values, and experiences and how these things are brought into the study (Creswell, 2013). Because of my own experiences working in acute care and with patients who were experiencing end-of-life, I needed to be aware of my experiences and pre-conceived ideas about this phenomenon, so that I could be neutral in completing both the interviews and the analysis of the interviews. While at times I was able to agree with the thoughts and opinions of the participants I interviewed, I found myself frequently surprised by their responses. This demonstrates that I did not influence the responses of the participants and reflects the rigor of this research. Additionally, I kept notes during the interviews, and made further notes when reviewing the transcripts so that I was able to reflect upon and be aware of my thought processes accurately throughout the completion of this project. The combination of member checking, triangulation, and reflexivity contributes to the validity, dependability, and credibility of the findings of this research study.
**Limitations**

In terms of limitations in this study, participants may have been concerned about how their work in the health care system would be portrayed through this study and as a result they may have attempted to downplay any undesirable answers to interview questions. Additionally, this study looked at the members of multidisciplinary health care teams as they exist in two hospitals in the same city. It should be noted that hospitals in other cities or provinces may have different models of multidisciplinary teams and differences in the roles each member of those teams is responsible to fill.

**Anticipated Benefits**

This study identified obstacles the multidisciplinary health care team faces in transitioning to end-of-life care in the acute care setting. With the identification of these obstacles, possible solutions have been recognized, hopefully resulting in better end-of-life care for patients on acute care wards in hospitals.

**Summary**

A qualitative approach was appropriate for this study because the objective of the study was to examine the phenomenon of how members of multidisciplinary health care teams experience the transition from curative care to end-of-life care in the acute care setting. A hermeneutical phenomenological research approach was used to describe and understand the essence of the experience the members of the multidisciplinary health care team have in making this transition. Reflexivity was important as I completed this study as I was a member of the population I chose to study and therefore needed to acknowledge and reflect on preconceived ideas and biases I brought into the study.
Data was collected via audio-recorded, semi-structured interviews with members of multidisciplinary health care teams who have participated in the transition from curative care to end-of-life care in the acute care setting. A combination of criterion and convenience sampling was used. Data was transcribed and coded manually for thematic analysis. Verification of the collected data took place with each participant. Validity of the study was upheld by the use of member checking, triangulation, and reflexivity. While the data may be limited in its application to other acute care centres that have different multidisciplinary team structures than those used in this study, the data has identified obstacles faced by multidisciplinary teams in the acute care setting, and possible solutions to these obstacles have been identified. There were six overarching themes identified throughout this process, and a number of subthemes within each theme. These themes and subthemes were analyzed to reveal the essence of this hermeneutic phenomenological research study.
Chapter Four: Findings

This chapter examines the common themes that arose throughout interviews with the participants in this study. There are six main themes: communication, discomfort and fear of dying and death, acute care is not set up for end-of-life care delivery, collaboration, valuing team members, and the emotional burden. Each theme is further broken down into subthemes. Combined, the subthemes and themes reveal the essence of the study, or the lived experience of the participants. Each participant expressed the belief that end-of-life care is important, and each participant expressed the desire to do a good job in providing this care.

Sample

There were ten participants interviewed in this study from six disciplines. The participants were all experienced practitioners. Because the sample was limited to the two hospital in Regina, further identifying information has not been included in this study. Regina is a small city, and out of concern of protecting the identities of the participants in this study, information regarding the units the participants worked on, their ages, and the specific number of years they have been working for, is not included although I do acknowledge that having some of that information could provide further context and insight into participant responses. Ultimately, participant confidentiality takes priority here.

Themes

I was surprised by many of the participants’ responses. While the literature and my own experience was suggestive that one of the main barriers in providing end-of-life care to patients and families is the discomfort of healthcare professionals with dying and
death, the responses of the participants did not echo this. Instead, participants focused largely on the need for communication amongst team members, patients, and families; the inadequate set up of acute care for providing end-of-life care; and the difficulty patients and families had with accepting end-of-life care. Some participants spoke of discomfort with providing care to patients at end-of-life, but this was not something that was highlighted as a main concern and seemed instead to be a symptom of the location of their practice rather than a reflection of their skills.

**Theme One: Communication**

When discussing end-of-life care, every participant spoke about communication. Some participants spoke about their experience communicating with the patient and family, some spoke of the importance of communication amongst the multidisciplinary team members, and some spoke of the lack of good communication amongst all parties. Certainly, every participant noted that communication is an important piece in the provision of end-of-life care.

**Communicating with the Patient and Family.** While some participants stated it is difficult to know when to start having a conversation with a patient and patient’s family about end-of-life care, others have worked this topic into their everyday practice. Contributing factors to when a conversation was started were the location of the patient and the discipline of the professional. Participant 4, who initially meets some patients prior to their admission to hospital, stated that it is important to “start the conversation [about end-of-life care] before they’re admitted”, while Participant 1 advised that … in this unit we tend to initiate end-of-life conversations actually with everybody. That’s just an expectation of entering our unit, is that we will discuss
values and goals at the end-of-life. Because unfortunately in critical care sometimes those conversations, if they’re not held right off the bat, end up being held in a terrible or crisis situation in the middle of the night with someone they may not know. So, we actually talk about end-of-life goals with everybody that comes in.

On the other hand, some participants voiced that they wait for the patient or family to open the conversation about end-of-life care. For example, Participant 3 stated that “typically the patient will open the door to that kind of conversation, which is an opportunity for me to open that discussion, give them some of that information.” This was echoed by Participant 6 who stated:

I don’t know how you recognize other than if they’re able to communicate with you and say… a lot of people say things like “I don’t want this to be the way it goes”, “I don’t want my family to remember me like that”, “I’m tired”-- that’s a big one. So, I think when they start saying things like that, you have to start having those conversations with family and with physicians and make that transition.

Finally, Participant 2 voiced that it was a combination of the health care professional recognizing when a patient and family was ready to have the conversation, and initiating the conversation upon that recognition:

It’s kind of using your judgment call and your critical thinking of “would this be something they would be open to?” So, if they can’t come back from a disease or a condition, or if the pain is too much and you know, we’re just prolonging
something that is inevitable, then that’s, I think, when the conversation needs to be started.

Regardless of who or how the conversation was initiated, participants were clear that patients and families were not always prepared to accept or understand that end-of-life care was the most appropriate care going forward. Participant 9 explained that an end-of-life conversation involved:

… a lot of education and discussion. A lot of discussion, because it’s hard for people to A) imagine their loved one not being there anymore. Some-- a lot of denial takes place in there, so it’s mostly a lot of support and education.

This was reinforced by Participant 4 who stated “… that’s the thing, I think, people have to remember, is that you may not achieve comfort measures at the first meeting. You might have to do multiple meetings.” These statements suggest that with the right education and appropriate amount of time provided, most patients and families will accept that they are in an end-of-life situation. Even still, participants acknowledged that regardless of the time and education provided, and regardless of how obviously imminent death seemed to be, some patients and families were unable to accept it.

Participant 1 spoke of a case where the team “had 38 separate family meetings, at which time we tried to explain the concept of even DNR-LAI but the family would not accept it, and he would not accept it.” Patients and families being in denial seemed to be a contributing factor to health care professionals’ inability to effectively communicate with patients and families about the need to change to end-of-life care:

The biggest barrier sometimes can be family. Sometimes it’s the patient is in denial. Like the more recent ones we’ve had, the patient was at an end-of-life
Participant 6 explained:

I know we have advance care planning and that helps but it’s so individual and some people don’t ever want to make that transition. They want to fight ... and who are we to make that decision really, we’re just here to support them.

Another participant stated:

Ultimately, I [have] to make the decision saying “if they don’t understand after I’ve spoken with them, they’re not going to understand and they’re not willing to understand.” And if people are not willing to understand or willing to try to understand and compromise I-- you can’t talk to them. (Participant 4)

Difficulty with communicating to the patient and family why acceptance of end-of-life care is appropriate though, was only one part of this puzzle. Additionally, participants spoke about the dynamics of the patient and family communicating amongst themselves.

Participants shared examples of how family members disagreeing about how to proceed negatively impacts the patient at the end-of-life. Participant 6 explained “there’s families that can’t agree and I think the only person that suffers in that is the patient.” Participant 1 explained that it is not always consistent in terms of which party is unable to accept death, “sometimes the patient is ready to accept the fact that they’ve had palliative needs but the family’s not quite ready; sometimes the family is ready to accept there’s palliative needs but the patient’s not quite ready.” Participant 5 recalled a scenario where the patient was unable to voice her own wishes, and her children were unable to agree:
... there was an instance where a patient wasn’t-- she had advanced dementia. And her daughter and son were in disagreement of how she should proceed, she was not awake enough, or even when she was awake could not participate in anything orally so she went days and days without any nutrition probably just IV hydration and then her family-- her daughter-- her son was the decision maker because he was the eldest. And then I spoke with him and he said he relinquished his decision-making ability to his sister because she was in Regina. I spoke with her, she did not-- she was very defensive of what I was saying and did not accept my rationale for how I was approaching the situation and what my concerns were.

Unfortunately, regardless of the amount of communication and education provided to patients and families, a resolution was not always found. However, it is relevant to note that all of the participants in this study believed that, regardless of the outcome, it was necessary and important to provide education and to communicate as effectively as possible with the patient and family in an effort to provide the best and most appropriate care to the patient.

**Communication amongst the Multidisciplinary Team.** Communication about the end-of-life care of a patient amongst the multidisciplinary team varied from one participant to the next. In nearly every example given, nurses were included in the conversation; beyond that, each participant had a different combination of multidisciplinary interactions. These interactions varied in size from just the physician and nurse, to a group that included the physician, nurse, respiratory therapist, social worker, and health educator from Métis and First Nation Health Services. Most
participants did identify that larger meetings were atypical. Participants shared many examples of positive communication amongst the team. Unfortunately, the examples of when the team failed to effectively communicate with one another demonstrated how this had dire consequences for a patient and family during an already difficult time.

