Making Decisions about Potentially Life-Sustaining Treatment at End of Life: A Metasynthesis Exploring Relational Dynamics and Healthcare Philosophies

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Abstract

Background: Decisions about potentially life-sustaining treatment are often not raised with patients and families until end of life (if at all), and are influenced by their many relationships.

Objective: Understand how patients and families' relationships impacted their experiences of making these decisions, and how healthcare philosophies impacted authors' portrayal of these experiences.

Methods: Qualitative metasynthesis design. Purposeful sampling was used to select the 19 qualitative studies included. Relational ethics and meta-study (an approach to metasynthesis) guided data collection and analysis.

Findings: 1) *Closeness in relationships* was valued. Healthcare professionals' (dis)honesty and (lack of) empathy affected closeness with patients/families; 2) Patients' *identity and quality of life* was considered in decisions, and was maintained through close relationships; 3) *Reliance on relationships* occurred for information, care and support; 4) Decision makers felt a *sense of responsibility* to consider their relationships when deliberating treatments; 5) *Normative discourses* were reflected in authors' writing.

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[1] Liu et al, 2014, p. 33.
[2] Sarabia-Cobo et al., 2016, p. e8.
[3] Norton et al., 2019, p. 672.
[4] Seah et al., 2013, p. 1023.
[5] Maura et al., 2019, p. 1.

Chapter 1: Introduction

In most healthcare settings in Canada, acute care as well as long term care and community, healthcare professionals will utilize therapies that are potentially life-sustaining (e.g. cardiopulmonary resuscitation (CPR), dialysis, artificial hydration or nutrition) when a patient's physiological status requires it, and do so until the patient or their surrogate decision makers (persons–often family members –who can legally make medical decisions on behalf of the patient when the patient is unable to) decides or agrees to forgo or withdraw such interventions (Frenette et al., 2017; Gjerberg et al., 2015; LégisQuébec, 2014). Decisions to withhold or withdraw potentially life-sustaining treatments often represent a turning point in the patient's care when the focus shifts from curing or treating the disease to palliation of symptoms. These decisions and transitions often happen in the patient's final phase of life and are influenced by patients and families' many relationships (particularly, those with healthcare professionals) (Frenette et al., 2017; Johnson et al., 2018). Deciding to move away from curative treatments can be difficult for patients and their families within a healthcare system which socializes users to expect and prioritize such therapies (Lamahewa et al., 2018; Sellars et al., 2019). In addition, given that making decisions about potentially life-sustaining treatments involves values and opinions from everyone involved, disagreements and conflict about these decisions for patients in the terminal phase of their illness are common (Baumrucker et al., 2018; Janvier et al., 2014). Decisions about whether to pursue, withhold, or withdraw potentially life-sustaining treatments for patients at the end of life are complex; significant decisions that merit consideration. This is the focal point of this thesis. This metasynthesis study seeks to synthesize existing qualitative research on this topic so as to gain a more comprehensive understanding of how patients and families experience this phenomenon.

My interest in decisions about potentially life-sustaining treatments at end of life originated from my two and a half years of clinical experience as a nurse clinician on a surgical unit, and deepened during my subsequent two years of experience (and current work) on a palliative care unit. The majority of patients on the acute surgical care unit are admitted to recover from major or minor surgeries or receive medical management for an underlying disease (often cancer) or acute issue. During their hospitalization on this surgical unit, most patients' care involves decisions about potentially life-sustaining treatment (e.g. whether to receive chemotherapy or not, whether to receive artificial nutrition or not). These decisions seemed (mostly) uncomplicated in healthier patients, but I noticed that these same decisions became difficult and more complex in patients who were dying. The following case narrative represents an amalgamation of scenarios and conversations I have experienced and observed in this acute care setting and embodies my inspiration for this study:

Emma is an 85 year old woman with metastatic intestinal cancer. Two weeks ago, she underwent major abdominal surgery to excise her tumors and hopefully cure her of her cancer. After the surgery, Emma is admitted to the surgical unit to recover until she is well enough to go home. Unfortunately, Emma's recovery is prolonged by the development of a postoperative ileus (which required the insertion of a nasogastric tube for many days), and the deterioration of her mobility. Previous to this surgery, Emma was a very active, independent woman who lived at home with her husband. After her surgery her pain and nausea were so severe that she remained in bed for many days. Now, it is difficult for her to spend much time out of bed, despite the encouragement from her husband and the health care staff.

As the weeks pass, Emma's health does not improve. Her appetite is very poor and she is now practically bedridden. In addition, she has multiple abdominal abscesses that developed

after the surgery, which cause her significant pain, and required the insertion of two abdominal drains and the use of intravenous antibiotics. Given Emma's history of cancer and chemotherapy use, it is difficult to maintain intravenous access and the nurses frequently need to reinsert an intravenous catheter due to infiltration. In addition, one of the abdominal drains often leaks, which is irritating and causing redness to Emma's skin and requiring frequent changes of the dressing holding the drain in place. One drain begins to periodically output blood and when it does, blood transfusions are provided to treat Emma's blood loss. Despite these many complications and the general deterioration of her health, Emma is still able to meaningfully interact with her husband who visits every day. Discussions with her husband reveal he remains optimistic that his Emma will make it through this health crisis because "she is a fighter."

More weeks pass. These issues persist and over time, Emma slowly becomes less alert and participatory with her surroundings. A scan is performed to assess Emma's increased abdominal pain and the results show that her cancer is spreading again. Watching Emma's health slowly deteriorate and knowing her cancer has returned, health care professionals begin to see where Emma's situation is headed, as they have seen similar cases before – patients too sick to ever get better, who will probably die soon, on this acute care unit, without any or much palliative care.

Health care professionals from all disciplines start to question why Emma is still "full code;" she is clearly at the end of her life and they should therefore be focusing on her comfort. They collectively wonder why Emma and her husband have decided to hold on – do they not understand how poor Emma's health is? Nurses start to become distressed about Emma's suffering and anxious that they would need to perform CPR on Emma's frail elderly body when

her heart eventually stops – which would likely break her ribs and make for what they consider a terrible death.

One day I am the nurse caring for Emma. Since Emma's intake of food and water is still low and she does not have any documents in her chart indicating a desire to restrict any potentially life-sustaining treatments (like all patients admitted within this establishment, it is assumed Emma has agreed to a "level of intervention 1" meaning no restrictions of interventions, unless otherwise specified), I approach a colleague and the medical team to discuss what we can do for Emma. I learn that, according to hospital practice, parental nutrition is not provided to patients like Emma –someone with a poor prognosis. The medical team also suggests that this would be an inappropriate intervention to offer given Emma's low quality of life – it would just prolong her state. I wonder if Emma and her husband agree with this assessment.

As I assess Emma during my morning routine, I find her to have an elevated pulse and an oxygenation that is lower than normal. She is also more lethargic than usual and has difficulty keeping a conversation. I administer some oxygen, which helps her vital signs return within the normal range. When I report my findings to the medical team, they reply that it is time to discuss level of intervention. The medical resident approaches Emma and her husband. I do not hear the exchange between them, but after some time, a document is placed on Emma's chart indicating she is now "level of intervention 3." This means Emma and her husband have agreed to forgo CPR and transfers to ICU, but reversible conditions should be treated. The resident documents that Emma and her husband have understood what this means, and the palliative care team is consulted to ensure Emma's comfort is optimized.

In the following days, I begin to notice a change in medical orders for Emma; blood tests are being discontinued, even though a finding like low hemoglobin would technically be reversible, at least in the short term. Now that Emma is level of intervention 3, I also find myself prioritizing care differently. The three other patients I am caring for, who have a level of intervention 1 (i.e. no treatment restrictions) are demanding my attention – one has a fever, another needs to be prepared for a test and the other has just been admitted following a surgery that ended hours ago. I manage to glance into Emma's room and notice that she is sleeping and appears comfortable, so I assure myself I can assess her later. This continues throughout the day –I am too busy providing care and completing biomedical tasks for patients whose care focus is life prolongation to enter Emma's room as often as I'd like. Every so often, I manage to ask if Emma or her husband need anything, but I don't stay for too long as there is not much for me to do – at least bio-medically –for Emma anymore. Nonetheless, recognizing that a change to level of intervention 3 may be difficult for Emma's husband, when I have a moment, I approach him to assess how he is coping. He says that everything has happened so fast and that he did not expect this surgery and hospitalization to turn out this way. Eventually, Emma is moved to the palliative care unit where she dies a day after the transfer.

Cases like Emma's raise many questions for me; I wonder if the conversation about level of intervention was approached because we thought making a decision to withhold potentially life-sustaining treatments (i.e. CPR, ICU transfer) was in Emma's best interest, or if there was some other motivation (e.g. our discomfort with providing these interventions to a frail, dying older woman). If it was the latter, why was that? How did Emma and her husband come to agree to a level of intervention 3 and eventual transfer to palliative care? Was that decision based on their wishes or was it an interaction they had with staff or family member(s) that swayed them?

Did they receive a balanced presentation of options from staff? I also wonder how Emma and her husband perceived the change in care after the level of intervention form was signed –without adding the full scope of palliative care services; did they feel less cared for? I hoped not. I also wonder; did anyone ever address Emma's husband's distress related to her deterioration? I hoped so.

I began working on the palliative care unit of this hospital after writing the case narrative above and I am now assured that Emma's husband's distress was likely addressed after her transfer to palliative care, even though she was on that unit briefly. I also find myself wishing that the healthcare team would have consulted palliative care sooner so that Emma could have benefited from all that palliative care has to offer for more than a day. In addition to offering services with the intention of augmenting quality of life (such as massage and music therapy), it is my experience that palliative care genuinely seeks to achieve patient, family and person-centered care. Working on a palliative care unit has also deepened my interest in this topic because these discussions, decisions and dynamics (e.g. healthcare professionals being concerned for the kind of care and death patients are/will be receiving) occur there too.

Much like Emma's case, offering options or exploring patients and families' preferences about the general use of potentially life-sustaining treatments frequently does not occur until the week before death, if at all (Frenette et al., 2017; Kim et al., 2022; Sellars et al., 2019). This delay occurs despite the importance placed on respecting patient autonomy within healthcare – which is defined as acknowledging a patient's right to make choices and take actions related to their health that are within the law and based on their own beliefs and values (Canadian Nurses Association [CNA] et al., 2015). For much of patients' illness trajectories, their care decisions are guided by the curative culture of the biomedical approach to care – a healthcare philosophy

which asserts that healthcare decisions should primarily be based on that which empirical research and data suggest is best (Wilkinson et al., 2018). A palliative approach to care –a healthcare philosophy more centered on patient wishes and autonomy –usually only comes into view at end of life, if at all (Freeman et al., 2013). Before end of life, it is often presumed that patients and families prefer to receive potentially life-sustaining treatments.

The literature often explains that delaying discussions about potentially life-sustaining treatment preferences until someone is clearly dying soon is problematic because such a delay fails to prevent "aggressive" care at the end of life (Chang et al., 2020; Bellamy, 2017; Sellars et al., 2019). However, what I find more concerning is that patients and families are left with little time to be involved in care decisions or to contemplate alternatives to curative care. As well, initiating discussions about treatment preferences within the week before death decreases the possibility that the patient will be involved in the discussions and decisions (e.g. because of decreased level of consciousness when death is imminent). Given this, and the fact that patients' wishes are often not discussed or documented beforehand, patients' families are often left to decide whether potentially life-sustaining treatments should be pursued, withheld or withdrawn at end of life, which is often a significantly distressing, difficult experience for them (Eliott&Olver, 2008; Chiang et al., 2021; Sellars et al., 2019).

I have also come to doubt the quality of the conversations about potentially life-sustaining treatments that do occur, and wonder whether patients and families are genuinely included in or able to contribute to the decisions made (via a shared decision-making process), should that be desired. For one, there are differing, inconsistent understandings about what it means to share the decision-making process with patients and families (Gjerberg et al., 2015; Johnson et al., 2018). As well, there are dominating beliefs about what constitutes "appropriate"

care at the end of life – commonly referred to as notions of a *good death* – which influence healthcare professionals' approach and openness in discussions about potentially life-sustaining treatments at end of life (Johnson et al., 2018). These good death ideals, which include features such as acceptance of death, and no excessive use of treatments, originated from an attempt to return death to what it was before our "hyper medicalized" healthcare system –a personal event at home. However, these ideals have instead come to limit the choices at end of life and influence healthcare professionals' recommendations and relational approaches with patients and families when illness is advanced (Cottrell & Duggleby, 2016; Johnson et al., 2018). For example, physicians sometimes utilize advance care planning processes (which often address decisions about potentially life-sustaining treatment) to encourage patients to accept their death and choose less "aggressive" treatments (Billings, 2012; Johnson et al., 2018). While assisting patients to accept/prepare for death is not inherently problematic, the issue is that the good death philosophy may cause healthcare professionals to neglect the possibility that there are patients for whom accepting death is not helpful or desired (Wright & Gros, 2012).

Some healthcare professionals feel comfortable making a unilateral decision about potentially life-sustaining treatment at end of life (i.e. disregarding patient autonomy) if they believe it is in the patient's best interest, or required to achieve a good death (Billings, 2012; Johnson et al., 2018). Not uncommonly, when a patient or family insists on receiving potentially life-sustaining treatments at end of life, healthcare professionals assess that the patient or family have misunderstood just how poor the patient's prognosis is or just how aggressive the treatment is (Johnson et al., 2018; Kilpatrick, 2017). This assumed misunderstanding is often cited as a reason to override autonomy (Blumenthal-Barby & Ubel, 2018). Sometimes, however, what appears to be a difference in insight and understanding is actually a difference in values. In

general, healthcare professionals may be overestimating how often denial occurs and assuming optimism is damaging or that optimistic decision makers need their minds changed (or for us to decide for them), which is not necessarily true (Blumenthal-Barby & Ubel, 2018).

Problem Statement

Current approaches to decisions about potentially life-sustaining treatment at end of life are possibly leaving patients and families feeling excluded, pressured or unsupported. Notions of a good death, the biomedical approach to care, the palliative approach to care, and views about shared decision-making models are influencing the ways in which healthcare professionals approach discussions and decisions about potentially life-sustaining treatments at end of life. This impacts patients and families' experiences and decisions, by extension. These philosophies have also likely influenced authors' study and portrayal of these decisions and experiences.

The theoretical framework of relational ethics –which guided this thesis –asserts that decisions occurring within the context of relationships are impacted by our connections to others and the values therein (Pollard, 2015). This includes decisions about potentially life-sustaining treatments at end of life, which necessarily occur within relationships (at the minimum, between a patient-healthcare professional dyad).Thus, analysing qualitative descriptions of patient and family experiences of these decisions with the intention of gaining insight into the inter-subjective nature of these processes is merited.

Research Purpose and Objectives

This study is a metasynthesis of qualitative research that focuses on patient or family (including surrogate decision makers) experiences of making decisions about potentially life-sustaining treatment at end of life. A metasynthesis is especially pertinent when there is an accumulation of qualitative research on a topic (Sandelowski et al., 1997), which is the case for

this phenomenon. The goal of my study (and of metasyntheses more generally) is not to account for the state of the literature on this topic, or to uncover "the truth" by analysing and synthesizing every relevant article, but rather is to gain a fuller, more enriched understanding of this phenomenon (Thorne et al., 2004).

The research question guiding this study is thus: What does qualitative research reveal about patients and families' experiences of the process of making decisions about potentially life-sustaining treatment at end of life? Guided by relational ethics, the aims of this study are: 1) to understand the relational ethical dimensions of this phenomenon –that is how patients and families experiences of contemplating and making these decisions, and how the decisions themselves affect and are affected by the relationships with a particular focus on the relationships with nursing and 2) to explore how healthcare philosophies have impacted the description, study and analysis of these experiences.

Overview of Chapters

In the following chapters, I outline the steps taken to address the aforementioned research question and achieve my study aims. The next chapter (Chapter 2) is a review of the literature relevant to my topic; decisions about potentially life-sustaining treatment at end of life. Although a metasynthesis entails a review of the literature, the review in Chapter 2 serves to provide context for my study and demonstrate the importance of, and thus why I've chosen to focus on how relationships, values, and healthcare philosophies impact these decisions. In Chapter 3, I outline the theoretical underpinnings that guided my metasynthesis, and the methods and practical steps I followed to conduct the study. In Chapter 4, I present the findings of my study, five overarching themes that were uncovered from my analysis and synthesis of the included articles. Finally, Chapter 5 offers a discussion as well as reflections about my study findings,

including implications for nursing practice, education and research, limitations of the study and the impact it has had on my own practice as a clinical nurse.