Some participants spoke of physicians as being the unaccepting member and the difficulty in having a physician understand and accept what the team, patient, and family may be trying to communicate to them. This lack of acceptance was understood by other team members as being the result of an ethical dilemma, “We do have [unintelligible] doctors in palliative care but some of our [non-palliative] doctors aren’t-- I think what their ethics are, are to keep them alive” (Participant 2). Participant 10 described one experience where the physician’s unacceptance of the need for end-of-life care had a large impact on the patient’s quality of life:

I think if the doctor might have been-- because I think he was hoping for curative because the person was so young. He was just so-- but I think for so many of these patients, the doctors, they’re giving them this last line of hope that is so unlikely. I don’t think I’ve ever seen that last line of hope work. And, and often it like probably speeds the demise and makes it more terrible because people like, the chemo makes them so sick, and they’re feeling so like, they’re feeling terrible, and it like, it kind of robs them of the quality they might have had at the end and I think the doctors in their own way are trying to do their best but ultimately I don’t think that’s always the case.

In addition to a team member’s inability to recognize and understand that a patient was at end-of-life despite the communication occurring within the team, there
were other times where there was simply a breakdown in communication and a team member had not been informed of a patient’s code status and end-of-life wishes. When this type of breakdown in communication occurred, it was catastrophic for the patient when their medical status changed; Participant 6 shares an example of this where:

… a woman who came into hospital with her advanced care directives decided and she was a do not resuscitate. And there was miscommunication between the… I can’t remember where she came from. I want to say ICU or Emerge, one of the two. And they had brought her up, she was being pushed down the hallway by porter on a stretcher and she wasn’t doing well. And she actually—her heart stopped and they coded her.

This example made it abundantly clear why communication amongst every member of the team was so important, especially when the care of the patient was being transferred from one person or team to another. While the breakdown in communication here was very simple (the receiving and transferring parties were not informed of the patient’s end-of-life wishes), the resulting circumstances were catastrophic and unforgivable. Perhaps a contributing factor in circumstances like this was the lack of role clarity amongst a team. Participant 7 described the difficulty in identifying a clear process amongst the team to initiate palliative services:

I found it in a couple of the cases I dealt with. I found that there’s a bit of, should I just say, miscommunication happening. So, the doctors and the nurses and social workers were kind of like, “Who is making the call?”, “Who is going over -- who made that initial call?” And how that referral should go through and how it should be done.
Fortunately, participants were able to identify and discuss many positive and successful examples of good communication amongst the team in end-of-life situations. Participants spoke of the experiences they have had in communicating with the rest of the team, as well as the team members that most commonly are involved in end-of-life conversations. Participants were able to easily identify what was important in order to have good team communication.

Participant 4 identified which team members were important to include when having end-of-life discussions:

You have to have a spiritual advisor if they have one, like a priest or a pastor or someone of that sort. You also have to have a pharmacist that is dealing with the medications. You have to have a palliative care physician. You have to have the [most responsible physician] of that patient. And you have to have a nurse, a bedside nurse, or someone who is looking after the day to day, hour to hour care. And you also need involvement by family, if they have family, and if they don’t have family, friends who can be the advocate for that patient.

Participant 1 spoke of the team members who were most commonly involved, as well as which other team members were needed depending on each circumstance:

So, we have a core group of people; that would be doctor, nurse that will be involved in the discussion and then we branch out and broaden that circle to either include social work or [First Nation and Métis] services, sometimes [respiratory therapy], and then in really difficult situations we actually bring multiple physicians in.

Participant 7 involved nearly every discipline in her discussions:
When a consult is forwarded to me, I go see my patients and talk to the families and talk to the -- well the doctors, with the bedside nurses, with the charge nurses, physiotherapy and all of that. Everyone. And then have this, you know, kind of like a shared information all put together and from there, you know, because my job is basically discharge planning from the hospitals. So that kind of leads me -- all that information combined together kind of leads me towards having this conversation with my patients, having this conversation with families.

Participant 2 echoed this and stated that “I’ve had conversations about changing to end-of-life care] with all [team members]-- I’ve had them with managers to social work to family to doctors to consulting doctors.” These experiences demonstrated that these health care providers valued their counterparts and recognized the importance of communicating effectively with each other. However, they also recognized that this communication does not always occur the way it should, and they understood that the consequences of poor communication result in negative outcomes for the patient.

Some participants spoke clearly of things that should change to improve communication, as well as their hopes for the future. Participant 4 expressed a desire for a process change that he recognized as being important and currently missing. He stated, “I think that formal rounds should be done, where they do it with a team, as I said, multidisciplinary [when a patient becomes palliative)” because it would encourage better communication amongst the team leading, hopefully, to better care of the patient.

Participant 8 described a future state she hoped will come to fruition:

I look forward to working in an acute care environment in which physicians actively engage (and are comfortable doing so) in these conversations with these
patients (and families) in order to make proactive changes in goals of care with
the patient.

In conclusion, Participant 2 summarized when she said, “I think staff should be
knowledgeable in starting the conversation [about end-of-life care].”

**Theme Two: Discomfort and Fear of Dying and Death**

Another dominant theme that emerged from the interviews was that of discomfort and fear of dying and death. Participants discussed their own level of comfort with dying and death, and also spoke of their perception of the level of comfort and fear the patients and families they worked with had. Through these discussions, it became apparent that time, experience, education, and training all contributed to a participant’s level of comfort with dying and death. Some participants identified that, as a society, death remains a taboo subject that we are generally uncomfortable talking about. Participant 1 suggested that society was somewhat in denial about the fact that we all die, “I think it’s something that we as a society need to understand and accept, that unfortunately we, as much as we don’t want to admit it, we will all meet our time.” Participant 6 summarized her experience as perceiving dying and death as an uncomfortable topic:

> I think comfort level has a lot to do with it. Nobody… nobody wants to talk about it. Like, nurses, physicians, social workers, patients, families. I think it’s a hard conversation for them to have. And it’s hard to have with someone you don’t know.

**Patient and Family.** How a patient or family received and participated in conversations about dying and death largely impacted the care path. While participants varied in their responses about their own comfort with dying and death, most responses
about patient and family acceptance and willingness to discuss dying and death were similar and indicated that patients and families were uncomfortable with this topic, and often unable to accept death promptly enough to start end-of-life care as soon as it could be started. Participants identified a variety of contributing factors to this unacceptance and discomfort.

Participants discussed family members disagreeing with a prognosis in one way or another as the biggest delay in transitioning to end-of-life care. This disagreement occurred in a multitude of ways: denial of the disease process or disease existence, denial that there was nothing more to be done, disagreeing with the patient’s end-of-life wishes no matter how clearly they were laid out, or cultural reasons that prevent the acceptance of end-of-life care. Participant 1 shared his experience of people who denied the existence of some common terminal diseases and how that contributed to difficulty in transitioning to end-of-life care:

I can think of a few cases-- especially younger people who have diagnoses that are either not entirely clear or sometimes we’ve had where they’ve had disputed diagnoses or I’ve had a few people who don’t believe in, for whatever reason, don’t believe that cancer is a real thing. I’m not quite sure how that happens, but I can assure you it’s real. And some of those people had horrific symptomatology’s and despite having, I can think of a few cases, where we’ve had multiple family meetings.

Participant 7 described how some people have difficulty accepting that there were no further medical interventions that could help:
A lot of times, if patients have been in the hospital for a very long time and they knew it was coming, with families, a lot of times, it’s always this-- this-- the stages of-- almost like the stages of grief. You know there’s denial, there’s maybe, maybe, if maybe we do this, maybe things will change.

Participant 9 explained that healthcare providers tried to educate and explain to patients and families so they could understand:

We spent a lot of time with the family, there was a lot of communication, a lot of communication with [the] physician, we tried to give as much time as we could to get them to accept things, and the way the patient was declining and the way things were happening, and I don’t know if there was any more we could do at this level.

Participant 6 identified that difficulty in having a family agree and accept that a patient was at end-of-life, while difficult and frustrating for the healthcare team, ultimately hurt the patient the most, when she recalled, “there’s families that can’t agree and I think the only person that suffers in that is the patient.” Participant 10 summarized the struggle with patients who were dying when she simply said, “many people aren’t even acknowledging that it’s the end of their life.”

**Healthcare Providers.** Many participants identified that, early on in their careers, they were uncomfortable with providing care to patients at end-of-life. However, as they became more experienced and exposed to dying and death, they became increasingly more comfortable in providing care during a patient’s end-of-life journey. Unfortunately, gaining those experiences and increasing their comfort levels was often difficult and came at the expense of the patient and family. That is, most participants did
not have positive experiences through which to grow, but rather learned through trial and error.

Participants spoke of how time and experience increased their ability to provide care at end-of-life. Participant 6 described how at the beginning of her career this type of care was unsettling for her, but as she continued to work in healthcare it became less distressing:

I’m pretty comfortable with it now, but I’ve been nursing for 8 years so. I can remember it being really hard in the beginning and at first. And it doesn’t get easier, you just-- you learn the right things to say and how to feel more comfortable in the situation, rationalize it to yourself-- what you’re doing, you know. “Yes, I’m giving this so they don’t have to be in pain, or so that their breathing is easier so the family can have their time with them,” and different things like that. I’m comfortable going in and doing the care but it’s not easy.

Participant 9 shared a very similar experience:

You know when I first started 10 years ago, they were-- it was hard, because you didn’t know the right things to say at the right times, and you really have to read where the patient and family’s at, what they’re willing to hear, what they’re not willing to hear. So, you become better at it with experience for sure, but yeah, I’m comfortable with that now.

Some participants who had experience or training in palliative care discussed how that contributed to their comfort in providing end-of-life care, suggesting that experience was imperative to being comfortable and competent in end-of-life care. Participant 1 stated, “All of the physicians that work here have done palliative care training so we are
comfortable managing the vast majority of palliative symptoms, in which case we would offer the palliation right here.” Participant 8 advised:

There have been many times (too many to count) where I have drawn on my skills/experience in the palliative program in discussions with colleagues. Often, it is a lack of knowledge of what is possible and available-- there are many ways in which we can assist people in staying home as long as possible or even attempting to have a home death.

On the other end of the spectrum, participants also discussed the lack of education and training available to them at the start of their careers, which made it difficult to feel comfortable and competent in those situations. Participant 7 summarized:

… training plays a big role but, however, the amount of training that staff receive. It’s a hit and miss. What if they don’t come across that situation while they are in training? So, there we go, the training has passed and you never came across such a situation and now you’re six month, eight months in, and you’re dealing with this situation and the expectation is that you should know. And you may not know.

Regardless of their experiences and comfort levels, participants were clear that they tried to do the best they could in each circumstance, with the tools and support available to them.

**Theme Three: Acute Care is Not Set Up for End-of-Life Care Delivery**

Acute care, by its very nature, is meant to treat and cure people of their ailments with a goal of discharging the patient. However, cure and recovery are not always attainable or appropriate, which results in the death of some patients. Given the fact that
we know some patients are going to die while admitted to an acute care hospital, it is reasonable to believe that services and supports for end-of-life care delivery are accessible and available in an acute care hospital. Unfortunately, this did not appear to be the case based on the information provided by participants in this study. High workloads, role restrictions, and high patient flow demands were all identified by participants as evidence that the current acute hospital state they work in was not set up for end-of-life care delivery.

**High Workload and Role Restriction.** When they described workload concerns, participants identified two main things: first, that patients who were dying and required end-of-life care also required a lot of time and attention; second, participants described how their workload (perhaps in the form of patient-load most commonly) did not change to accommodate the dying patient’s needs. Therefore, while participants were able to identify what was needed, at the very base, to provide care to the end-of-life population, they also quickly identified that the system was not flexible enough to be able to staff appropriately and meet the care needs of the dying patients and their families.

In addition to the lack of staffing, or perhaps as a result of the lack of staffing, some participant’s roles in acute care restrict which patients they are involved with. One participant described how the direction given to some team members was to discontinue those patients who are end-of-life from their caseloads. Perhaps less obvious, was that other roles were restricted simply as a symptom of workload and inappropriate staffing levels. For example, while a nurse is not directed to discontinue care to a patient who is dying, the nurse is unlikely to be able to dedicate the appropriate amount of time to the
dying patient when their patient load has not been altered to support this. So, while the nurse continues to provide care, the nurse is restricted in practice.

Participant 8 explained the direction therapy staff received in acute care, and also voiced concerns with this direction:

Other obvious specific barriers include decreased staffing, lack of programming, role definition (e.g. acute therapists are directed to follow and prioritize people that have rehabilitation potential). As an acute care therapist, when someone is deemed comfort measures only or end-of-life, our involvement more or less stops— we discontinue the patient from our active caseload. It, of course, isn’t appropriate for the acute care therapist to provide active ongoing aggressive therapy, but the therapist could still have a valuable role in advice on positioning, comfort, end-of-life. Or if the family is considering taking the person home, and perhaps they don’t qualify for the palliative home care program but they could benefit from consultation with therapists to make that happen.

Participant 8 further explained that “social work and other disciplines aren’t staffed and supported to put patients and families first in this context.” Participant 9 simply explained that a patient load prevents healthcare providers from being able to do as good a job in providing end-of-life care as is available in an actual palliative unit:

I think with acute care there’s often times where the time factor would be the biggest—like another barrier, I guess. Time factor because we have seven other patients who are acute, and these patients and families deserve a lot of time, they need a lot of time, they need that lengthy conversation, and I think the staff does a great job. We do a great job in trying to provide that, but time would probably
be something that is lacking with trying to care for a full patient load. And that’s where palliative care does their thing, and they have the time and they have the expertise.

A slightly different perspective was shared by Participant 4, who identified that the palliative care physicians are also restricted in providing the best end-of-life care to patients who remained in an acute care setting:

…looking after palliative care patients is an exhausting process, not necessarily physically, but more mentally. And we have to be cognizant of the fact that these physicians who do palliative care come back and forth between the two sites and that’s a big emotional burden. And if you had someone that was just at one site and some at the other site, your coverage would be better, they could spend more time with a patient which I think is addressing those concerns.

**Patient Flow and Care Setting.** Because there are a limited number of available acute care beds, managing patient flow in a hospital is important. Unfortunately, this impacted the care patients received at end-of-life. For example, Participant 8 discussed how “acute care is very much about ‘patient flow’ which is important but not always the most important.” Because of the importance assigned to patient flow, Participant 8 went on and said:

… in acute care, I feel there is a lack of really defined roles, especially for social work-- they aren’t able to provide that counselling and that support. I guess the social work role is defined but, in my opinion, is too focused on discharge planning.
Additionally, while some participants identified that the hospital unit they worked on was quite prepared to provide appropriate levels of palliation, patient flow and demand prevented this. Participant 1 explained that:

… barriers from our unit specific nature is just simple bed pressures. There’s a limited number of critical care beds within the city and you know, if we take an example like today where I’m 12 out of 12 beds full and the ICU is six out of six beds full, offering palliation just might not be an option because somebody in the Emergency Department or the community needs to come to us to get their critical care, in which case would then would have to transfer and offer palliative care somewhere else.

The other obvious patient flow issue was related to the limited number of beds available within the palliative care program. Many participants identified the need for more palliative care bed access. Participant 3 shared that “sometimes palliative can’t offer them those beds, there isn’t the amount of beds maybe needed, they’re always full, there’s no room,” while Participant 1 stated, “palliative care is sometimes full. They have 9 available beds, sometimes they just can’t take people as well and for the same reason we have bed pressures.” Finally, Participant 4 echoed this concern when he said, “What I do see as a barrier is the lack of palliative care beds. So, our palliative care unit is, I don’t think is as big as the one in Saskatoon, and I think that’s a big barrier.”

Outside of patient flow contributing to acute care not being appropriate for end-of-life care, the actual setting and function of the acute care units was also discussed as being inappropriate for patients who were dying. Visiting policies, shared rooms, lack of
appropriate equipment and supplies, as well as the location of the palliative care unit were all identified as barriers.

Participant 4 highlighted the issue with the current visitor’s policy in acute care and how it negatively affected those individuals who were in acute care and dying:

To try to start or initiate comfort measures, in a room that’s not private is, I think, inappropriate, particularly in the setting of our current “visitors can visit at any time” policy. So, you have a busy patient who might have visitors all night long, and then you have a patient who is trying to be palliative. It’s inappropriate, it’s disrespectful, and it’s unforgiving.

Participant 8 also discussed the ineffective physical design of the acute care hospital as contributing to poor end-of-life experiences: “Lastly, there is a real lack of spaces [where] challenging conversations can be had, as well as where families can gather at a time like that.”

Processes to obtain specialty equipment or access to specialty programs were also identified as challenges in providing end-of-life care. Participant 7 discussed the criteria a patient needed to meet in order to be eligible for some palliative care programs:

I know in some cases there’s like this time frame the patient is almost ready [to accept palliative care], but because prognosis are not-- I don’t know if it’s like three months or six months or less or, you know, more than that, then that kind of plays a role and they’re like, “no, no, no, because of this time frame we cannot have this person in this care system.”

Participant 8 explained the difficulty in obtaining something as simple as a specialty mattress for a dying patient:
The specific barriers I think, in acute care, is there isn’t really, there isn’t really a prioritization for end-of-life patients. So, for example, with an ostomy mattress, a person completes a Braden Scale, and they submit a request, but it goes into the queue. This means that is isn’t necessarily prioritized any higher even if it is an end-of-life situation and because there’s so much demand on certain types of things then they’re-- people aren’t getting the right thing at the right time.

Finally, Participant 4 identified the difficulty with having a palliative care unit located at only one hospital: “I honestly do [think there should be a palliative care unit in both hospitals]... because I think that having only one unit at one hospital, at one site-- think about it, you’re [the physician] not giving good patient care either.”

**Theme Four: Collaboration**

Another recurring motif identified throughout the interviews was that participants needed to balance meeting the needs of the patient, the patient’s family, and the multidisciplinary team when providing end-of-life care. It was abundantly clear that end-of-life care was not being achieved without collaboration from these three groups. In fact, Participant 1 felt so strongly about including family in the end-of-life care treatment that he stated, “I think for end-of-life care we need to remember there are two separate patients involved. One is our actual patient and the second is their family, loved ones, extended family.” The need for collaboration can be categorized into the need to recognize the whole patient and patient experience, the importance of looking after the family of the dying patient, and the importance of recognizing the value of each team member.
**Patient Autonomy.** At the centre of any end-of-life care plan is the patient. The patient’s experience is of tantamount importance. In order to maximize the patient’s experience of dying, participants identified the importance of recognizing the patient as a whole and the need to continually advocate for the patient. Participants explained that once a patient is at end-of-life, treatment needed to include more than just medical management. Participant 10 explained that end-of-life care for the patient was:

… maximizing whatever the patient wants to-- to accomplish: if they want to get home, if they-- sometimes they just want to get out of bed because they’re so hot and sticky, and they just want to stand up and feel the ground under their feet sometimes.