Word Choices

Among the many things I have learned through the completion of this thesis is that the language we use matters. Here, I explain certain word choices (or word omissions) that were intentional when writing this thesis:

1) I chose to prioritize the use of "patient and family" instead of "patient and surrogate decision maker," unless referring to organization/policy documents that use this term. This is mainly because the term "surrogate decision maker" obscures and erases the multiplicities of roles and history that are embodied in their relationship, toward a narrow and singular focus on their role as "decision maker." My use of the word "family" is broad and includes persons with a significant, personal relationship with the patient. Similar to this, I considered using the term "person" rather than "patient" throughout this thesis, so as to not obscure patients' identities and narrowly focus on their illness, however, for the sake of clarity (that I discuss persons in a healthcare context), I prioritized "patients."
2) I chose "potentially life-sustaining treatment" instead of "life-sustaining treatment" to acknowledge that these treatments do have limits and, unfortunately or not, are not guaranteed to sustain a life (especially not long-term).
3) I chose "end of life" instead of another alternative (e.g. terminal) because of its association with death – I wanted to remind myself and readers that, although some patients with advanced illness may be talking and participating in a study, or seem relatively healthy, their illness *is* significantly advanced and, therefore, they may very well be living the final phase of their life – whether that be the final hours, days, or months. Thus, by "end of life"

I refer not only to patients whose death may be imminent but also to patients with a significantly advanced illness for whom death will likely occur in the near future.

4) I chose "decision makers" in its plural form instead of "decision maker" when referring to the patient and/or family members who made the decision, because, although one person may verbalize the final decision, decisions rarely come from one person.
5) I chose to limit my use of the words "appropriate" and "futile" because, as Macdonald and Murray (2007) explain, these words ascribe value and thus reinforce notions of what type of care is "the right choice." As I hope to convey in this thesis, there is rarely ever a "right choice" that exists within the complex moral landscapes of healthcare.
6) Lastly, I wish to clarify my intention when I use the term "values." With this word, I reference that which is valuable and important to an individual, whether it be the overarching ethical, religious, political, social principles that guide how they live their life, or their beliefs about what is right and fair in their actions and interactions with others (which are influenced by their overarching principles) (CNA et al., 2015).

Chapter 2: Literature Review

In this chapter I present a review of the literature, performed to provide context and support for my study. To note, the literature review and synthesis in this section is different than the review and synthesis completed for the metasynthesis. The literature reviewed in this chapter was performed through an iterative engagement with the literature that was investigative and ongoing. When new topics and ideas were found to be important to this discussion (through review of articles or discussions with experienced researchers), my search was deepened. Matters that I deemed relevant and that I will discuss below include advanced care planning (ACP) processes, decisions about potentially life-sustaining treatment, palliative care, and healthcare philosophies (including the biomedical approach and good death philosophy).

Advanced Care Planning Processes

In their position statement on palliative care, the Canadian Nurses Association (CNA) Canadian Hospice Palliative Care Association (CHPCA) and Canadian Hospice Palliative Care Nurses Group (CHPCN-G) (2015) have defined ACP as "an ongoing process of reflection, communication and documentation of a person's values and wishes for future health and personal care in the event that they become incapable of consenting to or refusing treatment or other care" (p. 7). The main intention of ACP is to promote patient autonomy, first by revealing patients' wishes for future health care and second by establishing a surrogate decision maker and clarifying the patients' wishes for that surrogate decision maker (through the communication ACP encourages). Consequently, ACP seeks to ensure that when future care decisions are made, they can and will be aligned with what the patient would have chosen had they been able to. Upholding patient autonomy in medical treatment decisions is fervently endorsed by the literature and by certain laws –especially in the context of end of life (CNA et al., 2015;

LégisQuébec, 2014). For example, Quebec's *Act Respecting End of Life Care* exists to "ensure that end of life patients are provided care that is respectful of their dignity and their autonomy" (LégisQuébec, 2014, c. 2, s. 1.). It has been argued that, when patients are incapacitated (e.g. by disease progression or potentially life-sustaining treatments) "humanity is mainly preserved by consideration of [patients'] individual will, values and priorities" (Grignoli et al., 2018, p. 1). As such, much importance has been placed on engaging in, and completing ACP, so that patients' end of life wishes can be known and followed (Dunbrack, 2006). In instances when no ACP occurred prior to end of life, a patient's family (or, surrogate decision makers) are expected to, as closely as possible, decide as the patient would have (a principle called "substituted judgement") to uphold patient autonomy (Devnani et al., 2017).

Preferences uncovered through ACP are communicated to others by documentation, often using forms (e.g. advanced directives, do not resuscitate forms, do not hospitalize forms, level of intervention forms) that are meant to initiate and guide ACP discussions (Ells, 2010; Brinkman-Stoppelenburg et al., 2014). These forms differ in complexity but generally serve to indicate which potentially life-sustaining treatments patients do and do not want (e.g. CPR, transfer to ICU/hospital) either in writing or by checking off the desired option(s) (Brinkman-Stoppelenburg et al., 2014). Multiple authors emphasized that, when adequately approached, ACP should occur in an ongoing manner throughout the patient's life as preferences can (and do) vary throughout illness (Bellamy, 2017; CNA et al., 2015; Dunbrack, 2006). As such, ACP forms can (and should) change throughout the patient's life/sickness, to reflect any changes in preferences. Indeed, Quebec law dictates that a physician must "inquire whether the directives still correspond to the person's wishes" when there is "a significant change in the state of health of a person capable of giving consent to care" (LégisQuébec, 2014, c. 2, s. 56).When ACP

documentation is not updated as health and preferences change, documented preferences may not reflect actual wishes, which would limit the usefulness of the ACP form (Lamahewa et al., 2018; Vig et al., 2011). Similarly, if the documented preferences are not fully applicable to the specific end of life scenario occurring, or if different stakeholders interpret the form differently, not only would the ACP form's usefulness be limited, but conflict and tension between parties could arise (Vig et al., 2011). These potential limitations are especially true for illnesses with unpredictable trajectories, such as heart failure or dementia (Lamahewa et al., 2018; Vig et al., 2011).

Another important consideration is, if the discussions that coincide with the completion of the ACP document guiding the conversation are poor in quality, the document created may not accurately represent the patients' preferences and thus, may not accomplish the goal of respect for patient autonomy. As such, many authors have warned us not to treat these documents as 'checkbox items' and have reminded us that the most important element of ACP is the communication aspect (which includes how these discussions are approached) (Dunbrack, 2006; Frenette et al., 2017; Izumi, 2017; Johnson et al., 2018). A systematic review of qualitative studies that sought to describe the perspectives of patients with dementia and their families on ACP revealed that, when the completion of an ACP document was not accompanied with sufficient explanation or time to process the information, decision makers felt rushed or confused about the ACP decision (Sellars et al., 2019). These authors found that "one carer who had completed a 'Do-Not-Hospitalise' form reflected that it had been completed in a rush and that they '[didn't] know … what [they were] signing'" (Sellars et al., 2019, p. 284). Another study that explored physicians' understandings of patient autonomy and how this influenced their approach to ACP found that some physicians felt ACP had little do with autonomy and served other functions instead such as to "make the system work better and to make doctors' lives

easier" (Johnson et al., 2018, p. 572). Johnson and colleagues (2018) have therefore cautioned us to remember the purpose of ACP (i.e. to encourage patients to share their wishes and respect autonomy), and to approach ACP conversations and present documents accordingly.

In spite of these potential shortcomings, ACP "can enable family members and partners to prepare for [the patient's] death, resolve family conflict and deal with the subsequent bereavement" (Bellamy, 2017, p. 242). Having access to their loved one's preferences in the form of ACP can decrease the family's decisional conflict as it provides them with some insight as to how to proceed in the situation unfolding (Chiarchiaro et al., 2015). In their critique about ACP practices, Killackey and colleagues (2019) highlight that, with the increasing complexity of healthcare and increasing number of potentially life-sustaining treatments available, the best choice for a patient is not always objectively clear, which increases the need to include the patient and engage in ACP. As well, with the advancement of technology, quality conversations are becoming more important to ensure patients and families adequately comprehend the options available (Calbots, 2012; Janvier et al., 2014).

As many authors have counselled, ACP should begin well in advance of serious illness to be successful (CNA et al., 2015; Dunbrack, 2006; Frenette et al., 2017). However, as in Emma's case (Chapter 1), the majority of studies have revealed that healthcare professionals do not engage in any sort of ACP conversation or documentation until days before death, if at all (Brinkman-Stoppelenburg et al., 2014; Frenette et al., 2017; Sellars et al., 2019). The reasons for this delay and low prevalence of ACP engagement are manifold. Many authors have cited healthcare professionals' discomfort with discussing the sensitive topic of death and dying, as well as the fear that such topics would destroy patients' and families' hope as the central reason healthcare professionals do not engage in ACP more frequently (Bellamy, 2017; Dunbrack,

2006; Killackey et al., 2019). In a book chapter about ACP, Bellamy (2017) have suggested that death and dying are taboo subjects that many people find embarrassing, uncomfortable and distressing to discuss. Dunbrack (2006) found that patients were also often reluctant to engage in ACP as the medical technology now available has "raised expectations that medicine can keep us alive forever" leaving individuals to feel that ACP is unnecessary as "they do not to expect to die" (p. 8). Bellamy (2017) also suggested that individuals living with chronic, life-limiting illnesses like heart failure or chronic obstructive pulmonary disease may not view their condition as life limiting and therefore do not see the importance of discussing their end of life preferences. Healthcare professionals tend to feel similarly, and wait for prognosis to be definitively poor before initiating ACP conversations (Bellamy, 2017). However, in her article, Izumi (2017) has reminded us that ACP is not only applicable to end of life decisions or only appropriate for the terminally ill, and thus ACP can and should be initiated earlier. Facilitators for ACP engagement and completion include open communication, initiating ACP before a health crisis, training for healthcare professionals, trusting relationships, as well as systems/structures that support ACP engagement (e.g. time and resources) and ACP implementation (Dunbrack, 2006).

Nurses' Roles in ACP

It has been suggested that nurses' regular contact with patients and families gives nurses many opportunities to initiate or participate in ACP (Rietze & Stajduhar, 2015). Clabots (2012) has explained that nurses can help clarify the treatment plan and answer the patient and family's questions about their health status, treatment options or illness trajectory. According to a literature review, nurses agree that they can play critical roles in initiating, informing, advocating and managing ACP (Ke et al., 2015). However, when investigating nurses' actual role in ACP, many researchers have found that nurses tend not to be involved or to consider themselves as

very involved in ACP (Frenette et al., 2017; Izumi, 2017; Ke et al., 2015; Rietze & Stajduhar, 2015). According to literature reviews, nurses cite organizational barriers (e.g. no time for ACP discussions, ACP does not impact care), personal barriers (e.g. inexperience with ACP discussions) and patient related barriers (e.g. patients not willing to discuss their end of life) as reasons they were unable to engage in ACP (Ke et al., 2015; Rietze & Stajduhar, 2015). In Emma's case, when the medical team approached her and her husband to have a discussion about level of intervention (i.e. engage in ACP), I, her nurse, was not present. Although I may have contributed to the ACP process in other ways (e.g. supporting Emma and her husband before and after the conversation/decision), I now wonder why I was excluded from the formal conversation and am troubled that, according to the literature, this is not a unique occurrence.

Decisions about Potentially Life-Sustaining Treatments

This section will explore the intricacies of decisions about potentially life sustaining treatment. It will begin by describing the ethical and relational aspects of these decisions. I will then describe the different decision-making models that exist. I will also discuss the literature regarding decisions to withhold or withdraw potentially life-sustaining treatment at end of life and decisions to pursue potentially life-sustaining treatment at end of life.

Ethical Dimension

Though much importance has been placed on the principle of autonomy in treatment decision making, there are limits to autonomy as an ethical principle. Often, attempts to respect the principles of beneficence (do good), non-malificence (do no harm) or justice (distribute resources fairly) interfere with patient autonomy; especially when it comes to decisions about potentially life-sustaining treatment at end of life (Dzeng et al., 2015; Wilkinson et al., 2018). In fact, much debate exists in the literature as to which of these principles should predominate in

these decisions and whether healthcare professionals should be allowed to unilaterally (i.e. without consulting the patient or family) withhold or withdraw treatments that they assess would not offer the patient any benefit and/or would cause the patient or others "undue" harm – treatments often referred to as "futile." Wilkinson and colleagues (2018) suggested that there are two forms of "futile" treatment: 1. treatments that will have a net harm for the patient (i.e. harms of treatment outweigh the benefits) and 2. treatments that will harm other patients (e.g. using an ICU bed for a patient who may not benefit, thereby not having an ICU bed available for another patient who would likely benefit).

In the literature, healthcare professionals recurrently exhibited a willingness to override autonomy for the sake of safeguarding patients' well being. This occurred in two seemingly opposite contexts (but I would argue are two sides of the same coin). First, healthcare professionals exhibited an unwillingness to fulfil wishes to withhold or withdraw treatment that they deemed to be in the patient's best interest (e.g. refusing prescribed medication) (Pollard, 2015). Second, and more frequently at end of life, healthcare professionals exhibited an unwillingness to comply with patients and families' wishes to pursue treatment that they deemed clearly not in the patient's or others' best interest (i.e. would cause net harm) (Baumrucker et al., 2018; Johnson et al., 2018). Indeed, Johnson and colleagues (2018) found that most healthcare professionals in their study described autonomy as having limits. Take this quote from a physician: "So, I mean, we tend to respect autonomy, but the other side of the coin is somebody says, "I want you to resuscitate me no matter what my underlying condition is," then I won't respect that autonomy" (Johnson et al., 2018, p. 568). The physicians in this study recognized that patient autonomy is bound by medical norms of what is considered reasonable care and by

the availability of services. Although the two contexts described above are different, ultimately, what is at stake in each situation is the same – patient autonomy.

In their qualitative study that explored how institutional cultures and policies impacted physicians' approaches to DNR decisions at end of life, Dzeng and colleagues (2015) warned that allowing physicians to make unilateral treatment decisions (based on beneficence, non-malificence or justice) could lead to arbitrary decision making based on the individual physician's values and beliefs. As well, Carnevale and colleagues (2017) explained that the principle of beneficence (or best interest) can exclude patients and families from the decision making process as it tends to assume that there is one "true" view of what is in the patient's best interest and that this should be uncovered and followed, whether or not the patient or family agrees. However, research has shown that "patients are willing to accept treatment for benefits much smaller than what medical professionals may consider reasonable" (Koczwara, 2013, p. 221). Thus, basing treatment decisions on the principles of beneficence/non-malificence creates certain questions such as; what does it mean for a treatment to be in the patient's best interest and who decides? Wilkinson (2013) affirmed in his editorial about "futility";

> "[there is a] philosophical uncertainty about how we should assess the benefits and burdens of treatment and determine whether treatment is harmful. Given this uncertainty, it is not clear why we should privilege a medical view over the patient's view. To do so appears unjustifiably paternalistic" (p. 223).

To note, I do not mean to imply we should disregard healthcare professionals' assessment of what is best (or exclude this from decision making), but I do wonder; whose opinion of what constitutes a "reasonable" benefit-to-harm ratio should prevail?

Relational Dimension

Relational ethics (described in detail in Chapter 3) is a conceptual framework which explains that all ethical decisions are made within the context of relationships and that the relationships and decisions affect one another (Pollard, 2015). Decisions about potentially life-sustaining treatment at end of life are ethical decisions influenced by the decision makers' many relationships–particularly the relationships between patients, their families and the healthcare professionals involved – and the values therein. Given my study's goal of investigating the relational component of this phenomenon, I will not go into much detail here but, briefly, each stakeholder involved has previous experiences, values and beliefs which can impact their approach to these decisions. Patients and families' past experiences with health challenges – which the patient survived –can enhance their hope and impact their willingness to make a decision to withhold or withdraw treatments at end of life (Chidwick et al., 2013). On the other hand, healthcare professionals have likely witnessed how harmful potentially life-sustaining treatments can be, which can influence their willingness to accept a decision to pursue potentially life-sustaining treatment at end of life (Daneault et al., 2010). Patients and families' religion or culture may also indicate which types of care choices are acceptable (Jotkowitz et al., 2010; Chidwick et al., 2013). The values reflected in philosophies of a good death also tend to influence healthcare professionals' relational approach with patients and families as well as their views of the type of care that is acceptable at end of life (Kehl, 2006; Johnson et al., 2018).