In looking at the patient as a whole, participants acknowledged that end-of-life care for each patient looked different, because each patient was unique. End-of-life care is not a “one size fits all” plan and needs to be tailored to the person receiving the care. Participant 7 summarized this:

People have to be compassionate about this and caring when they’re providing this-- and be sensitive towards people’s unique needs because not everybody has the same needs. You know, people come from different walks of life, people come from different cultures, different backgrounds, different belief systems. So therefore, probably, their end-of-life care should also alter the way it fits their needs.

Participant 1 further explained:

I think we need to identify both the medical needs of care required at end-of-life, that’s the active symptom management, as well as the spiritual needs at end-of-
life, that’s managing values, goals, beliefs, as people transition near the end of their life.

Participant 4 echoed the need for end-of-life care to be holistic:

… if they’re Aboriginal and First Nation, I usually call the Elder, I usually ask before “are you guys Traditional, and if you are, would you like an Elder involved?” Many of them will be-- have been raised in a Catholic or Anglican background, in which case we would access those people on call.

Participants also provided examples of when they needed to advocate for the patients, who were no longer able to speak for themselves or who were receiving pressure from family. Participant 6 discussed how these conversations were really difficult but are important so that the family recognized what the patient wanted at end-of-life: “saying ‘I know this is a hard decision for you, but what would your mom/your dad want?’ And they’re really tough conversations. It’s trying to be the voice of that patient.” Participant 6 further explained that “it’s having that conversation with the patient and making sure their family understands that it’s them [the patient] wanting that and this is what they [the patient] have expressed to me.” Participants also gave examples of when they did not follow the direction of the family as it went against the wishes of the patient. Participant 5 provided an example where the team “followed what the patient wanted. We made them comfortable, but the family members didn’t necessarily agree with it.” Participant 4 voiced that “[his] job is to the patient, it’s not to the extended family.”

Beyond advocating for the patient to the family, participants also spoke about advocating for the patient to the rest of the team. Once a patient had expressed their end-
of-life wishes to a team member, the team member communicated those wishes to the rest of the team and advocated for those wishes to be met. Participant 3 noted that:

   I’ve had those discussions with physicians, with therapies, with nursing staff.
   Yeah. Often times, if that’s what the patient is expressing to me, I will express it to every member that is involved with that person, so they know exactly where their thought process is at.

Participant 2 explained the process she followed to have a patient’s requests met:

   You have to ask the attending physician so then it’s kind of like giving your assessment and what your knowledge is to that physician and sometimes they say “no, no it’s not time right now.” But if you’ve had that discussion-- because we’re open to having discussions with the family-- so if we say “per family request” or “we’ve had this discussion with family and this is where we’re at”, some physicians trust some of us older nurses that have been here for longer versus some of the younger staff. So, if we open that up and we’re honest about everything, then they will give us the palliative--but we’re advocating for those patients, so if we talk to the family and how their wishes were, that’s when we can then advocate.

These examples demonstrate that, not only was it important to recognize the needs of the patient and advocate for them, but to also listen to the family and recognize how to support the family.

   **Looking After the Family.** Frequently, participants talked about transitioning to end-of-life care with patients who were too sick to speak for themselves, or talked about providing end-of-life care and how that provision of care also included looking after the
family of the dying patient. Participants spoke about the importance of the use of language, the need to recognize the unfamiliarity of the hospital environment to the family, and the need to educate the family about what was happening. Participants also discussed how important it is to help the families grieve appropriately. Participant 6 explained that:

… working with the patient is really important, making sure they’re comfortable, turned, not in pain, you know, all of those things. But I think working with the families is an important part because it’s harder on them and it’s always unexpected. They don’t want to be in the hospital. They don’t know when it’s going to happen, that’s the biggest question: “How long do we have?” You’re like, “I don’t know… but let me hug you.”

She went on further, and discussed the importance of explaining what was happening:

I think explaining to them [the family] what’s happening too. We do a lot of subcutaneous lines and things like that just to give those pain meds and to give different drugs-- Atropine, and things to keep them comfortable. And [families ask] “what are you doing? Why are you doing that? Why does that go there?” I think that part’s really tough. Really hard to explain.

This demonstrated the fear and unknowing that a dying patient’s family experienced in the hospital, and why the family needed the support from the acute care team during this time. Participant 5 provided an example of a patient who:

… chose to continue eating at risk and continue with the comfort measures only status. Unfortunately, he did-- his pneumonia got worse, and so he ended up passing away. But the family was appreciative to have the information that I
provided them, because now they had a reason for his pneumonias. So, I think they felt some comfort in that.

This example demonstrated that education and medical reasons for a person’s death provided comfort and relief to a family after the death occurred.

Participants also acknowledged the need to address the emotional needs of the family in terms of feeling responsible for transitioning to end-of-life and the burden this placed on families. Participant 4 explained:

I used to call it Compassionate Terminal Care, now we just refer to it as Comfort Measures. And I think there’s connotations associated with “terminal care” because when we think of [the phrase] Compassionate Terminal Care, we think of-- we’re terminating their life. And to families, that is a, I think, a big misnomer because to them, they want to feel comfortable that they’re doing the right thing, and a lot of them don’t feel that they can sign off on a form.

This shows the importance of using language to support the family and ease the grieving process. Participant 4 further explained, “I usually tell them ‘the decision was made by your family member’, meaning their physiology is not permitting them to survive this, right?” By eliminating the family’s responsibility for the patient’s death, the family will hopefully be less likely to feel regret and concern that they made the wrong decision in not continuing life-saving measures.

Regardless of the explanation being provided to families during that time, emotions can run high and families may still question the decision that has been made. Participant 2 discussed how families “start to panic when they actually see that dying process” and that she supported them by “just taking them aside, doing eye to eye
contact and you know, giving them literature, and giving them ‘this is okay, it’s going to
be okay.’” Participant 1 discussed end-of-life conversations he has had with the families
of patients, and noted that:

… the other thing I always tell families: Envision, “is this what they wanted for
their life?” and number two, “my job is not to impose my values on you, my job
is to understand your values so I can help you realize them.”

Participant 7 summarized the process the team member experiences in providing support
to the family of the dying patient:

As health care professionals it’s not easy to sit down with these families and to
walk them through that. A lot of times it’s very sad, but I mean at the end of the
day, you need to do your best. You need to provide them the information that
they need and give them support services, give them other resources available in
the communities so they can access that. And at the end of the day you feel like,
“Okay, I’ve done what I can do.”

Members of the healthcare team hold much responsibility in their role of looking
after the patient, advocating for the patient, and supporting family members to have the
best end-of-life experience possible. This can be exhausting and burdensome work.
Team members relied on one another and valued the skills that each team member can
provide through these situations.

Theme Five: Valuing Team Members

While some participants referenced that the different disciplines of the healthcare
team worked independently of one another for the most part, there was no doubt that
they value one another and the skills and role that each discipline played in the end-of-
life care of a patient in the hospital. Participants identified that the team members they involved was dependent on the end-of-life circumstance of the patient. Typically, the need for many members of the team to be involved in end-of-life planning came with complex end-of-life patients.

Participant 6 described some of the reasons why there was a need for multiple team members to be involved in an end-of-life care discussion:

… usually we have our social worker and physician, if it’s a big meeting; like families, and the patient can’t make their own decision. If they can make their own decision, I mean that can be done by anyone: social worker, nurses I think would be the usual, who are sitting there and have the time to have those conversations.

Participant 1 further advised that:

… if there’s a dynamic in which we expect there’s significant familial issues or maybe discordance within the family-- one part of the family wants to go palliative, the other lives in Los Angeles, and hasn’t seen their mom for 10 years and now flies in and isn’t ready for that. Often then we’ll add our social work or spiritual support teams or [First Nation and Métis] services.

This suggests that the team frequently looks to the discipline of social work or spiritual support to help with emotional issues, or family discord. Participant 6 provided an example of why the team often leaned on these disciplines in those circumstances. She talked about a time when a patient’s goals of care had been changed but the family had not been aware of this, which caused some discord in the patient’s care:
It hadn’t been communicated to the family that it was changed so there was just a lot of drama, I guess. And people who weren’t well-versed in it. Like, we could have really used [social work] there to maybe coach through that conversation that was happening between a newly trained learning physician and a family who was very upset.

When asked what a “good death” looks like, Participant 8 drove home the need for all disciplines to be included: “I would define end-of-life care as a multidisciplinary approach managing all of the needs including physical, emotional, spiritual, psychosocial and eliminating all of those undesirable symptoms as much as possible to hopefully allow a peaceful passing.”

Perhaps unsurprising, given the literature available on this topic, outside of the therapists interviewed, other participants did not include the need for therapies to be involved in end-of-life care discussions. Participant 8 expanded on this, and described the gap that was left when therapies were not included in end-of-life care planning:

It is unfortunate because there’s still therapy goals - almost planning in reverse. So, this person now needs more support, more equipment, obviously more education, and their needs for comfort and all of those things increase, so there’s still a valuable role that Therapies can play between that ongoing active therapy involvement and when and if they do get a chance to get connected to an aspect of the palliative [care] program.

Participant 4 stated, “we felt we were doing the right job, but that’s because we live in our silos and assume that we’re doing the right job”, which lent reason to why some disciplines were overlooked and not included in end-of-life planning for patients.
**Theme Six: The Emotional Burden**

While most participants believed they provided good end-of-life care, it was not without heartache, sadness, or frustration. Participants described a myriad of emotions that they have experienced. While they were quick to identify the positivity they feel when they provided good end-of-life care, there was no shortage of experiences shared where they felt upset or heartbroken. These feelings were attributed to decisions by other team members, by family, or sometimes by the patient in addition to system barriers. Ultimately, negative feelings were related directly to someone not having good quality of life at the end-of-life, as perceived by the participant.