Thus, patients, families, and healthcare professionals have values and beliefs (influenced by their culture, religion, roles, experiences, etc.) which can impact their interactions with one another and inclinations about the use of potentially life-sustaining treatment at end of life. Further considerations are also required for the additional influences of the wider healthcare system context. For instance, prioritization of care is necessary to achieve the principle of justice

(i.e. fair distribution of resources) when making decisions about potentially life-sustaining treatments at end of life in a social healthcare system (Wilkinson et al., 2018). In light of all this, Killackey and colleagues (2019) suggest considering relational autonomy instead of individual autonomy when making decisions about potentially life-sustaining treatment at end of life, as the former takes relational influences into account. Relational autonomy views autonomy as "an interdependent process that involves mutual respect and understanding" (Killackey et al., 2019, p. 9). Similar to relational ethics, relational autonomy holds that we are socially embedded persons whose relational and social contexts and obligations need to be considered when making decisions (Eliott & Olver, 2008; Killackey et al., 2019).

Decision Making Models

Charles and colleagues (1999) outlined a decision making continuum with three predominant models of decision making, each with different amounts of input and participation from the stakeholders involved: paternalism, shared decision-making and the informed model. As Charles and colleagues have explained (1999), in paternalism, the physician deliberates which treatment is best and decides alone which treatment to implement, requiring the patient only to consent to care. In the informed model, healthcare professionals share information with the patients who "could be filled up (like an empty glass) with new knowledge and thereby transformed into informed and willing decision-makers," after which the patient is left to make the decision alone (Charles et al., 1999, p. 655). Authors have cautioned us not to equate the informed model of decision making with respect for patient autonomy (Dzeng et al., 2015). As Dzeng and colleagues (2015) have warned, without healthcare professionals' recommendations and guidance, this model "may result in patients choosing treatments that are neither in their best interest nor consistent with their goals and values" because patients may be "overwhelmed by,

do not want to, or are not able to choose from the menu of different options" (p. 813).The shared decision-making model, instead, involves information exchange between all stakeholders. In this model, the healthcare professionals share medical knowledge and the patient and family share their preferences and values (Charles et al., 1999). Then, depending on the patient and family's preferences for participation in the decision, they deliberate which option is best, together (Charles et al., 1999).

Charles and colleagues (1997) have suggested that shared decision making is ideal for decisions in the context of life threatening disease, where there is substantial uncertainty, no treatment option is objectively best, and treatment options may impact patients' well-being (e.g. chemotherapy). Thus, this model is the ideal choice for decisions about potentially life-sustaining treatments at end of life. This model also supports patient autonomy without discouraging input from healthcare professionals. Makoul and Clayman (2006) explain in their concept analysis about shared decision making that not all patients and families wish to participate in the decision-making process. These authors "contend that shared decision making can occur even if patients ask physicians to take decision making responsibility, provided that the essential elements [of shared decision making] are present" (Makoul & Clayman, 2006, p. 307). Essential elements include sharing medical knowledge (about the problem, options and benefits/risks), eliciting patient values and preferences, making medical recommendations, and assessing patient understanding, ability to decide, and desire to partake in or defer the decision (Makoul & Clayman, 2006). Thus, as these authors suggested, though not all patients and families wish to make the final treatment decisions, sharing medical knowledge and eliciting patient values and preferences should occur first in all scenarios, so that the patient and family may properly discern

and determine their preference for participating in (or deferring) the treatment decision (Makoul & Clayman, 2006). Thus, it is the decision making *process* that ought to be shared.

Decisions to Withhold or Withdraw Potentially Life-Sustaining Treatment

Deciding to withhold or withdraw potentially life-sustaining treatment at end of life is often a difficult decision for patients and families with many viewing it as a choice between life and death (Chiang et al., 2021; Eliott & Olver, 2008). Many families also experience guilt and distress as a consequence of these decisions and describe deciding to withhold or withdraw potentially life-sustaining treatments as judging the value of their loved one's life and choosing to give up or choosing death (Chiang et al., 2021; Handy et al., 2008; Sellars et al., 2019). Handy and associates (2008) have explained that this may be because families overestimate the ability of potentially life-sustaining treatments to prevent death. Our health care system has also conditioned us to equate biomedical interventions with caring for patients, making it difficult to separate a decision to withhold or withdraw potentially life-sustaining treatments from abandonment (Hardwig, 2005). This may be especially true when the withdrawal of these treatments is not "replaced" by anything else, such as comprehensive palliative care. Patients and families have also come to expect that there is always another treatment to try (which can be true, given the advancement of medicine today), leaving patients and families wanting to say "what else [do] you have up your sleeve. There has to be something else" when treatment has been unsuccessful (Daneault et al., 2010, p. 2310). Hardwig (2005) has suggested that the lack of discussions about death and dying may also be contributing to patients and families' reluctance to withhold or withdraw potentially life-sustaining treatments at end of life. As Hardwig (2005) has explained, if healthcare professionals offered more preparation, were more open about the limitations of treatments, more forthcoming about the trajectory of the disease, and discussed

goals of care and death more openly (ideally, from the time of diagnosis) maybe then we would not have to unrealistically expect patients and families to "turn completely around, in a day or two, from a hopeful and cautiously optimistic stance to agreeing to withdraw all life prolonging treatments" (p. 338).

As previously alluded to, contrary to patients and families' reluctance to withhold or withdraw potentially life-sustaining treatments at end of life, healthcare professionals recurrently considered that these treatments should be withheld or withdrawn at end of life in order to preserve patient well-being and dignity (Baumrucker et al., 2018; Johnson et al., 2018). However, as authors have explained, in the spirit of autonomy, most healthcare systems require patients and families to agree to withhold or withdraw potentially life-sustaining treatments before this can occur (Eliott & Olver, 2008; Kim et al., 2022).

Decisions to Pursue Potentially Life-Sustaining Treatments

The literature that discusses decisions to pursue potentially life-sustaining treatments at end of life mostly focuses on healthcare professionals' perspectives –on their concerns with the decision makers' choice, and whether the decision makers were properly informed or satisfied with their decision (Brinkman-Stoppelenburg et al. 2014; Kilpatrick, 2017). An article which discussed the importance and difficulties of distinguishing between hope and denial affirmed that healthcare professionals tend to assume decision makers who wish to pursue potentially life-sustaining treatments at end of life are in denial, that they have misunderstood something and therefore need convincing to choose otherwise (Blumenthal-Barby & Ubel, 2018). Although it may sometimes be relevant to distinguish which of denial, self-deception or unrealistic optimism is occurring, Blumenthal-Barby and Ubel (2018) have warned us that we cannot always assume that decision-makers' expectations are unrealistic because they are different than our own. As

well, Zimmerman & Wennberg (2006) have reminded us that what may appear to be denial (because of a persistent desire to pursue potentially life-sustaining treatment) may instead be the decision makers' way of coping with the patient's approaching death. When healthcare professionals deem denial to be present and that the decision makers are just being "intractable and irrational," it shuts communication down, fuels anger and hostility, and decreases the likelihood that the final decision will be one that everyone is comfortable with (Hardwig, 2005, p. 336). Therefore, Hardwig (2005) has suggested that, rather than "vilify" family members who request treatment, healthcare professionals should instead assess the motivation behind their request, and address these family members' "very human emotions connected with the death [of their loved one]" (p. 342).

Palliative and End of Life Care

Palliative care is both a potential outcome of decisions about potentially life-sustaining treatment and a healthcare philosophy (see section below). In their joint position statement, the CNA, CHPCA and CHPC-NG (2015) have defined palliative care as care that "seeks to improve a person's quality of life once a chronic, life-limiting condition is diagnosed. It then continues until death and into family bereavement and care of the body" (p. 2). End of life care, on the other hand "starts in the final stage of dying," (CNA et al., 2015, p. 2) making end of life care a component of palliative care. Many authors have summarized palliative care as a holistic approach to care that emphasizes whole person care and aims to relieve suffering in all its forms (CNA et al., 2015; Freeman et al., 2013; Chan et al., 2018). Caring for the whole person (not just their disease or diseased parts) is considered "person-centered care" and is the essence of a palliative approach (CNA et al., 2015). Person-centered care seeks to ensure dignity, and support patients' values and wishes by promoting respect for autonomy and shared decision-making

(CNA et al., 2015). The CNA and colleagues (2015) explain that the principles that are important for successful palliative care are dignity, personal autonomy, control, hope, comfort, and quality of life.

The CNA and colleagues (2015) have suggested that proper use of palliative care would make for a more effective and sustainable healthcare system as it would reduce hospitalizations and avoid misuse of resources (since resources would only be used when they are in line with patient wishes) (CNA et al., 2015). Similarly, Freeman and colleagues (2013) argue access to quality palliative and end of life care should be a human right under Canadian law. These authors have suggested that quality palliative care can benefit the patient-family unit as it "helps empower individuals to gain control over their lives," feel supported and better able to manage their symptoms, thus reducing the trauma they might experience at end of life (Freeman et al., 2013, p. 242). In my own practice, a palliative approach reminds me that I am caring for whole persons, not just diseased bodies, which prompts me to treat the person as such – as a person, no matter the state of their body, with individual preferences and needs.

Despite these benefits, currently, less than half of Canadians who would qualify for palliative care have access to it, with many only receiving palliative care in the final 6 months of life (Devlin & Maida, 2017; Freeman et al., 2013), the reasons for which are manifold. This is partially due to a lack of resources, with access especially difficult in settings where palliative care specialists tend not to be stationed such as rural areas, long-term care facilities and non-specialized acute medical-surgical units (such as the one Emma was admitted on) (Freeman et al., 2013). Other times, possibly also due to resource limitations, policies dictate that palliative care should only be provided when prognosis is inferior to 6 months (Freeman et al., 2013). Additionally, as Devlin and Maida (2017) explain in their commentary on the state of palliative

care in Canada, many healthcare professionals wait for a patient's prognosis to be definitively poor before referring them to palliative care because they see palliative care as incompatible with life-saving culture/treatments and because they misunderstand palliative care as being equivalent to end of life care. Devlin and Maida (2017) suggest this misunderstanding can be due to the language we use, for instance, we often refer to actively dying patients as "palliative patients" (p. 191), which creates an association between the words "palliative" and "end of life." Healthcare professionals are also often uncomfortable initiating discussions about palliative care and thus, delay these conversations, either due to lack of training or time, or fear of distressing the patient and family who also misunderstand a referral to palliative care as an admission that the patient is dying, or equivalent to "giving up" (Freeman et al., 2013).

Nurses' Roles in Palliative and End of Life Care

As CNA and associates (2015) have stated; "nurses in all clinical practice settings are responsible for providing and advocating for safe, compassionate, competent, ethical and evidence-informed palliative and end-of-life care" (p. 1) that is accessible to all Canadians. Indeed, as Schroeder and Lorenz (2017) explain in their editorial about the nursing role in the provision of palliative care; nurses provide palliative care in "varied settings including patients' homes, residential hospices, clinics, long-term and skilled care facilities, and acute in-patient facilities" (p. 5). Gagnon and Duggleby's (2014) literature review found that nurses felt a commitment to provide quality palliative care to patients and felt deeply rewarded and privileged when they were able to do so. The Code of Ethics for Registered Nurses also urges registered nurses to use a palliative approach to care (i.e. one that embodies palliative principles) throughout a patient's lifespan (CNA, 2017). To this end, the CNA and associates (2015) outline ways that nurses can, and do engage in a palliative approach to care, which includes initiating

conversations about patient wishes, honoring patient wishes, advocating for resources required to respect their wishes, supporting persons in their experiences, providing comprehensive, compassionate and holistic care, attending to suffering and providing a therapeutic presence.

Healthcare Philosophies

In addition to the shared decision making model and palliative approach to care described above, two other healthcare philosophies influence decisions about potentially life-sustaining treatments at end of life: the biomedical approach to care and notions of a good death.

Biomedical Approach to Care

Despite the fact that the CNA and colleagues' (2015) have asserted that the palliative approach to care should be integrated in all healthcare settings; many authors have suggested that the biomedical approach to care tends to predominate instead (Chan et al., 2009; Feo & Kitson, 2016; Mazzotta, 2016). Biomedicine is characterized by a reductionist approach, wherein mind is separate from the body, and "phenomena are better understood outside their context, separated from related people or objects and the emotions or meaning that patients associated with them" (Chan et al., 2009, p. 118). Fox (1997) explained in her editorial that, within a biomedical approach, optimal treatments are determined solely by empirical research or clinical results; not by patients' preferences and values. Cure is the ultimate goal of the biomedical approach, making this approach antithetical to the palliative approach as it views death as the ultimate failure (Fox, 1997; Kilpatrick, 2017).

Feo and Kitson (2016) have articulated that the biomedical approach's focus on biology has allowed for the discovery of invaluable treatments such as antibiotics and vaccinations and has substantially increased our life expectancy. The use of tangible data and viewing the body as a "set of composite systems comprising organs, tissues, and cells" can also be useful when we

seek to diagnose and treat physical pathology (Wright &Brajtman, 2011, p. 20). Fox (1997) also has suggested that the efficiency of the biomedical approach, due to its focus on the part of the body to be fixed, may be helpful in healthcare settings, where time is often lacking.

Despite these benefits, the biomedical approach to care is not without issues. Feo and Kitson (2016) explain how the biomedical approach can discourage fundamental aspects of care;

> "Within the strict adherence to this model, social, psychological, relational, cultural and spiritual determinants of health and illness are routinely overlooked in diagnosis and treatment. Likewise, non-physical aspects of healthcare delivery, such as the relational elements of compassion and empathy are thought to contribute little to the core activity of cure" (p. 4).

Thus, this biomedical view of persons as components or parts has been referred to as "incomplete" since it does not consider the multiple dimensions that make up a person, such as their psychological, social and spiritual dimensions (Wright &Brajtman, 2011).

Tensions between the Biomedical and Palliative Approaches to Care. Decisions to withhold or withdraw potentially life-sustaining treatments often involve a transition from a biomedical approach to a palliative approach to care and, often within an acute care setting, where the biomedical approach tends to prevail. Studies have shown how the tension between these two philosophies can impact nursing care. In her scoping review exploring how the biomedical approach influences nursing care, Mazzotta (2016) found that this approach caused nurses to focus on medical directives and made it difficult to provide holistic care. As Mazzotta (2016) wrote; "a biomedical approach and technology in high acuity areas has the potential to overshadow humanistic caring" (p. 98) as it does not encourage a holistic view of patients.

Chan and colleagues' (2018) study discovered that the busyness of an acute care setting obliged nursing staff to prioritize care, and biomedical tasks and management of acute medical crises had top priority. The prioritization of these tasks and a poor understanding of palliative interventions led healthcare professionals in the acute care setting to feel how I felt in caring for Emma – that there was nothing to do for dying patients whose care focused on comfort. Take this quote from a nurse:

> "…they're usually left at the end of my priority list […] Even if I'm trying to be more attentive to them […] It's just, task-wise, there's nothing to do. So I always go towards the other patients – dressing changes, IVs to be put in" (Chan et al., 2018, p. 457).

Similarly, a literature review investigating nurses' experiences of providing end of life care on acute medical-surgical hospital units revealed that nurses felt "managing the divergent needs of a mixed patient load (i.e. curative and palliative care patients) in a biomedical culture of care that is heavily oriented toward care and recovery" made it challenging to provide quality care to terminally ill patients (Gagnon & Duggleby, 2014, p. 393).

These tendencies do not go unnoticed by patients and families. Nurses in Chan and colleagues' (2018) study spoke of instances where "they were accused by family members of 'not doing anything,' particularly in the time leading up to the death. Indeed, this could entail not coming to the room as frequently, in part because there were fewer tasks to perform" (p. 460). These tendencies also likely perpetuate the misconceptions about palliative care (as being equivalent to end of life care and/or as "giving up") as well as patients and families' apprehension of withholding or withdrawing potentially life-sustaining treatments (as the care that is withdrawn does not get adequately "replaced" within acute care settings).

Notions of a Good Death

Another healthcare philosophy impacting decisions about potentially life-sustaining treatment at end of life is that of a good death. Many authors have attributed the contemporary definition of a good death to the origins of end of life and palliative care, otherwise known as the hospice movement (Cottrell &Duggleby, 2016; Hart et al., 1998; Meier et al., 2016). The modern idea of a good death "arose as a backlash against the medicalized death" happening in institutions (Cottrell &Duggleby, 2016, p. 687). It is an attempt to return to a natural death, one that could be controlled by the dying person's preferences instead of hospital culture (Hart et al., 1998; Zimmermann & Wennberg, 2006). According to Hart and colleagues (1998), who performed a sociological analysis of the good death, the concept of a good death was first described by the French historian Phillip Ariès who depicted the "tame death" (or natural death) as desirable and the "wild death" as the hyper medicalized, undesirable deaths happening in hospitals.

Over the years, many researchers have attempted to define a good death. In a concept analysis by Kehl (2006), being in control was found to be the attribute most associated with a good death. "Being in control" included having wishes honoured, and having "control over the death event including control of location, timing, and presence or absence of others" (Kehl, 2006, p. 281). Costello's (2006) qualitative study, which investigated nurses' experiences of death and dying, found that nurses shared this sentiment. Take this quote from a nurse: "When [death] is expected, we can plan and make arrangements and be prepared for the relatives. It's always better if you can anticipate the likely time of death and be ready for it" (Costello, 2006, p. 598). When bereaved family caregivers were interviewed about their views of the patient's end of life, they shared that a good death "maintains dignity, features acceptance and awareness [of death], encompasses a degree of control and symptoms are controlled without sedation"

(Holdsworth, 2015, p. 839). Participants in this study described that social interactions with nurses, and nurses' sensitive guidance and encouragement throughout the patient's end of life, impacted how they saw the quality of the patient's death (Holdsworth, 2015). Cottrell and Duggleby (2016) add that a good death is expressed in the literature as one that is peaceful, dignified and timely (in that it occurs at old age), occurs at home surrounded by family, and follows a predictable course. Healthcare professionals tend to define deaths as good if there is awareness, acceptance and preparation for death (Costello, 2006; Hart et al., 1998).

Based on the above, it is clear that there are benefits to these notions of what constitutes a good death. For one, the good death ideals attempt to return control at the end of life to the dying patient (Hart et al., 1998; Zimmermann & Wennberg, 2006). These death ideals also provide some guidance during end of life and depict what is potentially attainable (if desired) through adequate planning (Hart, 1998). Achieving a good death also has positive benefits on nurses' morale and can increase job satisfaction (Costello, 2006; Cottrell & Duggleby, 2016).

On the other hand, there are many potential issues with attempting to define a good death. For one, though Costello's (2006) study demonstrated that good deaths benefit nurses, bad deaths instead were traumatic; they had a negative impact on nurses' morale and could cause conflict. Recall in Emma's case how the nurses caring for Emma felt distressed at the idea of providing Emma with what they considered a bad death – a death that included CPR. I wonder whether the nurses in Costello's (2006) study and those represented in Emma's case would have experienced this emotional turmoil if we, as a collective society, never started qualifying deaths as good or bad. What is more, although many authors have found that good death ideals are "highly individual and variable" (Kehl, 2006, p. 279), are complex and context-dependent (Costello, 2006; Meier et al., 2016), influenced by each persons' social relationships, culture and

religion (Smith & Periyakoil, 2018) and thus, will be different for each person, "the contemporary 'good death' is a powerful, constraining discourse that limits spontaneity and encourages one way to die" (Cottrell & Duggleby, 2016, p. 686). Cottrell and Duggleby (2016) wrote: "within the 'good death' discourse, dying individuals are encouraged—even coerced—to be aware, autonomous agents who make choices about their dying experience. But their repertoire of sanctioned choices is strictly limited; their power, illusory" (p. 710). This is a sentiment articulated earlier by Hart and colleagues (1998) who suggested that the good death philosophy creates socially approved ways to die and pressures patients and families to behave and choose a certain way. Cottrell and Duggleby (2016) and Hart and colleagues (1998) also suggested that we end up labelling patients and families who do not participate in the good death (e.g. by remaining non-accepting of their approaching death) as "bad" patients who are violating the established norm, further obliging individuals to concede to our notions of a good death.

Therefore, although the good death philosophy began in an effort to return control to patients and families, it seems the pendulum has swung too far –we are now (unintentionally) limiting patient and families' choices in an attempt to create a good death. To avoid constraining the choices of our dying patients, Smith and Periyakoil (2018) wrote: "We have a responsibility to respect diversity in goals of care perspectives and preferences. This requires clinicians to reflect on their own assumptions and […] be open to supporting patients' preferences and choices that we would never make for ourselves" (p. 857).

Furthermore, fixating on creating a good death *event* neglects the dying process. For instance, deaths are rated as higher in quality if opioids were being used to relieve suffering, even if this care began only days before death (Chang et al., 2020; Houttekier et al., 2014). Although the patient may have been comfortable at the moment of their death, what about their

quality of life throughout the final stages of illness? As Smith and Periyakoil (2018) have reminded us, with the advancement of technology and medicine today, "death itself has arguably shifted from being an event at a single point in time to becoming a process that occurs over years to decades" (p. 857). Therefore, ensuring that people have no pain the moment their heart stops beating may not be enough; they likely experienced a decreased quality of life and a considerable amount of suffering long before that. Maybe a "good dying process" should be our goal instead.

Overall, adopting a universal definition of a good death may not be helpful. Rather, healthcare professionals must evaluate each individual's idea of a good death to help them achieve this goal (Smith &Periyakoil, 2018). Also, as Zimmermann and Wennberg (2006) have suggested, rather than seeing a natural (or "good") and medicalized (or "bad") death as dichotomous, it may be helpful to recognize that technologies and medicine may be necessary to provide quality end of life care. We also need to remember that there is value in a death that may not meet the "good death" ideals above. To illustrate this, I offer a personal example. My grandfather had advanced dementia and spent his final days in the intensive care unit due to pneumonia, where he was unconscious and intubated. Based on the literature above, this "hyper medicalized" death could not be described as a good death, but I disagree. The technology used gave my family living abroad a chance to come say goodbye and gave my grandmother a chance to come to terms with the fact that he was dying. In the end, he passed away surrounded by family, peacefully. Thus, by suggesting that all deaths occurring in the ICU (surrounded by and using technology) are necessarily "bad," the good death discourse "obscures all that might be good regarding end-of-life care in the ICU" (Vanderspank-Wright et al., 2019, p. 380).

Of course, ideas of a good death can be helpful to the extent that they focus on relationality at the end of life. For example, common attributes of a good death (e.g. being in

control, being comfortable, and achieving a sense of closure) all require relationships to occur. Indeed, Vanderspank-Wright and colleagues (2019) point out that authentic engagement (a relational approach characterised by curiosity, concern, commitment, investment) may have more bearing on the quality of end of life care and experiences than other contextual factors (e.g. the presence or absence of technology). This further highlights the importance of considering the relational aspect of these decisions, and of approaching this scholarship with a relational ethics lens, which holds that the quality of human relationships should be the focus of our ethical attention (Wright et al., 2014).

Chapter 3: Methodology

To gain a better understanding of the relational dynamics and influences of healthcare philosophies on the study of this phenomenon, I performed a metasynthesis of qualitative studies about patients and families' experiences of making decisions about potentially life-sustaining treatments at end of life. This chapter details the theoretical considerations that underpinned this study as well as the study design, including procedures for data collection and analysis.

Theoretical Underpinnings

Metasynthesis acknowledges that theories influence the ways in which researchers approach and carry out their studies (Paterson et al., 2001). Referring to researchers, Paterson and colleagues (2001) wrote; "choice of theoretical framework influences the issues they choose to study, the questions they ask about those issues, the designs they create for the research process, their implementation of those designs, and their interpretation of the research findings" (p. 5). Therefore, in this section I make explicit the theories that influenced and guided my undertaking of this study, to offer justification for my decisions but also to foster transparency.

Healthcare philosophies (shared decision making model, palliative approach to care, biomedical approach to care and good death philosophy) described in Chapter 2 impacted my study design (my research question/aims and analysis). More precisely, my desire to undertake this study and the way I approached this topic was influenced by my alignment with the values underpinning the shared decision making model and palliative approach to care (e.g. how these approaches seek to account for persons' individuality and wholeness). This study was also inspired by my apprehension of the biomedical approach and the good death philosophy, or at least an apprehension around the ways in which the biomedical approach and good death

ideology tends to constrain choices and impose an agenda during healthcare interactions. The ways in which these theories guided my study will be described below.

Relational Ethics

My study design was also largely influenced by relational ethics. Relational ethics is a conceptual framework (and action ethic) developed by Canadian health scholars to guide healthcare practice and ethics (Bergum, 2013). A relational action ethic holds that relationships are the center of morality; that the relational space between individuals is where morality is enacted and where ethical questions (e.g. how to be, how to act) are asked and answered (Bergum, 2013; Pollard, 2015; Upasen, 2018; Wright et al., 2014). Pollard (2015) explains that our connections to others, which are established during interactions, necessarily create responsibility for the other. Thus, any action or decision occurring in the context of relationships (i.e. almost all actions/decisions) becomes an ethical question by virtue of its occurrence within a relationship (Pollard, 2015). This is because of the impact the choice would have on others who are interdependent and connected to the action taker/decision maker (Pollard, 2015). Therefore, every patient encounter, big or small has ethical considerations, since they all necessarily occur within relationships (Bergum, 2013; Wright et al., 2009). As such, relational ethics endorses exploring experiences of making decisions about potentially life-sustaining treatment at end of life from a relational lens – because it views relationships as the "starting point of ethical inquiry" (Wright &Brajtman, 2011, p. 23).

The development of relational ethics was a response to the limitations of individual autonomy and a challenge to its primacy in bioethics (Wright &Brajtman, 2011; Wright et al., 2009). Relational ethics emphasizes that the self is not individualistic but rather "embodied, interdependent and connected" (Pollard, 2015, p. 363). Importantly though, relational ethics does

not seek to undermine individual autonomy, but rather points out that autonomy must not neglect the fact that individuals are interrelated beings (Wright &Brajtman, 2011). Similarly, relational ethics is also a response to the limitations of beneficence as a guiding principle in healthcare (Carnevale et al., 2017; Pollard, 2015). When it is characterised by an attitude that healthcare professionals alone know what is best for their patients, beneficence becomes problematic as it negates the value of the other, assumes that patients are "separated, isolated" beings and thus, that "what is best" for patients can be uncovered without much consideration of their social realities (Pollard, 2015, p. 364). Relational ethics on the other hand recognizes our interdependence and endorses a respect for and inclusion of others' views of "what is best" (Pollard, 2015). To note, relational ethics does not reject the importance of autonomy or beneficence – it is a complementary ethic, and a response to the shortcomings of these principles, not a replacement of them.

Given its move away from individualism and its recognition of the complexity of human persons and relationships, relational ethics supports my alignment with the palliative approach to care, which is also committed to recognizing patients as whole, complex persons (Wright et al., 2009). It has also been suggested that relational ethics is particularly compatible with the discipline of nursing given that both relational ethics and nursing recognizes the primacy of human relationships and focuses on the "humanization" or "personhood" of individuals (Pollard, 2015; Wright &Brajtman, 2011). Personhood entails how we define ourselves conceptually, as persons, and acknowledges that persons can be whole, despite the presence of illness (Sofranas et al., 2018). According to relational ethics, it is essential that the personhood of others be considered and respected for an action or decision to be considered ethical (Pollard, 2015).

Relational ethics describes the interdependent tenets that create an ethical interaction: mutual respect, engagement, embodiment and environment, with mutual respect often considered the most important tenet of an ethical relationship (Pollard, 2015). As the name suggests, mutual respect entails a respect for the other – for their experiences, values, opinions and beliefs – especially if they are different from our own (Pollard, 2015; Upasen, 2018; Wright et al., 2009). Mutual respect requires us to bracket our existing assumptions and to strive to understand what patients and their families consider to be the ethical solution (Carnevale et al., 2017; Wright et al., 2009). This tenet therefore outlines the significance of fostering quality relationships, of working "with" and not "for" or "over" patients and families (Upasen, 2018). The theme of mutual respect also highlights the importance of unconditionally "humanizing" patients; of recognizing their personhood at all times (Upasen, 2018). In their literature review about relational ethics, Upasen (2018) explained that strategies to foster mutual respect include a friendly approach, openness, trying to understand, being there and maintaining confidentiality.

A second important tenet of relational ethics is engagement, because mutual respect cannot occur without an engaged relationship (Pollard, 2015). Engagement occurs when we move towards patients and families, work "with" them, and find a way of looking at something together (Pollard, 2015; Wright et al., 2009). However, Pollard (2015) has cautioned that engagement is not about envisioning how *we* would act/decide in any given situation, as this would lead to an imposition of our own values (p. 366). Engagement, instead, involves nurturing patients' humanity and individuality and seeks to "hear other's voices" (Pollard, 2015, p. 366). By genuinely engaging with others, we render decisions (e.g. those about potentially life-sustaining treatment at end of life) ethical, not because of the outcome, but because of the way in

which the decision was made (i.e. by genuinely including others) (Wright &Brajtman, 2011). Engagement is made possible by the third tenet of relational ethics: embodiment.

Embodiment acknowledges that humans are "embodied" beings, that our bodily emotions and feelings are important aspects of human experiences and decision making and thus, embodiment rejects the separation between mind and body, between subjective and objective (Upasen, 2018; Wright et al., 2009). Therefore, similar to the palliative approach (and unlike the biomedical approach), relational ethics does not discount the presence and importance of emotions in decision making. Instead, relational ethics seeks to give scientific knowledge and human compassion equal weight (Bergum, 2013). Embodiment also involves viewing persons as embodying a life of social connections (Wright et al., 2009), as people who experience the world through their bodies and whose sense of self is "inexorably linked" to their body (Wright &Brajtman, 2011, p. 25). Bergum (2013) explains that when life changes for one's body (e.g. due to illness), life changes for every person that this "lived body" is connected to (p. 132). Thus, embodiment explains that individuals do not exist in isolation, and that the self is a product of our relationships with others (Bergum, 2013; Pollard, 2015). This tenet suggests that each individual's perspective about "what is best" is interrelated with others' perspectives, because we are interrelated to others (Carnevale et al., 2017). By recognizing that individuals are embodied, interconnected beings, with a distinct history and social reality, applying embodiment would prompt healthcare professionals to authentically engage with patients and families and thus endorse ethical practice (Wright &Brajtman, 2011; Wright et al., 2009).

The final tenet of relational ethics is environment which, similar to embodiment helps us to appreciate that we are not separate entities, that a person's actions, decisions and experiences occur within an interdependent environment; within a family and larger community or society

(Pollard, 2015; Upasen, 2018; Wright et al., 2009). Environment includes the circumstances, objects or conditions that surround a person, such as the realities of a healthcare system and society at large (Upasen, 2018). As Carnevale and colleagues (2017) explain, approaching healthcare from a relational ethical lens requires us to recognize that "a person is situated in a moral landscape— shaped by one's family and larger community –that has articulated a socio-cultural constellation of meanings and moral values" which impacts an individuals' views of "what matters to them"(p. 275).Thus, relational ethics encourages us not only to recognize the complexity, and interconnectedness of individuals' values and choices, but also to extend our mutual respect and inclusion to patients' environments – their families (Wright et al., 2009).

In addition to these four tenets, Pollard (2015) has added a fifth tenet to relational ethics: uncertainty. Though not reiterated in most of the literature about relational ethics, I include the tenet "uncertainty" here given its relevance to my topic of decision making at end of life. Pollard (2015) has explained that uncertainty occurs when there is difficulty in selecting a course of action for questions involving values. Uncertainty encourages us to realize that certainty and perfection are not achievable in action-taking/decision making. As Pollard (2015) wrote; "when using a relational ethics framework one is completely aware that our knowledge is constructed within the context of the situation and is incomplete" (p. 367).

Given the above, relational ethics purports that sometimes, what creates moral tension and distress is not the surface issue at hand (e.g. decisions about potentially life-sustaining treatment), "but rather the way in which the issue is approached relationally" (Wright et al., 2009, p. 223). This further supports my desire to investigate this phenomenon from a relational ethics lens, and to explore how our relational approaches may be impacting the tension and distress that these decisions can bring. By approaching the study of these experiences from a

perspective of relational ethics, I gave particular attention to the influence of/on patients and families' relationships when these decisions were a part of the patient's illness trajectory. This meant the inclusion of questions about relationships in my study aims and analysis. Additionally, I gave priority to the inclusion of articles that had a focus on relationships.