**Helplessness and Frustration.** Helplessness was heard throughout some interviews, when participants recalled times where they did their best to educate and inform patients and families of prognosis and end-of-life care planning. As has been discussed throughout this chapter, there were times when participants were unable to help a patient or family come to the same conclusion as the healthcare team about how care should be provided moving forward; that is, patients and families did not always agree with the healthcare team about when it was time to transition to end-of-life care. In these circumstances, helplessness was a strong undercurrent of the words being spoken by participants. Participant 7 spoke of the importance of recognizing the limitations of the healthcare team in these circumstances and the importance of having to know when the team has done as much as they are able:

…as health care professionals it’s not easy to sit down with these families and to walk them through that. A lot of times it’s very sad, but I mean at the end of the day, you need to do your best. You need to provide them the information that
they need and give them support services, give them other resources available in
the communities so they can access that. And at the end of the day you feel like,
“Okay I’ve done what I can do.”
The helplessness in the words “I’ve done what I can do” was clear. This participant did
as much as she was able to and understood that it was up to the patient or family to make
a decision. Through this helplessness, sometimes frustration also came through.
Participant 1 spoke of frustration, enveloped in helplessness, when he and the team had
been unable to make a family understand what was happening, regardless of efforts:
And that’s-- sometimes, I think if anything is going to give us [post-traumatic
stress disorder] that’s going to do it. Because that’s just-- no matter how hard you
try, multiple family meetings-- those are the ones where I reference where we
have six or seven different physicians coming in and having family meetings, all
saying the same thing, and just not reaching a consensus, that death is imminent.
That unfortunately it comes. Sometimes no matter how hard we try.
The exasperation he experienced was apparent in his recollection of these situations, as
well as some notes of defeat. Perhaps even more telling of the helplessness and
frustration that healthcare providers felt when patients and families did not agree with
the prognosis, was the relief and gratitude the providers expressed when a patient or
family did agree with the prognosis and accepted the transition from curative care to end-
of-life care.

**Relief and Gratitude.** Many participants were eager to speak of times when
families and patients agreed with the prognosis and were connected with palliative care
services or were treated with a goal of comfort rather than cure. However, in many of
these examples, participants spoke of having feelings of relief, suggesting that they have had experiences where families and patients were not agreeable to this, or when a patient did not transition to comfort care early enough leading to poor quality of life during the dying process. Participant 10 explained that she felt relief in situations where comfort became the goal for these patients:

More often than not when it is going to go [comfort measures only] it’s like “oh thank goodness that they’ve come to move in that direction because it’s ultimately what’s going to happen” and if people have a chance to come to kind of a peace with that, it just makes it so much easier for everyone: the patient, the family, the care providers ‘cos, you know, people that are 92 and have a terrible prognosis and still want to be a full code—that’s just like the worst possible, worst possible case.

Even when discussing the positive points of a patient transitioning to comfort measures, the participant dichotomized the example with a “worst possible case” to validate the relief and gratitude she felt in those circumstances.

**Sadness and Grief.** Beyond the relief and gratitude participants expressed when they recalled these patients, they also expressed sadness and grief. Perhaps unsurprising, regardless of frustration, helplessness, gratitude, or relief, participants also felt sad and experienced some amount of grief in most circumstances. These feelings were related to the patient not having good end-of-life care, to the dynamics amongst the family at end-of-life, and sometimes just due to the fact that healthcare providers are people too and feel sad when a patient they worked with died.
Participant 10 spoke of patients and families that did not choose to accept palliative care or an end-of-life prognosis, and how it “is really heart breaking for us, knowing that ultimately, I mean it’s coming no matter, and if they would just accept the help they [would] have so much more support” at the end of their life. Participant 6 explained that “it is really hard to watch people bicker while their parent or grandparent is dying in front of them.” It is not difficult to imagine that participants had feelings of sadness in circumstances like this. However, even in more positive circumstances, where patients expressed gratitude or a patient was having a positive end-of-life experience, participants still felt sad. Participant 1 explained that “there is the peace that comes with knowing we can provide comfort and order to their passing; but it’s still sad. It adds up on us. We cry once in a while when our favourite people go.”

Providing end-of-life care to patients and their families required, it seems, some amount of emotional investment from healthcare professionals. Care providers experienced a myriad of emotions when looking after a dying patient, regardless of the path or circumstances that led to the death. While some circumstances certainly seemed to be more traumatic for healthcare providers, participants in this study clearly identified that they tried to provide the best care possible to their patients and their patients’ families during end-of-life, and there was some emotional burden that went along with this, regardless of circumstance. Participant 1 summarized that:

… we’re always saddened, like it’s sad; nobody wants to see somebody pass away. And you know what, sometimes I think that that burden starts to build up on you after a time, especially on a unit like this where we have a lot of people that pass away.
This statement left no question of the heartache and emotional burden that healthcare providers carried and indicated that healthcare providers invest so much more than just their medical knowledge when they looked after a patient who was dying.

**Interpreting the Essence**

As previously stated in Chapter Three, Hermeneutical Phenomenology is interested not only in discovering the themes of a certain phenomenon and the essence or lived experience of individuals who experience this phenomenon, but also seeks to interpret the essence (van Manen, 1990). While the essence of this study is that participants all believe end-of-life care is important and strive to be good at providing this care, when I look beyond the words and stories, I understand that they often did not feel supported within the system that they work in, and therefore were not set up to be able to achieve this goal.

**Summary**

Participants identified a number of influences and factors that affect their ability to provide end-of-life care to patients admitted to acute care hospital wards. Some themes identified were system-related, such as the focus on patient flow, availability of services, and physical lay out of the acute care wards. Other factors were human related, such as patient, family, and health care provider comfort and acceptance of death, efficacy of communication amongst parties, and the emotional toll that providing care has on providers. Ultimately, participants were quite clear that they always try to deliver the best end-of-life care they are able to and wish that they were better supported in this endeavor from a systemic perspective.
Chapter Five: Discussion

General systems theory will be used to examine and discuss how members of the multidisciplinary team in the acute care system are organized, influenced, and how they communicate information amongst each other and with patients/families in order to transition to the delivery of end-of-life care. The multidisciplinary team, acute care hospital, healthcare system, and patients/families comprise a system wherein they openly influence one another. Each member of this system is just as likely to influence another member as they are to be influenced themselves by a different member. Skoko (2013) describes healthcare as a complex adaptive system, stating that not only are the units within the system influenced by one another, but each unit’s actions are also unpredictable and interconnected. This discussion will be broken into two sections: system influences and human influences. System influences will focus on the influence different services, resources, and facilities have on one another and how members of the health care team transition from curative care to end-of-life care. Human influences describe how the different persons involved in the provision and receipt of care influence each other and the system in this transition.

System Influences

From a healthcare system perspective, there are a number of factors that influence decisions and actions in the provision of care to patients. These include resources and services that are available at the community level (outside of the hospital), the number of patients awaiting admission to a particular service in hospital, the availability of services to discharge patients to or transfer patients from the hospital, the logistics of navigating the healthcare system and accessing the services a patient
requires, and the physical layout of the hospitals. Any of these variables, either independently or combined with one another, can influence the end-of-life care pathway for the patient in the hospital.

**Rigidity of the System.** Participants identified a number of health care system designs and functions that influenced the care a patient received in hospital. As was expanded on in the discussion of theme three in Chapter Four, patient flow was identified as a priority in the health care system. The emphasis on keeping patients flowing through the system influences care providers and patients alike. Participant 4 described a situation where “we had one patient several years ago, where she was sent to the ward as a palliative care patient, and did not get palliation of symptoms.” This is an example of a patient who did not receive the care she was supposed to, as a result of the health care system influencing the location she was transferred to. In another scenario, Participant 1 identified that sometimes palliation could be offered in the location where the patient was situated, but because of system needs, the patient was required to transfer to another non-palliative acute care unit to receive palliative care. This is an example of how the health care system was organized to function in a specific way, and there was not flexibility in its design. While the health care system needed to have rules and boundaries, its rigidity came with a cost. In addition to the above scenarios, recall Participant 7’s concern that if a patient did not meet a certain timeframe for end-of-life, they were ineligible to receive some palliative care services. The rigidity of the health care system influenced what services the patient could receive and where the services were provided. Unfortunately, in the examples provided, the rigidity did not recognize that the service may not be available in the location that the system required the patient
to go to; some circumstances actually required the patient to be relocated to a unit where palliation was not offered very well, instead of accommodating the patient to remain on a unit where the services could have been provided quite adequately.

**An Inadequate System.** In addition to the rigidity of the system influencing a patient’s end-of-life care, participants also explained that there were times when the system was simply inadequately prepared to provide the identified services the patient required. For example, ideally a patient at end-of-life would have received care within a palliative care setting. However, if a patient was appropriate for a palliative care bed but there was an unavailability of this service, the patient remained in a different location to await this service. Additionally, in Regina, the palliative care unit is located within only one of the hospitals, which can prevent a patient who is appropriate for transfer to this service from receiving it if they are not stable enough to transfer to the other hospital. Both of these scenarios would require providers to then provide a service (palliative care) that they are not experts in, in a location that is not set up for that type of care, such as a semi-private room on a regular in-patient ward. It would also require that patients receive care from a palliative care physician based out of another location or unit which, as one participant explained, compromises the care the patient receives, in addition to being detrimental to the physician’s workload.

**Physical Layout of Acute Care Hospital.** In terms of the health care system impacting the provision of care to patients at end-of-life, one area that was highlighted in practice was the physical layout of the acute care hospitals in Regina. More than one participant identified a lack of private rooms, private meeting spaces, and family waiting rooms as having negatively impacted a patient’s end-of-life experience, and overall
provision of care. In addition to making it difficult for the providers to provide care and have effective communication with patients and families as a result of limited spaces available for private conversations, one participant also described how an open-visitor policy (that is, allowing visitors 24 hours per day) impacted a patient’s end-of-life experience when they were in a shared room with a patient who had frequent visitors.