Paradigm/Worldview: Constructivism

Before detailing the metasynthesis design, and the procedures I undertook to complete this study, I wish to discuss the worldview that I bring to this study and within which this study is positioned: constructivism. As Creswell (2009) wrote;

> "In planning a study, researchers need to think through the philosophical worldview assumptions that they bring to the study, the strategy of inquiry that is related to this worldview, and the specific methods or procedures of research that translate the approach into practice" (p. 5).

Creswell (2009) has defined a worldview as a "basic set of beliefs that guide action" that would "often lead to embracing a qualitative, quantitative or mixed methods approach" (p. 6). Guba and Lincoln (1994) have explained that worldviews or, paradigms, "define what falls within and outside the limits of legitimate inquiry" by outlining what can be known about the world (p. 108).

Constructivism entails a relativist ontology, which asserts that reality (or truth) is formed by individuals' socially, and experientially based constructions which are varied and multiple (Creswell, 2009; Guba & Lincoln, 1994). Constructivism also maintains a transactional and subjectivist epistemology, meaning that the researcher is assumed to be linked to the object of investigation. Findings, which, according to constructivism are inevitably shaped by the researchers' values, are created by the researcher as the investigation proceeds (Guba & Lincoln,

1994). Lastly, constructivism's methodology is both hermeneutical (i.e. findings are achieved by interpreting individuals' constructions) and dialectical (i.e. findings are achieved by seeking opposing constructions). Thus, with the assumption that, through interactions with others, individuals develop diverse, subjective meanings of their experiences, researchers with a constructivist paradigm seek to interpret the meanings others have about the world and "look for the complexity of views rather than narrowing meanings into a few categories or ideas" (Creswell, 2009, p. 8). The aim of a study guided by constructivism is to understand and reconstruct people's constructions of reality so as to become "aware of the content and meaning of competing constructions" and to appreciate these tensions (Guba & Lincoln, 1994, p. 113).

Researchers have explained that, given its assumptions, the constructivist paradigm supports the pursuit of qualitative research (Creswell, 2009; Florczak, 2013).Weaver and Olson (2006) explained that nursing research conducted within the constructivist paradigm involves "qualitative methods to gain in depth and detailed description, understanding and explanation of ordinary occurrences as experienced by those in the field" (p. 464). Qualitative research positioned in constructivism seeks "practical knowledge to help understand or change the social world" (Weaver & Olson, 2006, p. 462). As Creswell (2009) summarized, those who engage in qualitative research "support a way of looking at research that honours an inductive style, a focus on individual meaning, and the importance of rendering the complexity of a situation" (p. 22).

Thus, given my constructivist worldview, I believe there is no single "truth" to uncover, that individuals' social contexts, goals and perspectives affect their experiences, that experiences are diverse, and that existing qualitative research has been influenced by researchers' values and views (and that mine influence this study). The ways in which these beliefs influenced my undertaking of this study will be described in more detail throughout the rest of this chapter.

Study Design: Metasynthesis

Thorne and colleagues (2004) have defined metasynthesis as "a family of methodological approaches to developing new knowledge based on rigorous analysis of existing qualitative research findings" (p. 2). Metasynthesis seeks to synthesize what exists within a group of qualitative studies into a coherent product that is "fundamentally different from the original parts" (Thorne et al., 2004, p. 2).The ultimate goal of metasynthesis is to push qualitative scholarship beyond what was possible for each original researcher, for the purpose of revealing a new, "comprehensive and integrated understanding" of the phenomenon (Thorne, 2017, p. 4). By bringing existing qualitative research together, metasynthesis does not seek to summarize, or to uncover a single truth but to develop "ideas that will enlighten, enrich, elaborate, and enhance the understandings with which one approaches real-life problems in the health arena" (Thorne, 2019, p. 4). The outcome of a metasynthesis would thus be a fuller understanding of the phenomenon under study, not a consensual worldview or "the truth" (Thorne et al., 2004).

Scholars have offered much guidance as to how to conduct a metasynthesis – often in terms of what not to do or what it is not. Authors have explained that a metasynthesis is different than secondary research (Sandelowski et al., 1997) and that it is "something inherently different from a glorified literature review" (Thorne et al., 2004, p. 4). Recurrently, authors have also fervently explained that a metasynthesis should not resemble a metasummary or meta-analysis, wherein findings are aggregated or summarized (Bergdahl, 2019; Florczak, 2013; Thorne et al., 2004; Sandelowski et al., 1997). Metasummaries "reflect a quantitative logic: to discern the frequency of each finding" (Thorne et al., 2004, p. 17) and meta-analyses seek to average or reduce findings to a "common metric" (Sandelowski et al., 1997). In contrast to these, metasyntheses are interpretive and seek not to reduce or count findings, but to understand

differences as well as commonalities between studies (Bergdahl, 2019) and to build larger narratives, or theories from the articles they include (Sandelowski et al., 1997). Consequently, the novel interpretation of study findings (i.e. the larger narrative) that a metasynthesis offers would not be found in any one study included, but rather in the sample as a whole (Thorne et al., 2004).

Authors often ardently advocated to avoid aggregation of findings within a metasynthesis, and to perform interpretation instead, because of the nature of qualitative research, and because of the consequences aggregation would have on the product and on qualitative research as a whole. Recognizing that aggregation would involve summarizing individual articles with a few words, Thorne (2017) has called it a "problematic assumption" and "mistaken notion" to expect that "textual 'sound bites' reflective of themes found with some frequency across a data set" can effectively and reasonably represent the "complex and dynamic conceptualization" that is a qualitative study (p. 5). Similarly, Sandelowski and colleagues' (1997) have warned; "like a poem, a novel, or a painting, even one qualitative study cannot be summarized" (p. 366). Authors have also warned that attempting to summarize qualitative studies would likely exclude important contextual information, such as environmental information and authors' theoretical assumptions (Florczak, 2013; Sandelowski et al., 1997). As well, Bergdahl (2019) described that meta-aggregation "is not compatible with the qualitative research philosophy" (p. 1) because it tends to discourage creativity and critical thinking. Thorne (2017) has explained that aggregation of findings within a metasynthesis would also compromise "both our understanding of the phenomenon in question and also the credibility of the qualitative genre to advance knowledge in a meaningful manner" as it sends the message that qualitative studies should be treated quantitatively (p. 4).

Thus, as Sandelowski and colleagues (1997) have explained, a quality metasynthesis requires "carefully peeling away the surface layers of studies to find their hearts and souls in a way that does the least damage to them" (p. 370). These authors have also reminded us that, as we attempt to avoid aggregation and damage to qualitative articles, and attempt to account for all of the "wealth of information contained in a qualitative research report" (p. 368), researchers must also take care to produce a synthesized product that is usable. They wrote; "synthesists must analyze studies in sufficient detail to preserve the integrity of each study and yet not become so immersed in detail that no usable synthesis is produced" (Sandelowski et al., 1997, p. 370).

Despite these potential challenges, Sandelowski and colleagues (1997) have explained that a metasynthesis is invaluable when there is accumulating qualitative research on a topic, as a metasynthesis would allow a researcher to bring the knowledge together into a synthesized product and, as a result, gain a better understanding of said knowledge (and the topic). In fact, integrating accumulating, existing qualitative research on a topic by undertaking a metasynthesis has been called a "responsibility" by scholars (Thorne et al., 2004). Sandelowski and colleagues (1997) have explained that a failure to link existing qualitative studies would "endanger" qualitative research and would "relegate the findings of individual studies to 'little islands of knowledge,' separated from each other and doomed ultimately never to be visited" (p. 367).

Together, the above points to why I have chosen to complete a metasynthesis of qualitative research (rather than a synthesis that includes quantitative research). Firstly, I hoped to gain a better understanding of patients' and families' lived experiences of making decisions about potentially life-sustaining treatments at end of life, which is found in qualitative research and requires a metasynthesis. Second, my worldview (constructivism) is in line with the

assumptions that qualitative research and metasyntheses hold – that there is no singular truth to uncover, that authors' values influence their research, and that healthcare phenomena are complex and cannot be explained in simple, reductionist ways. Furthermore, there is an accumulation of qualitative studies on this topic, and thus, a metasynthesis of relevant inquiries is merited.

To note, although metasyntheses about this topic have previously been conducted, they have only included decisions to withhold or withdraw potentially life-sustaining treatment, focused only on family perspectives, or only acute care environments (Leung et al., 2017; Meeker & Jezewski, 2008). Though these are valuable perspectives, my inclusion criteria were broader than this, as I will explain below. My metasynthesis is also unique in its use of a relational ethics lens. Thus, I compared my metasynthesis to other metasyntheses on this topic to identify the gap that my research is responding to (as explained here). I also considered how my findings compared to the results of these metasyntheses (this will be included in Chapter 5).

Search and Sampling Strategies

The databases CINAHL and Medline were systematically searched by combining keywords with database specific subject headings (see Appendix A) for four main topics: 1. decision-making, 2. terminal care, 3. patient, family or surrogate decision maker and 4. qualitative studies. The titles and abstracts of the yielded citations were screened and articles that met these inclusion criteria were selected for full-text review: 1) reported qualitative research in English or French, 2) primarily focused on decisions about potentially life-sustaining treatment (including, but not limited to artificial hydration, artificial nutrition, artificial ventilation, CPR, dialysis, chemotherapy, antibiotics, surgeries) for patients at end of life, as defined in Chapter 1 and 3) reported data on patients' and/or their families' (or surrogate decision makers, if articles

used this term) lived experiences of making these decisions, from their perspectives. In this sampling process, no restrictions for age of participants and context/setting of studies were applied. Articles that also included healthcare professionals as participants were not excluded unless their views comprised the majority of the study's findings (any data about healthcare professionals' experiences was not included in the analysis or results in Chapter 4). During full-text review, these same inclusion criteria applied and, additionally, any articles that were based on hypothetical situations or that did not explicitly mention that the decision under study was about any potentially life-sustaining treatments were excluded. Additionally, previously conducted metasyntheses about this topic were not included given the distance this would create from the primary data, which would be subject to three authors' analysis and influence.

In general, exhaustive sampling (i.e. finding and including every pertinent study) has been discouraged for qualitative metasyntheses for two main reasons. Firstly, a large sample size would necessitate a superficial synthesis or summary of the qualitative articles included, which, as described above, many scholars have (strongly) advised against. Sandelowski and colleagues (1997) have explained; "as in any kind of qualitative research, overly large sample sizes tend to impede deep analysis and, therefore, threaten the interpretive validity of findings" (p. 368). Secondly, as Thorne and colleagues (2004) have explained, the goal of a metasynthesis is not to discover "the truth" but rather, enriched understandings of the phenomenon under study. Therefore, unlike quantitative systematic reviews where exhaustive sampling may be useful to limit selection bias or maximize the power of findings and thus help identify the truth, the quality of qualitative metasyntheses is not dependent on exhaustive sampling (Benoot et al., 2016; Booth, 2001; Sandelowski et al., 1997).

Many authors have suggested purposeful sampling as a solution, to avoid superficially synthesizing or summarizing articles included in a metasynthesis (Booth, 2001; Sandelowski et al, 1997; Suri, 2011). Sandelowski and colleagues (1997) have recommended using a purposeful sampling strategy when "more than 10 topically similar studies" are found (which was very much the case in my study). To select which purposeful sampling strategies should be employed, take Patton's (2002) statement that "the logic and power of purposeful sampling lie in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance" (as cited by Suri, 2011, p. 3). Authors have also suggested that finding differences, rather than similarities between qualitative studies is most valuable when undertaking a metasynthesis (Booth, 2001; Thorne et al., 2004; Thorne, 2017). In his commentary on the use of systemic review strategies in qualitative research, Booth (2001) explained that further occurrences of a pattern already uncovered "are only of interest in strictly quantitative terms, unless they expand on or modify an already identified theme" (p. 5) and thus, identifying varied or disconfirming cases is what is particularly important.

Thus, rather than perform exhaustive sampling, I purposefully sampled the articles included in this metasynthesis, after applying inclusion/exclusion criteria to the titles, abstracts and full-texts of my search results. Given the emphasis on finding information-rich cases, and varied, dissimilar cases, I adopted the sampling strategies employed by Benoot and colleagues (2016): a combination of intensity sampling, maximum variation sampling and disconfirming case sampling. These authors operationalized intensity sampling as choosing articles whose research question overlapped with the question of their metasynthesis (Benoot et al, 2016). Thus, I purposefully included articles whose research questions (either in study purpose or data collection) significantly aligned with mine (e.g. how do relationships impact patients and/or

families' lived experiences of making decisions about potentially life-sustaining treatments at end of life). Maximum variation sampling involves "identifying key dimensions of variation and then finding cases that vary from each other as much as possible" (Benoot et al., 2016, p. 5). Key dimensions of variation identified and thus used to sample articles were: country of origin, setting (e.g. critical care, acute care, long term care, or community), type of potentially life-sustaining treatment (e.g. withdrawing, withholding or pursuing artificial ventilation, artificial nutrition and hydration, chemotherapy, dialysis, resuscitation, etc.), timing of the decision (e.g. ACP, during a health crisis, when death is imminent) and patient population (e.g. patients, families, adults, adolescents, paediatrics, patients with advanced cancer, kidney disease, neurological disorders, etc.). Lastly, disconfirming case sampling entails including articles "that do not fit the emerging patterns" which was operationalized as selecting articles that offered a unique or contrasting perspective or insight, or challenged emerging notions and patterns. For example, as will be explained below, the article by Wilson (1993) was included given its unique focus on a decision to pursue potentially life-sustaining treatment. As is common in qualitative research, my sampling and analysis occurred concurrently so as to ensure disconfirming cases were included. I used these three purposeful sampling techniques, in combination to obtain my final sample of articles that were analysed. For instance, when two articles were similar in terms of sample or setting, I assessed which article had richer data, studied a decision or context not yet included, or offered a unique or contrasting view. Sampling stopped when prevalent patterns became apparent and any new articles only offered a repetition of ideas already articulated in included articles and/or did not further my understanding of the topic. A description of the final sample of articles is included in Chapter 4.

Despite the focus on acute care in Chapter 2, I chose not to restrict the context/setting of the studies included in this metasynthesis, and instead chose a wide variety of contexts/settings for two main reasons. First, as noted above, a metasynthesis encourages finding and considering the differences between qualitative studies on a topic (Thorne et al., 2004; Thorne, 2017). Second, and as I alluded to in Chapter 1, working in palliative care has shown me that the dynamics and patterns described in Chapter 2 also occur in settings where treatment is less obviously potentially life-sustaining. Indeed, studies confirm that these decisions, and the difficulties associated with them, occur in many different settings, such as nursing homes and the community (Chiang et al., 2021; Gjerberg et al., 2015; Lamahewa et al., 2018).

Quality Appraisal

In metasynthesis, it is also important to appraise the quality of research reports but, as Paterson and colleagues (2001) explain; "inclusion should not be restricted on the basis of the scientific merit of the research since such judgements will eliminate data that might have been useful for the purpose of the metasynthesis" (p. 42). Therefore, I considered the approach of Elmore and colleagues (2018) wherein only studies that were fatally flawed would be excluded. This means, only papers with unclear study aims or research designs, unclear or lacking accounts of how findings were produced, insufficient data to substantiate interpretations, or inadequate explanation of methods or analysis would be excluded on the basis of quality (Elmore et al., 2018). In the end though, because studies were purposefully sampled based on richness of data (i.e. intensity sampling), assessing for quality was woven throughout my sampling process, and thus, none of the studies I wished to include were fatally flawed. As Benoot and colleagues (2016) explain, articles containing richer data are more likely to be higher in quality.

Data Collection and Analysis

My collection and analysis of data was guided by an approach to data collection and analysis for metasynthesis called meta-study, which was first described in health sciences by Paterson and colleagues (2001). Meta-study encourages breaking down each article included in a metasynthesis, and analysing the studies' components (methods, theory and analysis) before synthesizing the data collected/analysed into a coherent whole. Rooted in constructivism, this approach aims to understand "how individuals construct and reconstruct knowledge about a phenomenon" (Paterson et al., 2001, p. 6). I chose to conduct a metasynthesis guided by meta-study because of its link to constructivism, and the fact that it seems to respond to authors' warnings about metasynthesis described above. Meta-study seeks to "carefully peel away the surface layers of studies," maintain the integrity of each article, and include all of an article's information in analysis. Meta-study is also intentional in its analysis of theory and authors' influence on knowledge generation which was appealing to me given my study aim of assessing how theory and authors' values have impacted studying this phenomenon.

Meta-study suggests three components of data collection and analysis which are frequently conducted concurrently: analysis of methods, theory and data analysis (Paterson et al., 2001). Analysis of methods is analysing the epistemological soundness of methods used in research studies. As Paterson and colleagues (2001) have explained, the intent of this appraisal "is not to critique the quality of individual studies, but rather to consider how the methodology that has been applied to the study of a phenomenon has shaped current understandings about it" (p. 72). Analysis of theory is analyzing the implications of the theoretical orientations of primary studies (i.e. theories used, both explicitly and implicitly, and the theories generated by the study) which "offers a systematic means of understanding and evaluating the theory that drives and arises from qualitative research" (Paterson et al., 2001, p. 92). Lastly, analysis of data analysis is

an analysis of primary qualitative research reports' processed data, which involves critically examining "multiple accounts of a phenomenon in order to reveal the similarities and discrepancies among accounts" and is meant to be interpretive rather than aggregative (Paterson et al., 2001, p. 10).

Based on these guidelines, and on recommendations from my thesis supervisor and thesis advisory committee, I developed analytical questions which guided my reading and analysis of the articles included in this study (see Appendix B). In the analysis of each component (method, theory, data analysis), I considered how authors accounted for the impact of/on relationships and how healthcare philosophies came into play. Additionally, I included an analytical question about relationships to prompt myself to more deeply deliberate the influence of relationships within each article. As I re-read articles that were likely to be included (based on my inclusion/exclusion criteria and sampling methods), I took detailed notes using these analytical questions. As metasynthesis scholars encourage, I attempted to account for all of the information within an article as I answered my analytical questions.

Analysis of methods entailed looking at how authors collected their data (Paterson et al., 2001). This involved considering the types of questions authors asked in their introductions and during data collection, and how they accounted for the impact of relationships in their recruitment and data collection. For instance, I considered whether authors chose to include more than one person within each interview, because I consider including more than one person per interview as recognition of the impact of relationships. The intention was not to determine causal associations (e.g. including one person in interviews leads to certain findings) but rather to explore tendencies. This component of analysis also offered an opportunity to reflect on how the environment and context of the study may have influenced patients and families' experiences.

Analysis of theory involved asking questions about the theory that influenced the study (or, seemed to influence, as many authors did not explicitly describe a theoretical framework) or what theory was generated (Paterson et al., 2001). Given that many authors were not explicit about their use of theory, I used Paterson and colleagues' (2001) recommendations to look at the types of studies the authors cited and the type of language they used throughout their article to assess theory. As well, given my intention to assess how healthcare philosophies influenced authors' study and portrayal of this phenomenon, when no theory was explicitly mentioned, I assessed which of these (if any) seemed to be present, and how and where they occurred. I grouped similar manifestations of theory together to observe and develop patterns.

Analysis of data analysis involved taking detailed notes of each article's processed data (i.e. their findings) followed by comparing and contrasting each article's main ideas in order to construct a coherent whole (Paterson et al., 2001). Paterson and colleagues (2001) explained that analyzing articles' data analyses involves considering, but not being restricted to the themes that authors chose to label their findings with. As with the other components of data collection and analysis, this component involved critically reading articles to consider what authors said at face value, but also to reflect on what the underlying idea was; to go "beyond the words."

Analysis of data analysis (i.e. analysis and synthesis of study findings) contributed significantly to addressing my first study aim; to understand the relational ethical dimensions of patients and families' experiences of making decisions about potentially life-sustaining treatments at end of life. Analysis of methods and analysis of theory on the other hand contributed significantly to addressing my second study aim; to explore how healthcare philosophies have impacted authors' description, study and analysis of patients and families' experiences. The findings from this analysis were organized thematically, into five themes which

will be described in Chapter 4. The fifth theme, *Normative Discourses*, represents the results of my analysis of methods and theory. To note, within my description of that theme, my tone shifts to a more critically reflexive one about authors' writing, and the values therein.

After analysing a subsample of articles that met my inclusion/exclusion and sampling criteria, emerging patterns and recurring ideas were organized. I worked closely with my thesis supervisor to develop these ideas further, conceptually. My sample of included articles, as well as the detailed notes taken with my analytical questions were read and re-read. Concept maps were developed to visualize and "make sense" of the data and to build the larger narrative that a metasynthesis calls for. Similar ideas were grouped together and opposing ideas added depth and nuance. As analysis ensued, purposeful sampling continued so as to develop and expand on the emerging narrative. Eventually, when new articles did not add to my understanding or build on the narrative further, sampling and analysis ceased.

Rigor

Paterson and colleagues (2001) have explained that metasyntheses must also attend to principles of rigor to ensure that the research findings are considered credible and trustworthy which is determined by neutrality, truth value, applicability, and consistency. Neutrality refers to "freedom from bias" in both the process and outcome (Paterson et al., 2001). By this, Paterson and colleagues (2001) seem to imply that researchers performing a metasynthesis should account for their bias and its influence. The use of disconfirming case sampling helped ensure my own values and biases did not unduly influence this study, as I intentionally sought to include articles that I disagreed with or opposed my views, both existent and evolving, on the topic. As well, to remind the reader of my presence and influence in the study process, I employed the first-person voice throughout this thesis.

Truth value involves "presenting data that resides in the primary research reports, rather than in prior conceptions of the researcher" (Paterson et al., 2001, p. 51). To ensure truth value, I frequently returned to the original articles during analysis and writing to assert that the citations I included remained true to the original context. Both truth value and neutrality can be achieved by reflexive journaling, which allows for awareness of the researcher's values and biases, not so they can be excluded, but to ensure that they do not mislead readers (Polit & Beck, 2017). Therefore, I engaged in reflexivity throughout this study, to remain aware of my values and biases. For example, if I felt an emotional reaction to something I read, I journaled about it and reflected on what it was that initiated my reaction (e.g. what value, belief or possible bias). This was not so my feelings could be excluded from the process, but rather was a means to remain aware of their impact, and reflect on what it was that I believed about this topic.

Applicability refers to whether there is consistency between the metasynthesis conclusions and the contexts the results may apply to (Paterson et al., 2001). These authors suggested that "those most intimately connected to the field" are the "arbiters of applicability" (Paterson et al., 2001, p. 52). Thus, by working with my thesis advisory committee and thesis supervisor who specialize in decision making, end of life and palliative care and relational ethics, I tended to the applicability of my study.

Lastly, consistency "relates to the degree to which the conclusions follow logically from the research processes and analytic steps" (Paterson et al., 2001, p. 52). As these authors have described, keeping a trail of the decisions made throughout the process of the study can foster consistency. Thus, I kept note of the decisions I made so as to be able to include and explain them in this thesis. As well, I worked closely with my thesis supervisor and sought the insight of

my thesis advisory committee to ensure that the findings of my study flowed logically from my research process and analysis.

Ethical Considerations

Research ethics approval is not required for synthesis of previously published literature.

Chapter 4: Findings

Search results

The search of electronic databases (Medline & CINAHL) yielded 3040 results. After abstract and title review, 169 articles remained and from these, 19 articles were purposefully chosen and included in this analysis. As described in Chapter 3, articles were chosen using a combination of intensity sampling, maximum variation sampling and disconfirming case sampling. Descriptions of the articles included in this analysis are detailed in Table 1 (see below). The narrative nature of these descriptions is intentional and is an attempt to avoid the break down or 'quantitative' treatment of qualitative studies that metasynthesis scholars discourage. Authors' disciplines include nursing, medicine, public health, psychology, occupational therapy, social work, social policy and medical/clinical ethics. Countries of origin include the United States of America (USA) (6), Canada (2), Australia (2), Norway, Netherlands, Spain, France, Ireland, Singapore, Taiwan, Japan and Kenya. The setting of the selected articles ranged from intensive care units (6), other hospital settings (4), nursing homes (3), community/home (4), and low resource settings (2) – including an American Indian reservation (Colclough et al, 2014) and Sub-Saharan Africa (Githaiga et al, 2017). The final sample of articles studied experiences of decisions to pursue, withhold or withdraw surgeries, artificial ventilation, artificial nutrition, dialysis, resuscitation, transfer to hospital, cancer treatments (chemotherapy, radiotherapy), antibiotics, pacemaker deactivation, and others (described as life support or life-sustaining treatment more generally by authors). The populations studied and views represented in the chosen articles include patient experiences and family, caregiver or surrogate decision maker experiences (with 3 studies including healthcare professional views). The family member(s) interviewed in the selected studies had diverse relations to the patients

they cared or made decisions for including parent/step-parent, spouse/partner (ex, current or "unofficial"), child, sibling, niece/nephew, grandchild, and friend. Five of the included articles studied this phenomenon in the paediatric population; most explored parent views (n=4) and one explored patient views (adolescent/young adult patients). Lastly, the diagnoses of the populations studied included advanced cancers, terminal or fatal neurologic conditions (advanced Huntington's, ALS, dementia, severe traumatic brain injury), respiratory issues (respiratory failure, anoxia), end-stage kidney disease, circulatory conditions (cardiac failure, cardiovascular disease, stroke), fatal infections, children with medical complexity, and other life-threatening illnesses (named more generally by authors). To note, despite its date, Wilson (1993) was included for two main reasons; 1. it is unique in its explicit and clear focus on a decision to pursue life-sustaining treatment (other studies included participants who decided to pursue treatment, but their stories were not apparent in the studies' findings), and 2. it provided insight on quality of life and personhood that studies conducted more recently did not offer.

Themes

The experience of deciding whether or not to pursue potentially life-sustaining treatments at the end of life is a very individual experience. However, this metasynthesis revealed the following four themes, which describe how these decisions impact and are impacted by relationships, and healthcare philosophies: "*Closeness in Relationships," "Identity and Quality of life in Relationships," "Reliance on Relationships,"* and *"Sense of Responsibility."*This chapter concludes with a fifth theme "*Normative Discourses"* which highlights the ways in which normative discourses (of objectivity, autonomy and false hope) were present in authors' writing. In this chapter I will detail each of these overarching themes and the ways in which they are connected to each other, where relevant. Patients and families longed for close, meaningful

Table 1. Summary of Articles Included

	Authors (year)	Authors' discipline	Study description
1.	Wilson (1993)	Nursing	Performed in Canada, this case study sought to investigate why the daughter of a woman who lived in a nursing home with advanced Huntington's decided to pursue tube feeding for her "incompetent and severely debilitated mother." This study uniquely shares the experience of an individual who chose to pursue potentially life-sustaining treatment at end of life. This report also offers unique insight into how quality of life and personhood can exist and remain intact despite advanced neurological illness.
2.	Long et al. (2011)	Nursing	Performed in a tertiary hospital in the USA, this study sought to uncover how "surrogate decision makers" (10) (parents, children, spouses) of patients with severe traumatic brain injury decided to withdraw or continue life support (surgeries, tracheotomy, feeding tube, transfer to hospital, palliative care) and whether the healthcare team could have been of greater help. These authors interviewed 5 family members who chose to withdraw treatment and 5 who chose to pursue. This study offered insight as to the internal/external resources families relied on during decision making, and how families' relationships with physicians and nurses impacted their experience.
3.	Lind et al. (2012)	Nursing	Performed in an ICU in Norway, this study sought to explore how family members (27) (spouses, children, parents, siblings) of patients who died in the ICU after a decision to withhold/withdraw ICU treatment experienced the nurses' role in the decision making process. This study offered much insight as to how nurses' relational approaches (in particular, their vagueness and distance) impacted families' decision making experiences.
4.	Schenker et al. (2012)	Medicine, public health	Performed in an ICU in the USA, this study sought to uncover "key intrapersonal tensions" experienced by "surrogate decision makers" (30) (spouses, children, parents, siblings, friends) of patients in the ICU and explore their coping strategies. These patients had suffered from respiratory failure, cardiac failure or shock, and neurologic failure and the family members made decisions about "life sustaining treatments." This study offered insight as to how conflicting responsibilities (e.g. to respect patients' wishes, to protect well-being, to pursue any chance of recovery and not be responsible for their loved one's death) could lead to distress. This report also offered insight as to how previous conversations and relying on others could alleviate some of this distress.

5.	Seah et al. (2013)	Medicine, psychology,	Performed in the community setting in Singapore, this study sought to understand why patients (9) with end stage kidney disease had decided to forego dialysis, as well as explore their experience with conservative non-dialytic management. As one of the few studies that explored patient experiences, this report offered much insight about the ways in which patients considered the burden to their families (financially and temporally) when making treatment decisions. It also offered insight as to how age and relationships can impact identity and quality of life.
6.	Liu et al. (2014)	Nursing, medicine	Performed in a PICU in Taiwan, this study sought to explore parents' (16) experiences of making a DNR decision for their child in the PICU. Their children (11) suffered from cardiac disease, cancer, rare diseases and complicated viral infections. One of the few studies that focused explicitly (and noticeably in its findings) on the experience of completing a DNR form, this report offered much insight as to the conflict parents experienced in wanting to protect their children from harm but also wanting to protect them from death.
7.	Foley et al. (2014)	Occupational therapy, social policy, medicine	Performed in the community in Ireland, this study sought to "illuminate how key components of the life course" shape how people with ALS (34) respond to impending mortality and made decisions about their healthcare (home care and artificial ventilation).Having explored the views of patients with an advanced neurological illness, this study offered much insight as to how patients considered their families in their decision making process and how their relationships (particularly, their reliance on relationships) contributed to patients' identity and quality of life.
8.	Colclough et al. (2014)	Nursing	Performed in an American Indian tribe living on a reservation in the USA, this study sought to identify the "tribal values" and factors that influenced bereaved family members (37), family members currently caring for patients (17) and patients' (10) end of life decisions (about cancer treatments, dialysis, intubation, transfer to another facility) in order to develop a "culturally congruent" hospice intervention. One of the few studies conducted in a resource limited setting, this report offered insight as to how differences in values can impact patients and families' relationships with healthcare professionals and by extension their decision making experiences.
9.	Zaal-Schuller et al. (2016)	Medicine, medical ethics	Performed in a PICU in the Netherlands, this study sought to explore the experiences of parents (17) and the involved physician (11) of making end of life decisions (withholding/withdrawing mechanical ventilation, tube feeding, dialysis) for children with profound intellectual and multiple disabilities who also had life-threatening illnesses. Included in part because of the unique population it studied (parents of children with profound intellectual and multiple disabilities), this report offered insight as to how relationships with physicians impacted parents' decision making experiences (e.g. long standing relationships were preferred, previous negative encounters negatively impacted relationships).