**Player Influences**

The different players involved in the patient’s care journey influenced the care pathway and the end-of-life experience. These players included the patient, the patient’s family and supporters, and the members of the multidisciplinary team including physicians, nurses, social workers, and therapists. Each of these players had the capacity and ability to influence the decisions of other players. These influences generally occurred within the realms of communication amongst all the players, and denial or acceptance of prognosis by either the patient, family, or a member of the multidisciplinary team.

**Communication.** Communicating amongst the team and patient/family about transitioning to end-of-life care was, perhaps, the most obvious area where the different parties were subject to influence by one another. The timing of this conversation was influenced by members of the multidisciplinary team, as well as the patient and/or family. In some instances, participants identified that they initiated those conversations. In those cases, the participant initiating that conversation was influencing the other parties to participate in that conversation. In other cases, participants identified that they waited for the patient or family to start talking about end-of-life care, therefore allowing the patient and family to influence those conversations. Similarly, the dynamics within
the patient and family also influenced the treatment the team provided and how communication occurred.

**Acceptance and Denial of End-of-Life.** Participants identified that when a patient or family was in denial of an end-of-life prognosis, this directly influenced the treatment that the team provided. The acceptance or denial of end-of-life and the subsequent treatment that followed also influenced the health care system. If a patient or their family continued to request ongoing treatment, regardless of futility, the patient was likely to remain on an acute care ward—certainly the patient was not going to be transferred to a palliative care ward or location if palliative care had not been accepted by the patient/family. Since the patient remained on an acute care ward, even though this was perhaps not the most appropriate setting, the system was then unable to accommodate another patient into that setting. When a patient/family were accepting of palliative care services and were able to be relocated to a palliative care ward, this provided the system with the means of continuing to move patients through.

Alternatively, sometimes it was a member of the multidisciplinary team who was unaccepting of an end-of-life prognosis. In these instances, participants explained that providers gave patients or families hope for cure even if it was unlikely to be successful, thus prolonging a patient’s end-of-life journey and possible pain and discomfort.

**Summary**

The way the health care system has been built, both physically and in practice, influenced how the health care team was able to provide services and how the patient and family were able to receive the services. The inability of the system to accommodate all patients with the appropriate services, in the appropriate location, required healthcare
providers and patients to adapt and change the way services were provided and received. When a patient was facing end-of-life, but was not imminently facing death, they were ineligible to receive some palliative care services; in these instances, providers were faced with adapting and providing care in another setting, attempting to mimic the service the patient was unable to access so that the patient’s care needs were still met. On the other hand, when the health care team or patient/family were unaccepting of a palliative prognosis and chose to continue pursuing curative care regardless of suspected futility, this contributed to ongoing patient flow pressures, as well as created hardship and heartache for those involved individuals who did not agree with this care path.

**Similarities with Existing Literature versus New Findings**

As stated at the beginning of this chapter, the responses of the participants of this study were limited in their similarities with the existing literature on this topic. While the main themes that arose throughout the literature review of this study focused on poor communication skills amongst the multidisciplinary team, poor collaboration amongst the multidisciplinary team, and a general discomfort with dying and death amongst both healthcare professionals and society, the themes that arose throughout the interview process for this study were more varied. While there was certainly some identification of poor communication, poor collaboration, and some discomfort with dying and death amongst team members, participants more clearly identified patients and families unacceptance of a prognosis as the main delay to end-of-life care, as well as barriers within the acute care system.

The similarities between the literature and the data collected in this study mostly pertain to the roles of the healthcare professionals in acute care, the limited time for end-
of-life discussions in acute care, the discomfort physicians had with transitioning to end-of-life care, and patients'/families’ discomfort with dying and death. New or contradicting findings in this study include the high level of comfort healthcare providers identified as having; the system and its focus on patient flow as a barrier to end-of-life care; the emotional investment providers had in end-of-life care; collaboration amongst healthcare providers as an important element to achieve good end-of-life care, and the value team members placed on each other through the end-of-life care journey.

**Roles of Health Care Providers as a Barrier**

As was examined in the literature review, participants identified that social workers in acute care were largely focused on discharge planning rather than on providing psychosocial support to patients and families. Furthermore, participants identified a lack of appropriate training and education specific to providing support in end-of-life care situations. Interestingly, while the literature on occupational and physical therapist involvement in end-of-life care was limited and highly suggestive of an absence of their participation in end-of-life care in acute care, one participant identified that these disciplines were in fact directed to discontinue patients from their caseload if they were at end-of-life. This direction was given despite the supportive literature and education that these disciplines are valuable to dying patients. Additionally, participants echoed the literature in identifying the confusion around who was responsible to have end-of-life discussions with patients and families.

**Time Restrictions**

The idea of time restriction as a barrier to end-of-life care in acute care came up generally within the discipline of nursing. The literature identified increasing tasks and
workload for nurses as one contributing factor to a nurse’s inability to provide appropriate end-of-life care or to have appropriate conversations about end-of-life care with patients and families. Participants in this study also identified these factors, in speaking about an increasing patient load or short staffing levels, as contributing to the difficulty they had in finding enough time in end-of-life care situations.

**Physicians’ Discomfort with Transitioning.**

The literature discussed at length why physicians may be uncomfortable with transitioning to end-of-life care, what their perception of death looks like (i.e. medical failure), and that frequently physicians want to try all medical interventions in an effort to preserve life. While the physicians that participated in this study did not identify any discomfort with death, and in fact were advocates of having conversations and transitioning to end-of-life as soon as is appropriate, other participants did speak of physicians that avoided discussions about death, and that tried all possible medical interventions regardless of futility. Additionally, participants identified that physicians were responsible for consulting palliative care specialty services, and thus dominated the plan of care which was also expressed in the literature.

**Patients’ and Families’ Discomfort with Dying and Death.**

Perhaps one of the most similar themes between the literature and the data obtained in this study is that of the discomfort and denial patients and families have with dying and death. As previously stated, participants in this study overwhelmingly identified patients’ and families’ unacceptance of dying and death as one of the main delays in accepting and transitioning to end-of-life care.
**Comfort of Healthcare Providers with Dying and Death.**

While the literature strongly identified that health care providers are uncomfortable in providing care to a dying patient, this was not as decisively apparent in the interviews with participants from this study. However, most participants did identify that early on in their careers they were more intimidated in providing end-of-life care, but through experience they became quite comfortable in providing care and recognize end-of-life care as being a very important aspect of working in acute care. This increase in comfort through experience and exposure was also prominent in the literature, demonstrating that the more experience and exposure a provider has to dying, death, and end-of-life care, the more likely they are to have positive attitudes about providing end-of-life care.

**The Acute Care System and Patient Flow as a Barrier to End-of-Life Care.**

Largely absent from the literature was the prospect of the acute care system and its focus on patient flow as a barrier to health care providers being able to provide end-of-life care. Both in its physical setup (lack of private rooms and unavailability of palliative care units at both hospital sites) and system setup (discharge focus rather than patient care focus), acute care was identified by participants as providing a disservice to health care professionals trying to provide end-of-life care, as well as to patients and families in receipt of end-of-life care. Things as simple as obtaining appropriate equipment for patients who were dying, to the focus on moving patients through the acute care system as quickly as possible, were identified as acute care system barriers by participants.
Collaboration and Value of One Another in End-of-Life Care

The literature definitively suggested that the healthcare team in acute care did not collaborate effectively nor value other disciplines’ perspectives in providing end-of-life care to patients. Certainly, participants in this study did identify some aspects of poor communication amongst the team, but overall participants spoke highly of their team members and recognized the value each member had in providing end-of-life care. If anything, team members were able to identify when other disciplines were not able to work to their full scope because of system barriers (for example, social workers being unable to provide psychosocial support because of their focus on discharge planning and patient flow).

Emotional Investment in End-of-Life Care

Completely lacking in the literature was discussion about the emotional toll that health care providers experienced when providing end-of-life care. The literature was unreservedly focused on how and why health care providers avoid and are uncomfortable with dying and death. However, the participants in this study were overcome with emotion, at times demonstrated by crying, when they discussed their experiences with end-of-life care. Following each interview, there was no question of the emotional investment and burden that each participant felt when they recalled their experiences of looking after a dying patient and that patient’s family.

Practice Implications

Healthcare Providers

It was very clear that participants’ competence to provide end-of-life care to their patients in the acute setting came with experience and exposure. As a result, healthcare
providers should be encouraged to seek out opportunities to learn about end-of-life care practices, as well as seek out opportunities to be exposed to real life end-of-life care experiences. More experienced, senior colleagues should be mentoring new practitioners when they are providing care at end-of-life.

Healthcare providers need to be well informed of the resources that exist to support patients through end-of-life, as well as how to access those resources in a timely manner. Practitioners that are in educatory or supervisory positions should be encouraged to take it upon themselves to support their team members in being aware of these resources, as well as how and when to access them. Knowledge of how to access resources could be as simple as knowing which team member or discipline is responsible for assessing for a service, much the same way as a physician may consult a physician from a different specialty.

Education and mentoring of communication skills should be fostered. Providers need these skills to be able to work effectively as a member of the team for the well-being of the patient. Additionally, it is important that all providers feel comfortable and confident in participating in difficult conversations with patients and families regarding the transition to end-of-life care. As some participants explained, having conversations about end-of-life care was their regular practice with all patients they were involved with; beginning these conversations early on in a patient’s acute care journey can help with normalizing the idea of death and end-of-life care when it becomes imminent.