10.	Sarabia-Cobo (2016)	Nursing	Performed in a long term care nursing home in Spain, this study sought to describe how family members (84) (spouses, children, siblings, nieces, grandchildren) of patients with advanced dementia (who lived in the nursing home) made decisions about treatments at end of life (resuscitation, hospitalization, artificial feeding and "treatments that do not have a clear benefit in the final stage of life"). This study offered much insight as to how relationships (or loss thereof with advanced dementia) impacted identity and perceived quality of life.
11.	Fournier et al. (2017)	Clinical ethics	Performed in a NICU in France, this study sought to explore how parents (14) and healthcare professionals (41) experienced and viewed the process of withdrawing artificial hydration and nutrition from newborns with multiple diagnoses (extreme prematurity, perinatal anoxia, infection, ischemia/stroke, polymalformative syndrome). The authors also had discussions with expert professionals (9). Included in part because of its unique population (parents of newborns), this report offered the unique view that healthcare professionals should control the timing of these newborns' deaths so that death does not seem to have been caused by the decision to withdraw treatment.
12.	Githaiga et al. (2017)	Psychology	Performed in the community setting in Kenya, this study sought to examine the "content and context" of end of life conversations and decisions (about DNR and other "end of life decisions") from the view of women family caregivers (13) of patients with advanced cancer. One of the few studies conducted in a resource limited setting, this report offered much insight as to why and how families preferred to discuss and make these treatment decisions.
13.	Romo et al. (2017)	Nursing, medicine, ethics	Performed in the community in the USA, this study sought to explore how older adults (20) with a prognosis of less than 1 year made healthcare decisions (about potentially life-sustaining treatments such as surgery, life support, ventilation) and the process they used when they were not in an acute health crisis. Included in part because of the unique population it studied (patients not in a health crisis), this report offered insight as to how being able to rely on someone they trusted impacted patients' experiences.
14.	Sellars et al. (2018)	Psychology, medicine, nursing	Performed in the community setting in Australia, this study sought to describe the perspectives and attitudes of patients (24) with end stage renal disease and their caregivers (15) (family or friends responsible for providing ongoing and informal care for the patient) about ACP (which included decisions about "future care" and dialysis). Participants had either not started, begun or completed ACP. The goal was to optimize the content and delivery of ACP for this population. This study offered much insight as to how patients considered their familial relationships when making decisions (burden, their wishes) as well as the impact relationships with healthcare professionals had.
15.	Norton et al. (2019)	Nursing, medicine	Performed in "multiple centers" in the USA, this study sought to describe the perspectives of family caregivers (92) (family, partner, friend, or someone involved in the patient's care) of the final month of life of patients with

			advanced cancer with a particular focus on whether and how chemotherapy was discontinued and the effect this decision had on family caregivers' perceptions of the patient's end of life care. This report offered much insight as to how healthcare professionals' relational approaches (open or distant) impacted families' experiences and decisions.
16.	Maura et al. (2019)	Nursing, medicine	Performed in multiple settings (home, nursing home and hospital) in Japan, this study sought to understand the experiences of caregivers (4 children) who wanted to refuse "life-prolonging treatment" (including surgeries, pacemakers, and artificial nutrition/hydration) for their elderly parents with advanced dementia. Included in part because of its unique context (families wanting to refuse treatment but healthcare professionals insisting on continuing treatment), this study offered much insight as to how interactions with physicians (particularly, what they said) impacted families' experiences and decisions.
17.	Needle et al. (2020)	Nursing, medicine	Performed in a paediatric hospital in the USA, this study sought to explore what influenced adolescents/young adults (10) aged 14-27 who were receiving bone marrow transplant for relapsed/high risk malignancies, hematologic disorders or immunodeficiency in their decision making for future care. Participants were asked if they were unsure, would continue or discontinue treatment in 4 end of life scenarios. Included in large part because of the unique population it studied (adolescent/young adult patients), this report offered insight as to how these patients considered their families when making decisions (e.g. their families' wishes and well-being), and how relationships impacted their identity and quality of life.
18.	Lord et al. (2020)	Medicine, social work	Performed in a tertiary care paediatric center in Canada, this study sought to explore bereaved family caregivers' (13 parents) experiences of completing ACP (including DNR orders, transitions to palliative care) of children with medical complexity (complex chronic diseases requiring specialized care and having functional disability). Included in part due to the unique population it studied (parents of children with medical complexity), this report offered insight as to the importance and impact of longstanding relationships with healthcare professionals.
19.	Moon et al. (2021)	Social work	Performed on the general medicine unit of a large public hospital in Australia, this study sought to explore bereaved family members' (28) experiences of making decisions (about antibiotics, surgery, dialysis) for patients (24) admitted to general medicine at end of life (with cancer, pneumonia, other infection, organ failure, cerebrovascular event, neuro disease, cardiovascular disease). Included in part because of its unique setting (inpatient unit other than an ICU), this study offered much insight as to how healthcare professionals' relational approaches (inclusive or distant) could impact families' distress and decision making experiences.

relationships with each other and with healthcare professionals. These types of interactions led to feeling supported, connected and contributed to an enduring sense of identity and quality of life among patients. Closeness to healthcare professionals affected patients and families access to, and comprehension of medical information. Indeed, decision makers relied on healthcare professionals for support and for clear (and sensitive) information about patients' treatment options and prognosis; the reception of which was facilitated by closeness in these relationships. Lastly, when making decisions about potentially life-sustaining treatment at end of life, patients and families experienced a sense of responsibility to consider the wishes and well-being of persons that they had a close relationship with and who relied on them (e.g. their children).

Closeness in Relationships: "Only the cold equipment surrounded her"[6]

The patients and families' physical and relational closeness to each other, to healthcare professionals and other family members impacted their experiences of making decisions about potentially life-sustaining treatment at end of life. Presence, empathy and honesty were essential to develop trust and closeness in these relationships. Closeness to others (or lack thereof) impacted patients and families' well-being, as well as their access to information and care, with closeness generally having a positive impact and distance generally having a negative impact on their experiences. Overall, patients and families appreciated and longed for "closeness in relationships."

Relational Closeness. In general, individuals with a close relationship to the patient (e.g. spouse, child, or sibling) were expected to act as surrogate decision makers when patients were unable to make their own decisions. These individuals were often considered suitable surrogate decision makers *because* of their relational closeness to the patient. When the daughter in

[6] Liu et al, 2014, p. 33.

Wilson's (1993) article sought advice from her family, rather than oblige, they referred to her closeness to her mother and said "*I'm sure you can make the best decision for her"* (p. 305). Family decision makers were inclined to agree with this notion, and considered that the advice from "*persons who knew the patients and their families well,*" whether it be other family members or friends, "*represented their parents' thoughts"* (Maura et al., 2019, p. 6). Similarly, almost all of the parents in Zaal-Schuller and colleagues' (2016) study felt they were "*the right person*" to make the final decision about potentially life-sustaining treatment for their child because "*these were decisions concerning their own child"* (p. 289). Patients were also comfortable entrusting their treatment decisions to surrogate decision makers that they had a close, trusting relationship with (Romo et al., 2017), with one patient telling their family to "go with their gut" when making treatment decisions (Long et al., 2011). Indeed, families did call on their "*personal knowledge of their loved ones"* (Schenker et al., 2012 p. 1659) when making these decisions. However, as Wilson (1993) found, "*tube feeding was a topic so far removed from ordinary conversation and ordinary life that she [the daughter] could not apply any knowledge of her mother's values to the tube feeding decision"* (p. 304). Therefore, relational closeness on its own was not always enough to guide families in their decision making.

Honesty, Empathy and Trust. Continually, patients and families preferred to engage in decisions about potentially life-sustaining treatment with healthcare professionals they were relationally close to, who knew the patient, and whom they trusted;

> *"The majority of children had a long-lasting treatment relationship with a certain physician, and parents mentioned that they strongly preferred to start the end of life decision making process with that physician. Parents believed that physician was more capable of giving tailored advice"* (Zaal-Schuller et al., 2016, p. 287).

As will be described below, relational closeness to healthcare professionals was impacted by physical closeness (or, physical presence), but, more frequently, closeness in these relationships was significantly impacted by healthcare professionals' relational approach; by their (dis)honesty and (lack of) empathy. There was a tendency for healthcare professionals to withhold information from patients and families at end of life, often in an attempt to protect their hope and well-being. However, rather than be protective as intended, this lack of honesty broke down trust, and negatively impacted relational closeness and patients and families' experiences. As Lind and colleagues (2012) explain; "*from a relational ethics perspective, the lack of transparency threatens to break down trust*" (p. 673). When honest explanations were lacking, families were left to draw their own conclusions about patients' deterioration and, sometimes attributed it to "*inadequate medical treatment*"; "*When families lacked appropriate and transparent explanation of deterioration, suspicion of medical negligence arose"* (Moon et al., 2021, p. 6). What is more, when no open, explicit conversations about end of life occurred, patients and families could tell that healthcare professionals were keeping information from them, which led to feelings of mistrust; "*mistrust, deception and betrayal were common themes: 'I know they (oncologist) knew more (about) how bad she was than they actually told us'"* (Norton et al., 2019, p. 673). Similarly, in Lind and colleagues' (2012) study, the nurses' "*evasiveness*" and "*vagueness*" led to feelings of being lied to;

> "*They were always doing tests. But the nurses just answered that they didn't know, that they hadn't heard anything. But we knew they'd heard something. When they took tests, they got results! I felt they didn't want to say anything"* (p. 670).

This quote reveals that honesty is not only crucial for relational proximity but also for access to information about the patient's health. Notwithstanding the nurses' vagueness in this study, these

authors suggested that nurses' knowledge and close relationships to patients and families make them the "*right person*" to "*encourage open dialogue*" (Lind et al., 2012, p. 673). This is a sentiment shared by patients' families, who desired openness; "*they (the relatives) want nurses to be responsible for moving the dialogue from casual conversation and a focus on measurable details to deeper, more purposeful and meaningful interaction through discussing value-laden topics"* (Lind et al., 2012, p. 673). A family member in Long and colleagues' (2011) study noted how a doctor's open approach benefited their experience and understanding;

> "*I really appreciated his approach, I mean understanding that he is very much a skilled mechanic. But he also had demonstrated some (humanity)…. He let some of his own emotion come out. I think he helped us deal with this is not black and white, it's complex—so let's talk through it. I think that was good*" (p. 209).

Thus, patients and families' experiences making decisions about potentially life-sustaining treatment at end of life were impacted by the openness and honesty of healthcare professionals' relational approach.

Despite the importance of openness and honesty, if information or treatment options were presented without empathy, distress often ensued. Across articles, patients and families frequently commented on the importance of an empathetic approach and the impact that lack of empathy had; "*the importance of healthcare professionals expressing compassion above all else was a common theme"* (Lord et al., 2020, p. 5). The use of "*insensitive*" language and the "*blunt delivery of bad news*" without preparation or support afterwards was upsetting to families (Long et al., 2011, p. 208). Similarly, patients and families felt ACP conversations should be initiated sensitively; "*It all happened so quickly and without much sensitivity"* (Sellars et al., 2018, p.

220). In Wilson's (1993) case study, the physician's lack of empathy and distant approach caused the patient's daughter distress;

> *"[The physician] told her that her mother should be left to die as she had already lived for a long time in a very debilitated condition. The daughter related that he was 'very professional sounding' and 'very matter-of-fact." She was distressed by this attitude and approach*" (p. 303).

Empathy (or lack thereof) was also displayed in the way healthcare professionals were (or were not) sensitive to the grandeur of the decision patients and families were being asked to make. A parent said; "*it was just, sometimes it needed a little more compassion and understanding for the fact that, our family is going through this and this is bigger than just, CPR"* (Lord et al., 2020, p. 6). Parents in Liu and colleagues' (2014) study felt similarly, and wished that healthcare professionals would be sensitive to the fact that a decision of this magnitude would take time;

> "*I knew they wanted me to hurry up and sign [the DNR] because his condition was not good, but I felt badly for my child's critical condition. Although the doctor explained his prognosis, I could not listen. […]You should just let me know what to expect and let the parents have time to think. There is no right or wrong decision made by parents and they need more support from health professionals"* (p. 32).

Liu and colleagues (2014) also suggested that the "*unpleasant feelings*" experienced when healthcare professionals lacked empathy could impact parents' understanding of information. In general, "*a delicate balance of honesty and comfort"* was most helpful for patients and families receiving information; "*He was reassuring, but not giving false hope"* (Moon et al., 2021, p. 3). The following quote from a family member summarizes how healthcare professionals' (lack of) empathy could impact families' experiences and understanding;

> *"I don't think [the physicians] understand it takes the family time to absorb things, because even though you're not the one laying in the bed, you're going through it too, at every level … you're all freaked out, and these people are all talking this language that you don't understand"* (Long et al., 2011, p. 209).

Thus, healthcare professionals' use (or lack) of empathy impacted patients and families' experiences making decisions about potentially life-sustaining treatment at end of life.

Together, lack of honesty and empathy, whether in the present or in the past, threatened patients and families' trust in healthcare professionals. All of the parents in Zaal-Schuller and colleagues' (2016) study described previous "*negative healthcare encounters*" which "*had contributed to a critical attitude towards physicians"* (p. 287).These encounters included situations where parents had received conflicting information, or had attributed their child's deterioration to physicians' treatment choices (Zaal-Schuller et al., 2016). On a broader historical scale, lack of empathy rooted in anti-Indigenous discrimination affected trust in the present;

> *"With denial and elimination of the traditional forms of healings and languages by Euro-Americans in the past, American Indians may be suspicious of Euro-American views and practices, including allopathic medicine"* (Colclough et al., 2014, p. 504).

Trust (or lack thereof) in turn affected patients and families' experiences of making decisions about potentially life-sustaining treatment at end of life; "*When high, trust enabled a sense of control by assuring participants that decisions were in the right hands"* (Romo et al., 2017, p. e73). Thus, trust in healthcare professionals (and others) was a "*resource*" which made the decision making experience "*easier*" for patients (Romo et al., 2017, p. e73).

In addition to the above, feeling unheard, disrespected or excluded in the decision making process impacted patients' sense of control (Romo et al., 2017) as well as their relational closeness to healthcare professionals;

> "*They (physicians) don't listen to us. They don't really understand us as native people. They talk down to us because they've seen the drunks go in there on a daily basis, […] they've seen a lot, and they've lumped us all in one category. We are still kind of the low totem pole*" (Colclough et al., 2014, p. 509).

As well, when healthcare professionals were not open to sharing decisions, patients felt "*pressured*" to align their decisions with healthcare professionals' recommendations and began distancing themselves from their physicians; "*There is really nothing to discuss with the doctor. […] all they would do is to encourage me to go on dialysis…*" (Seah et al., 2013, p. 1023). Relational closeness (or lack thereof) also affected patients and families' willingness to rely on healthcare professionals (a notion detailed further in the theme "reliance on relationships" below). Additionally, Lind and colleagues (2012) found;

> "*The conclusion of several participants is that their situation as ICU families was a lonely experience. They longed for proper conversation. […] 'I think in fact I kept myself in check so I wouldn't show my worry and desperation … I really pulled myself together… sitting there… I used up a lot of energy doing that… And there is a bit of support and a bit of… Well, what should I say really? But they (the nurses) are absolute strangers, they don't get close"* (p. 671).

Thus, importantly, with no relational closeness, patients and families were left feeling alone.

Physical Closeness. Recurrently, families longed to be physically close to, and spend time with the patient before they died. Potentially life-sustaining treatments were sometimes

viewed as an opportunity that gave families more time to be with the patient; "*I unwillingly chose central vein feeding, but maybe… it was good that I could spend time with my mother until her death"* (Maura et al., 2019, p. 7). Other times, these treatments were viewed as an obstacle that prevented physical closeness; "*she was young and was isolated from her parents. Only the cold equipment surrounded her. We could not be there and hold her… we were all aching…*" (Liu et al, 2014, p. 33). Once they had decided to withdraw potentially life-sustaining treatments, families were thankful for the chance to be physically closer to their loved one, to be able to say goodbye; "*[Parents] were grateful to have been given a few extra non-medicalized days with their baby, finally free of tubes, monitors, and treatment: 'the time to say goodbye'"* (Fournier et al., 2017, p. 368). For the parents in Liu and colleagues' (2014) study, it was the physical distance from their child (and lack of time to say goodbye) that led to feelings of regret;

> *"They did not regret that they signed the DNR form but regretted not having enough time to say "good-bye" and other loving words to their child and blamed themselves for letting their child stay in the PICU alone during their last moments"* (p. 33).

Nurses involved in patients' care regularly played an important role in creating space for families to be physically close to their loved ones during these final moments;

> *"During the patient's course of treatment, the surrogate had been counselled against touching the patient since his ICP [intracranial pressure] seemed to increase whenever she did so. After the withdrawal of life support, ICP was no longer an issue: 'I just said, I want everybody out of here and I want his bedside (rail) down, because I'm going to touch him,' and then the nurse just kind of let me go. She moved everybody aside and put the side down on the bed and let me just be with him. That's what she did"* (Long et al., 2011, p. 209).

Similarly, the family members in Lind and colleagues' (2012) study treasured nurses' efforts to make them feel welcome and able to be close to their loved ones within the "*busy*" ICU;

> *"It really meant something that the nurses found a way of working where the relatives were welcome to visit the patient as much as possible without feeling that they were getting in the nurses' way. The participants related that being by the bedside, able to see and touch the patient, helped them to come to terms with the situation"* (pp. 669-70).

Conversely, when nurses did not allow family members to be close to the patient in their final moments, it led to feelings of "*disappointment*" and being "*side-lined*" (Githaiga et al., 2017).