In order to reach a vision where healthcare providers work as a team, effectively communicate with each other, and receive appropriate education to foster these traits, interprofessional education programs could be implemented. While most disciplines are
currently educated and trained in isolation of one another, there is evidence that having healthcare providers receive training together are able to better work as a team which results in better patient outcomes (Engum & Jeffries, 2012). An interprofessional education model should include language that is common amongst the participating disciplines to promote understanding, various activities and scenarios to promote knowledge sharing amongst participants, and finally open communication forums (Grace et al., 2016). This type of model breaks down misconception one discipline has about the skills and knowledge of another discipline (Engum & Jeffries, 2012; Grace et al., 2016). Engum and Jeffries (2012) provide one example where a nursing student and medical student were provided a scenario and at the end of the simulation, the medical student was surprised by the knowledge and skills the nursing student possessed. Most literature regarding interprofessional education programs describe programs being used in post-secondary education programs, suggesting that this is a model not as commonly used in the workplace.

Keeping healthcare providers knowledge and skills current in an ever-changing environment such as acute care hospitals can be challenging. Participants in this study identified that educational and training opportunities in the workplace are limited. An interprofessional education program as described above, could encompass ongoing educational opportunities to ensure that providers continue to receive current education and skills. Additionally, those providers in mentoring or educating capacities could also prioritize informal learning opportunities for the team for discipline specific education. An informal learning opportunity might include a lunch and learn, a guest speaker to a staff meeting, or participation in a webinar.
**Social Workers**

In addition to the points above also being applicable to the practice of Social Work in the acute setting, I would like to discuss other practice implications as they relate directly to the *Code of Ethics* (Canadian Association of Social Workers, 2005) and the *Standards of Practice for Registered Social Workers in Saskatchewan* (Saskatchewan Association of Social Workers, 2017). In Canada, social workers are expected to adhere to six social work values as laid out in the *Code of Ethics* (Canadian Association of Social Workers, 2005); these values are:

- Respect for inherent dignity and worth of persons
- Pursuit of social justice
- Service to humanity
- Integrity of professional practice
- Confidentiality in professional practice
- Competence in professional practice (Canadian Association of Social Workers, 2005).

Based on these values, the Saskatchewan Association of Social Workers published the *Standards of Practice for Registered Social Workers in Saskatchewan* (2017), with a focus on “general practice requirements”, “record keeping and confidentiality”, “competence”, “professional relationships”, and “professional accountability”. Only those values and standards that are most relevant to social workers providing service to patients and their families at end-of-life in acute care will be expanded upon.

**Social Work Values and Standards.** Social workers are committed to respecting the inherent dignity and worth of all people, as captured in value one of the
TRANSITION FROM CURATIVE CARE TO END-OF-LIFE CARE

*Code* (Canadian Association of Social Workers, 2005) and section F1 of the *Standards of Practice* (Saskatchewan Association of Social Workers, 2017). Within this value, is the expectation that social workers will respect the autonomy and self-determination of the individual they are serving. Closely related to this value, is the second value which emphasizes that social workers, in their pursuit for social justice, will advocate for persons to have access to public services and benefits, and resources to meet their basic needs (Canadian Association of Social Workers, 2005). With respect to a patient who is dying, a social worker should be expected to advocate for what the patient (or in the absence of capacity or advance care plan, the patient’s substitute decision maker) has chosen. This means that in the event that family, or other health care team members, are not aware or respecting a patient’s wishes, the social worker involved should advocate on behalf of the patient. This advocacy could occur in two broad scenarios: the patient wants to continue to receive all medical treatments in an effort to prolong life or the patient wants to cease all medical treatments and allow death to occur. Generally speaking, all of the participants in this study, regardless of their discipline, spoke of their experiences advocating for the patient and the importance of respecting what the patient wants. The third value, “service to humanity”, encompasses the social worker’s ability to resolve conflict (Canadian Association of Social Workers, 2005). Participants in this study clearly identified that, when there was conflict in having conversations with patients and families, they frequently requested social work involvement. This demonstrates that social workers are being utilized appropriately in some respects by their colleagues in the hospital in these circumstances. Interestingly, value six of the *Code* (Canadian Association of Social Workers, 2005) speaks to the principle of social
workers “limiting professional practice to areas of demonstrated competence” (p. 8), and this is echoed in section E “Competence” in the *Standards of Practice* (Saskatchewan Association of Social Workers, 2017) with an expanded section regarding the upgrading of skills. Some participants in the study clearly identified that some social workers in the hospital, while expected to be knowledgeable and competent in the area of end-of-life care, may not be well educated in this area at all. This was also reflected in the literature in Chapter Two of this document, where I concluded that newly graduated social workers may not be well educated or exposed to end-of-life care. This suggests that social workers in the hospital have an ethical obligation to be well educated in the area of end-of-life care. However, a recurrent theme throughout the literature and interviews is that social workers in the hospital are largely focused on discharge planning and therefore do not have the opportunities nor time to focus on increasing their skills in the area of end-of-life care.

Social workers in hospital should demand opportunities and time be afforded to them so they can receive and participate in training and education regarding dying and end-of-life care. As an employer of social workers who will undoubtedly be faced with serving those individuals facing end-of-life care, the health care system and acute hospital does a great injustice to their employees and the public population by not supporting social workers in being adequately educated and trained to provide end-of-life care. Further, with the system placing pressure on social workers to be involved primarily in discharge planning from hospital, social workers are positioned in a difficult place as they try to balance their ethical commitments with the expectations of the system and their employer.
Summary

From a general systems theory perspective, it is easy to understand that there are many influences and moving parts in the health care system, and more specifically within the acute care hospital system. Both the literature and the participants of this study identified barriers within the system and its moving parts, as well as ways the system and its players worked together. Overall, the literature was quite suggestive that the human influence of healthcare providers in the acute care system was the largest barrier to good end-of-life care, while the participants of this study largely identified the acute care system as a barrier, in addition to the difficulty patients and families have with accepting end of life care prognoses.

One common barrier between both the literature and this study was that education and experience improve a health care provider’s ability to practice in end-of-life situations. Furthermore, when coupled with the Standards of Practice for Registered Social Workers in Saskatchewan (Saskatchewan Association of Social Workers, 2017) and the Code of Ethics (Canadian Association of Social Workers, 2005) that social workers in the acute hospital are expected to adhere to, this study exposes a gap. Both the literature and this study revealed that social workers’ primary focus in acute care is to assist with discharge planning and support patient flow. Ultimately, the acute care system is not set up to support the very ethics and standards that social workers in the province of Saskatchewan are expected to abide by. It should be noted that social workers, and all health care professionals in the acute care system in Regina should be better supported and have more access to education and training in the provision of end-of-life care. This study could be considered a starting point for further investigation into
how other acute care systems deliver end-of-life care, support the multidisciplinary team in being able to provide and be educated in end-of-life-care, and how the general public population perceives this care as well.
Chapter Six: Conclusion

With the majority of people continuing to spend their final days in hospital, it is imperative that health care providers be able to meet the needs of a dying patient. This study endeavored to examine the lived experiences of a number of multidisciplinary team members, including physicians, nurses, social workers, occupational therapists, speech-language pathologists, and physical therapists, who have been involved in the transition from curative care to end-of-life care with a patient in the hospital. This is a small study and is limited to the collection of data from two hospitals in a single urban setting. Certainly, there is much more research that can and should be completed in the future.

Future Research Implications

This study focused on the experiences of physicians, nurses, social workers, occupational therapists, physical therapists, and speech-language pathologists who were employed in one of two acute care hospitals in the same city. The participants who volunteered to participate in this study were all experienced practitioners. Therefore, future studies may garner different results if newer, less experienced practitioners were interviewed. This is especially important to note because both the pre-existing literature as well as the findings of this study, indicated that experienced health care providers were more comfortable with, and generally had more positive attitudes about, providing end-of-life care, as compared to inexperienced and new providers. Other areas that could also be explored would be the provision of end-of-life care in smaller, rural settings where specialty palliative care units and services may be unavailable. A comparison between two urban settings or an urban and rural setting may also reveal differences in
practice. Finally, comparing the experience of health care professionals with the experience of the families of patients they looked after would be helpful in determining if health care professionals are successful in their attempts to provide good end-of-life care.

Summary

By and large, the participants in this study expressed a desire to provide good care to patients and families at end-of-life. Participants identified a number of themes that influence this: communication amongst the team and patient/family; discomfort and fear of dying and death; the setup of acute care as an obstacle to end-of-life care delivery; the need for collaboration amongst the team and the patient/family; the need to recognize and value each team member’s contributions in providing end-of-life care; and that regardless of the end-of-life care journey, participants carry an emotional burden from providing this care.

The experiences of participants had some parallels with the literature, including some discomfort around death and poor communication. However, the experiences of participants were overall more positive than the literature suggested and instead the largest barriers to participants providing end-of-life care were revealed to be the delay of the patient and family understanding and accepting end-of-life prognoses as well as the set-up of acute care. Some of this difference might be attributed to participants volunteering for this study being experienced and therefore more comfortable with discussing this topic and sharing their experiences which may be different than newer, inexperienced health care providers. Therefore, future studies should explore the perceptions and experiences of new health care providers, who have much more limited
experience in providing end-of-life care. It may also be helpful to compare the experiences of health care providers with those of the families of patients who have died in hospital, to determine if there are specific areas that health care providers can improve upon in their delivery of end-of-life care.
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TRANSITION FROM CURATIVE CARE TO END-OF-LIFE CARE


[https://doi.org/10.1080/00981389.2010.499825](https://doi.org/10.1080/00981389.2010.499825)

[https://doi.org/10.1191/0269216303pm662ra](https://doi.org/10.1191/0269216303pm662ra)


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Appendix A: Letter of Invitation

PARTICIPANTS NEEDED FOR

RESEARCH IN END OF LIFE CARE IN THE ACUTE CARE SETTING

We are looking for volunteers to take part in a study entitled
The Multidisciplinary Health Care Team Members’ Transition from Curative Care to
End of Life Care in the Acute Care Hospital Setting: A Hermeneutical
Phenomenological Study

As a participant in this study, you would be asked to participate in a face to face
interview with the principal researcher.
Your participation would involve 1 interview,
which will be approximately 45 minutes long.
For more information about this study, or to volunteer for this study,
please contact:
Amanda Hahn, M.S.W. Student
Faculty of Social Work
at
306-530-5417 or
Email: AmandaHahn@uregina.ca

This study is being conducted under the supervision of
Dr. Nuelle Novik
Faculty of Social Work
306-585-4573
Nuelle.Novik@uregina.ca
Appendix B: Participant Consent Form

University of Regina

Project Title: The Multidisciplinary Health Care Team Members’ Transition from Curative Care to End of Life Care in the Acute Care Hospital Setting: A Hermeneutical Phenomenological Study

Researcher: Amanda Hahn, Graduate Student, Faculty of Social Work, University of Regina, (306)-585-5417, Amanda.Hahn@uregina.ca

Supervisor: Dr. Nuelle Novik, Faculty of Social Work, University of Regina, (306)-585-4573, Nuelle.Novik@uregina.ca

Purpose(s) and Objective(s) of the Research:
The purpose of this research study is to seek to understand how the members of a multidisciplinary health care team experience the transition from providing curative care to end of life care in the acute care hospital setting. It is hoped that this study will provide insight into the provision of end of life care in the acute care setting and identify what types of interventions are needed to improve this aspect of care. This study is designed to examine the thoughts, opinions, and experiences of health care professionals who work with a multidisciplinary team in a hospital setting.

This research study is being conducted as part of a Master’s thesis of the principal researcher, Amanda Hahn.

Procedures:
Information will be collected through face to face interviews with participants. Interview questions will be open-ended, and the interviews will be audio recorded and transcribed. Notes will be taken during and after the interview to enhance the interviewer’s ability to understand the conversation/discussion.

You may participate in this study if you have provided care in the last week of life to a patient in acute care. For the purpose of this study, the perspectives of social workers, nurses, physicians, occupational therapists, and physical therapists are being sought.

Interviews are expected to last approximately 45 minutes to an hour in length and will be conducted face to face. The interview will be facilitated in the location of your choice (off site and outside of your hours of work). Following completion of the interview, the principal researcher will transcribe the
interview. A typed transcript of the interview will be provided to you for review. The transcript can be provided to you via e-mail or hardcopy. Please advise the interviewer in which format you would prefer to receive the transcript. Please note that there is some limitation to confidentiality of e-mail, specifically as it pertains to your employee e-mail; for this reason, you are encouraged to provide a personal e-mail address if you wish to receive an electronic copy of your transcript. The purpose of having you review the transcript is to ensure accuracy. You will be able to add to the discussion, or choose to have certain comments omitted.

Please feel free to ask any questions regarding the procedures and goals of the study, or your role.

**Potential Risks:**

There are minor risks involved with participation in this study; there is a possibility of experiencing some emotional distress from the recollection of providing care to dying patients. In the event that you require support as a result of your participation in the study, you may access your Employee and Family Assistance Program:

Shepell Care Access Centre
Toll-Free: 1-844-336-3136 or www.workhealthlife.com

**Potential Benefits:**

Potential benefits to participants in this study include the opportunity to reflect on and share experiences in a safe, non-judgmental environment.

While participants may not otherwise benefit directly from participating in this study, the data gathered may identify obstacles to providing quality end of life care to patients in the acute care setting. With the identification of these obstacles, it is possible that solutions may be identified leading to improved patient experiences at end of life in acute care settings.

**Confidentiality:**

Participants will not be identified in any reports or publications. Pseudonyms will be used, and any information that identifies a participant will be removed. The interviews and collected data will be stored in a secured location in the office of Dr. Nuelle Novik on the University of Regina campus for five years following the publication of the study. Only Dr. Novik and Amanda Hahn will have access to this data. Direct quotation from the interviews will be used with your permission.

**Right to Withdraw:**

Participation is voluntary and you may choose to withdraw from the research study at any point without penalty. You are only expected to answer the questions you are comfortable with.
Should you wish to withdraw, please contact Amanda Hahn via e-mail or telephone at the contact information listed on page 1 of this consent form. Your audio recorded interview will be deleted and any transcripts or notes related to your interview will be shredded.

Your right to withdraw data from this study will apply until 2 months after the initial interview is completed. Following this time period, the writing of the study will have already commenced and it will be difficult to remove your data.

Follow up:

To obtain results from this study please provide the principal researcher, Amanda Hahn, with your e-mail address at the time of the initial interview.

Questions or Concerns:

Any questions or concerns about this study should be directed to the researcher or her supervisor using the information on the top of page 1.

This project has been approved on ethical grounds by the University of Regina Research Ethics Board. Any questions regarding your rights as a participant may be addressed to University of Regina committee at 306-585-4775 or research.ethics@uregina.ca

Consent:

This consent will remain in effect for one year from the initial date consent is signed, for the purpose of future interviews. Consent will be immediately terminated if you choose to withdraw from the study as outlined above.

Your signature below indicates that you have read and understand the description provided. Further, through your signature, you are indicating that:

- I have had an opportunity to ask questions and my questions have been answered.
- I consent to participate in the research project.
- A copy of this Consent Form has been given to me for my records.

<table>
<thead>
<tr>
<th>Name of Participant</th>
<th>Signature</th>
<th>Date</th>
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Researcher's Signature  Date

A copy of this consent will be left with you, and a copy will be taken by the researcher.
Appendix C: Interview Guide

Interview Guide

Time of Interview: ________________________________

Date of Interview: ________________________________

Location of Interview: ______________________________

Interviewer: Amanda Hahn

Participant: ______________________________________

Job Title: Physician / Nurse (LPN or RN) / OT / PT / Social Worker / Other: __________________

Hospital and Ward: ________________________________________________

Questions:

1. How do you define end of life care?
   a. Prompt: What does end of life care mean to you?

2. What do you feel is important in providing end of life care?

3. How do you recognize when someone is dying?

4. How do you access end of life care for your patient?
   a. Prompt: When do you start end of life care?
   b. Prompt: What is the process in order to access end of life care, for example- palliative care services or hospice care?
5. How do you feel, as a health care professional, when the goals of care change from curative care to end of life care (i.e. compassionate terminal care)?
   a. Prompt: What is your level of comfort in providing end of life care?

6. Can you tell me about a time the transition from curative care to end of life care went well?
   a. Prompt: Who did it go well for (i.e. the patient, the staff, the family)?

7. Can you tell me about a time the transition from curative care to end of life care did not go well?
   a. Prompt: Who did it not go well for (i.e. the patient, the staff, the family)?
   b. Prompt: How could it have gone better?
   c. Prompt: Is there anything you would do differently in that situation now?
Appendix D: Transcript Release Form

FACULTY OF SOCIAL WORK
Regina, Saskatchewan, Canada S4S 0A2
Phone: (306) 585.4654  Fax: (306) 585.4872
www.uregina.ca/socialwork

I, ____________________________, have received and reviewed the complete transcript of
my personal interview that occurred on ____________________________. I have
been provided the opportunity to alter, delete, and add information in the transcript. I concede
that the transcript accurately conveys what I said in my personal interview with Amanda Hahn. I
hereby release the transcript to Amanda Hahn to be used as described in the Participant Consent
Form. I have received a copy of this Data/Transcript Release Form for my own records.

___________________________  __________________________
Signature of Participant       Date

___________________________  __________________________
Name of Participant           Signature of Researcher (Amanda Hahn)
Appendix E: Research Ethics Board Certificate of Approval
Appendix F: Letter of Authorization to Conduct Research

September 24, 2018

Amanda Hahn
Faculty of Social Work
University of Regina

Study Title: The Multidisciplinary Health Care Team Member’s Transition from Curative Care to End of Life Care in the Acute Care Hospital Setting: A Hermeneutical Phenomenological study
File Number: OA-18-001

Authorization Granted By:
- Sheila Anderson, Executive Director, Urban Primary Health Care Services
- Sandy Euteneier, Executive Director, Surgical Services
- Jan Besse, Executive Director, Rehabilitation, Spiritual Care, Native Health & Respiratory Services
- Vicki Ehrlich, Director, Cardiosciences & Critical Care
- Lori Garchinski, Executive Director, Provincial Programs-Tertiary Care
- Taryn Lorenz, Director, Medicine Inpatient Programs

RE: LETTER OF AUTHORIZATION TO CONDUCT RESEARCH

Dear Amanda,

This letter is to notify you that the above-listed research study has been reviewed and meets all criteria for Operational Approval within the Saskatchewan Health Authority (SHA) – Regina and Area.

*Please note that this approval is conditional on the following:
- Study team cannot interview during work hours or impact staff during patient care

Please note that Operational Approval is conditional upon continued review and approval by the Research Ethics Board (Former RQHR). Should Research Ethics approval lapse or be revoked, Operational Approval will also be suspended. In addition, Operational Approval is issued based upon the details provided in the Operational Approval Application Form. Should the resource utilization deviate from what was requested in the initial application, Operational Approval may be revoked and an amendment must be submitted for review.

This letter serves as your official authorization to conduct research; study activities may now commence.

If you have any questions, please contact the Research Approval Coordinator, Jenny Wang, at 306-766-0893 or ResearchApproval@rmhealth.ca

Sincerely,
Dr. Elan Paluck
Director, Research & Performance Support
Saskatchewan Health Authority