Physical proximity also impacted relational closeness; frequent contact fostered a sense of familiarity and knowing of other. This was true for both patient-family and patient/family-healthcare professional relationships. Lind and colleagues (2012) seemed to suggest that physical proximity contributes to building of relationship and knowing of other because part of their inclusion criteria was "*that the relative had visited the patient regularly"* (p. 668). Indeed, parents recurrently considered themselves "*experts*" on their child (Lord et al., 2020; Zaal-Schuller et al., 2016) because they had been physically close to them their whole lives. Since they had been there in the past, parents had knowledge that could guide their child's care, including which treatments had been successful, and where to insert an IV; *"I didn't want her poked a million times. I knew where the best place was…"* (Lord et al., 2020, p. 6). Frequent physical closeness to healthcare professionals fostered relational closeness and allowed for a certain stability that facilitated "*meaningful discussions*" and decisions about potentially life-sustaining treatment; *"The trouble is when you're attached to a dialysis unit you see so many doctors. They change—they rotate; you don't have that meaningful discussion with any of them because half the time they don't even know you"* (Sellars et al., 2018, p. 221). This was

especially true for the parents of children with a complex medical history (Lord et al., 2020; Zaal-Schuller et al., 2016). For these parents, "*having someone who's already been there*" meant families did not have to "*retell their story over and over again*" which was described as "*helpful*" (Lord et al., 2020, p. 6). This also applied to counselling after their child's death, as a parent described that seeking counselling from someone who had 'not been there' throughout their journey was "*tough"* (Lord et al., 2020, p. 7). When their child died, a loss of physical closeness to the healthcare professionals who 'had been there' led to real loss and grief; "*It's just empty. Everything's gone. Your child's gone. Your family, your, your medical family is gone.… And your community's medical family is gone. And you're alone. It's like waking up, and it's like everyone's dead*" (Lord et al., 2020, p. 7). This highlights the meaningfulness of relational closeness to families, and the impact that losing these relationships can have.

Physical closeness to healthcare professionals was required to have access to information and guidance; "*the staff…were often too busy with everyday tasks to stop and talk about the later stages of the disease"* (Sarabia-Cobo et al., p. e8), as well as to be included in the decision making process, making physical proximity a precursor to shared decision making;

> *"'It's kind of like sports. I wish there was more of a play-by-play… you know, the thing that drives you crazy is that you see (the physicians) talking to each other and you're not part of the conversation, and you're told to wait in the waiting room, and you're not part of that decision. Obviously we're not doctors, but… I wish we would have a little more communication with the doctors"* (Long et al., 2011, p. 209).

Most of the families in this study felt that the medical team was "*inaccessible*," which led to feelings of "*frustration*" and that they lacked information (Long et al., 2011, p. 209). On the other hand, the families in this study noted that *"nurses made the experience of sitting vigil with*

a patient easier because of their presence and support" (Long et al., 2011, p. 210). The nurses' "*availability*" and presence made the experience "*easier*" (Long et al., 2011, p. 210).

Physical proximity to healthcare establishments also impacted patients and families' access to care and by extension the options and choices available to them (Sellars et al., 2018); "*The presence of medical supports in their local community, such as physicians, home and school nursing, and the resources in their tertiary care hospital, including subspecialty teams and access to higher intensity care, were important factors that influenced ACP"* (Lord et al., 2020, p. 4). Decreased access to healthcare services and thus, options due to physical distance was especially prevalent in resource limited settings, such as an American Indian reservation where, given weather, transportation and economic conditions there was "*limited access to a full range of health care services"* (Colclough et al., 2014, p. 504). A similar situation occurred in Githaiga and colleagues' (2017) study, where the healthcare systems were "*under resourced*" and palliative care resources were mostly situated in rural towns, meaning "*some urban dwellers [might] not have access to these services"* (p. 1-2). For the family caregivers living in urban areas, "*this [physical distance] bears implications for end-of-life care, which is often delegated to family members and relatives residing in Nairobi*" (Githaiga et al., 2017, p. 2). Thus, the lack of physical proximity to healthcare facilities providing palliative care required family members, who were physically close to the patient, to assume the end of life care of their loved ones.

Identity and Quality of Life in Relationships: "What kind of life is being in a room…unable to relate"[7]

Across studies, terminal illness or potentially life-sustaining treatments impacted patients' ability to relate to others, and this in turn impacted patients' sense of identity and

[7] Sarabia-Cobo et al., 2016, p. e8.

quality of life. Identity and quality of life, which are presented together in this section because of their interconnectedness, also affected patients and families' preferences and decisions about potentially life-sustaining treatment at the end of life.

When patients' ability to relate to others changed, their relationships and roles were sometimes altered, which could impact their sense of identity or personhood (i.e. the quality of being a person), as well as the identity of the individuals they had a relationship with. This perceived change in relationship, role and identity could in turn impact experiences; "*One participant said, "I changed my role as a daughter, and I became a caregiver and [I] really do not like that role….*" (Sarabia-Cobo et al., 2016, p. e8). On the other hand, as Foley and colleagues (2014) found, sometimes patients with advanced illness were able to "*maintain roles within the family (e.g., as parent, spouse, or partner) even though they become physically dependent on family"* (p. 75). Maintaining roles (and thus identity) occurred when patients maintained an ability to meaningfully connect with others. In Wilson's (1993) case study, despite her mother being bedbound and unable to verbally relate due to her advanced Huntington's;

> *"The daughter believed that her mother fulfills a grandparenting role for her children […] the children were accustomed to their grandmother's appearance and choreic movements. They played in the room, talked to their grandmother, and would touch and kiss her"* (p. 305).

This daughter also "*derived enjoyment, support and purpose in [her own] life from visiting her mother*" and felt loved by her mother. Thus, her visits and interactions with her mother allowed her to maintain her role and identity as a beloved daughter, and allowed her mother to maintain her role and identity as a loving mother and grandmother. Both of these perceptions of intactness of identity influenced the daughter's decision to pursue artificial nutrition for her mother.

Across the sample, there was a correlation between age and both willingness and acceptability of declining potentially life-sustaining treatments. Physicians encouraged the pursuit of potentially life-sustaining treatments in younger patients; "*He just kept encouraging me to go on dialysis. He told me that I was still young, why don't I consider dialysis"* (Seah et al., 2013, p. 1023) and patients felt similarly; "*If I was younger…in my forties or fifties, I will opt for dialysis… but not now at this age"* (p. 1023). Age seemed to influence the (un)acceptability of death, which in turn influenced decisions about potentially life-sustaining treatments. This was partially due to the influence of age on sense of life completion, identity and sense of responsibility to other; "*With advanced age obligations towards family have largely been met, patients express a sense of life completion and contentment that comes with achievement of goals that explains the lack of motivation to prolong life*" (Seah et al, 2013, p. 1027). Similarly a patient with ALS shared; "*I don't mind death at all but I feel sorry for people that would get it young, you know. God, I would hate to have it younger. I've my kids raised and everything*" (Foley et al., 2014, p. 70). These quotes suggest that the conclusion of patients' identity as a parent, and thus of their sense of responsibility to their children, contributed to patients' decisions to decline potentially life-sustaining treatment. Foley and colleagues (2014) proposed that "*aging is more than a biological process or chronological marker,"* and they explained that "*different stages of life are characterized by change in their roles*" (p. 68) suggesting that age impacts relationships and identity. The acceptability of death with advanced age also seemed partially due to a presumption that quality of life was lower in elders;

> *"One young participant commented, 'Being an old man who has probably other things (morbidity) going on, the whole thing is more acceptable. It's like a car: If the car is old*

and starts getting trouble it's going to the scrap yard, because the car has done its bit'" (Foley et al., 2014, p. 71).

Of note, this tendency to assume acceptability of death and poor quality of life in the elderly was troubling for some patients; "*Due to patients' advanced age and chronic health issues, participants had been concerned that physicians would restrict treatment options based on assumptions of poor quality of life*" (Moon et al., 2021, p. 4). To note, my highlighting that advanced age is linked to a tendency to more willingly decline potentially life-sustaining treatment is not a commentary on whether this tendency is right or wrong, but rather offers some insight as to why a timely death tends to be preferable or referred to as 'good.'

As the above begins to reveal, quality of life was commonly considered by patients and families when deliberating potentially life-sustaining treatments at end of life. Patients completing ACP noted that "*focusing on the bigger picture and defining what quality of life meant to [them] was regarded as 'the most important thing'"* (Sellars et al., 2018, p. 218). Physical symptoms did, of course, contribute to quality of life in a significant way and were a consideration, however, almost more commonly, patients and families spoke about how the presence or absence of relationships impacted their quality of life. The participants in Seah and colleagues' (2013) study chose to decline dialysis partially because of the symptoms dialysis created, but also because declining dialysis allowed them to maintain their relationships; *"Reasons for their satisfaction with conservative management include the flexibility it gives them, lesser intrusion to their daily life and less pain, while giving them the opportunity to have greater control over their lives and continue to build relationships"* (p. 1025). An acceptable quality of life recurrently included the ability to communicate with others. As one niece said of her aunt with advanced dementia in Sarabia-Cobo and colleagues' (2016) study;

> "*You get to the point where you start to think you are not having a life anyway. What kind of life is being in a room and being in a bed unable to relate,' said a niece. 'If there is no quality of life, nothing, she –my aunt – does not look at anyone. She will not talk to anyone. She stopped eating. That's what I call being without quality of life'"* (p. e8).

On the other hand, if the ability to communicate was maintained, quality of life seemed preserved and treatment was preferred; "*one 76-year-old woman did not want to be kept alive 'artificially' but would undergo treatments that would allow her to continue quilting and communicating via email, activities she defined as 'my life'*" (Romo et al., 2017, p. e72). In addition to being able to communicate with others, the ability to recognize their family was also a common consideration for 'a life worth living.' A young adult declined potentially life-sustaining treatments that would cause significant mental and physical disability saying; "*I wouldn't know who I am. I wouldn't know who my family is. I wouldn't want to do that*" (Needle et al., 2020, p. 286). These quotes also suggest that it may be the loss of identity, through the loss of relationships that creates an undesirable quality of life in these circumstances. What is more, patients were willing to choose potentially life-sustaining treatments that would bring about serious side effects if it meant being able to sustain their relationships (implying that they prioritized relationships over physical comfort when it came to quality of life). In regards to life-sustaining treatment one family shared; *"Her answer was 'I would do anything and endure any amount of pain just to be able to look at my grandchildren's faces for as long as I could' so she prioritized living"* (Moon et al., 2021, p. 4). Relationships with healthcare professionals also factored into patients' quality of life, which impacted experiences and decisions. For the participants in Seah and colleagues' (2013) study who decided to decline dialysis; "*their satisfaction with their decision is inextricably linked with the positive experiences of the*

programme and meaningful relationships with palliative care personnel" (p. 1025). They appreciated all of the commitment to support them at a humanistic level, and they valued the healthcare professionals' caring, positive and sensitive approaches. The daughter in Wilson's (1993) article also felt that the "*caring nursing staff*" was "*important for her mother's quality of life*" (p. 305), which was a factor in her decision.

Given the important contribution of relationships to quality of life, for many, quality of life could exist amid severe disability or illness, and this affected patients and families' experiences and motivation to pursue potentially life-sustaining treatments at end of life. Patients with ALS focused on their "*supportive relationships as they advanced in the disease and severity of illness had little impact on what they found most meaningful in their lives*" (Foley et al., 2014, p. 68). Similarly, a parent noted how quality of life could exist despite the use of treatments;

> "*You look at your child and yes there are tubes, and yes, they're in a wheelchair or a special stroller, but what are their mannerisms? Are they smiling? Are they laughing? What's the most quality they can have? Are they a happy child? We looked at her as a person. Don't look at all the stuff you have to do to keep her alive, how is she doing?*" (Lord et al., 2020, p.6).

Similarly, in Wilson's (1993) article, despite the mother's advanced Huntington's and inability to communicate verbally, "*the daughter believed her mother had some quality of life that made her mother's life worth living"* (p. 305);

> *"The daughter believed her mother was conscious and was able to communicate with her eyes at times. She did not perceive her mother to be 'a vegetable.' The daughter believed she could positively influence her mother's quality of life through weekly visits*" (p. 305).

Thus, even with an altered or reduced ability to communicate, relationship was still experienced, thus quality of life was still present and, consequently, treatment was pursued. A participant's story in Maura and colleagues' (2019) study suggested that a physician agreed with this notion – that an ability to relate is analogous to "being alive." A family member shared that they "*didn't understand the purpose of using respirators"* so the physician brought her to the ICU ward and asked a women on a respirator to raise her hand; "*and the old woman with a respirator raised her hand slightly. The doctor said that we could see that our mom would still be alive even if she were in such a condition …*" (p.5). On the other hand, when healthcare professionals did not consider that quality of life could exist in the midst of suffering and disability, disagreements occurred; "*Several parents in this study reported that an important reason for disagreements with their physicians was their feeling that these physicians regarded the life of their child as less valuable than the life of a typically developing child"* (Zaal-Schuller et al., 2016, p. 291). This provides some insight as to how a difference in values (here, the difference of what constitutes a meaningful life) between families and healthcare professionals could lead to disagreements when making decisions about potentially life-sustaining treatment at end of life.

Findings suggested that "identity and quality of life in relationships" was related to the theme of "closeness in relationships." Families' relational proximity to patients fostered a knowing of patients' identity and quality of life; quality of life came from, but was also known through relationships. A close relationship with the patient meant families knew when a patient's identity was altered by disease or treatment; "*I felt something different. She was sleeping more, and she looked blank even when I talked to her. I felt something different*" (Maura et al., 2019, p. 4). In Norton and colleagues' (2019) study, families agreed to stop chemotherapy because of physical changes that occurred in the patient; "*Often, from the caregivers' perspective, the*

patient's body had made the decision [to stop chemotherapy]" (p. 671). Knowing a patient's identity prior to illness also permitted families to assess how much the patient had lost, and if the patient's current state of being would be acceptable to the patient, which guided decision making; "*one surrogate said that she knew her previously athletic and social husband 'would not have been happy not being able to walk and talk and function as a 30 year old in society*" (Long et al., 2011, p. 207). Although being able to recognize when identity had deteriorated was helpful in guiding decisions, recognizing that the patient's identity was fundamentally changed could also be distressing;

> "*As the mother's symptoms worsened and her delusional behaviours increased … [the daughter's] thoughts about providing subsequent treatment to her mother changed and gradually strengthened her determination to reject life-prolonging treatment.* "*She slept more and struggled to stay awake, and she was delusional … when I visited her, she said things such as, 'Go back, now!' or 'You'll be attacked by someone!' I didn't want to hear such words anymore*" (Maura et al., 2019, p. 4).

Families recognized that relational closeness brought about a knowing of other's identity and quality of life. Given their proximity and knowledge of their child with profound intellectual and multiple disabilities, parents in Zaal-Schuller and colleagues' (2016) study *"felt the need to be the 'translator' of their child for physicians, e.g., explaining how their child was feeling and whether their child was in pain"* (p. 289). As well, due to their relational closeness to their children, parents felt that they should be the ones to judge whether their child's quality of life was acceptable and thus whether treatment could/should be continued. When deciding whether to withdraw artificial nutrition/hydration for their child in the NICU;

> "*Most of the parents thought that they should be the ones entitled to judge the threshold of tolerance for a disability, not the health care team: 'It is not the doctor's business to decide whether we want a handicapped child. I could not have stood for anyone else to make such an important decision for us'"* (Fournier et al., 2017, p. 368).

Moon and colleagues (2021) seemed to agree with this notion that closeness cultivates knowing of others' identity and quality of life as they advocated for the recognition of families' expertise with regards to patients' quality of life and treatment preferences;

> "*Acknowledging families' insight regarding patient's quality of life, values and treatment preferences conveys respect and collaboration. Physicians can then provide an individualized and patient-centered rationale for the beneficence or futility of active treatment"* (p. 6).

In addition, physical closeness tended to positively impact quality of life, with many patients craving to be physically close to their families. A young adult chose to decline potentially life sustaining treatment because of the distance the treatment would create between them and their family; *"I'm not going to spend the last little amount of time I have left here [in the hospital]. If I can I'd want to travel or, again, just be with my family. They're the most comforting thing I have*" (Needle et al., 2020, p. 286). Similarly, a participant who refused dialysis said; "*I'm at home, I can spend time with my children and grandchildren… this is the kind of life I want to live, rather than to be stuck in a dialysis centre"* (Seah et al., 2013, p. 1025). Thus, physical proximity to their loved ones was an important contributor to patients' quality of life.

Reliance on Relationships: "We were hearing from the oncologist – there was so much hope"[8]

[8] Norton et al., 2019, p. 672

When making decisions about potentially life-sustaining treatment at end of life, patients and families relied on healthcare professionals for information, guidance and support to understand and have access to treatment options, to be included in decisions and to understand the patient's illness. Without such information and guidance, patients and families were left feeling unprepared for the patient's end of life and the decisions associated with it. As illness advanced, patients also relied on their families for assistance, care and support.

Reliance on Healthcare Professionals. Firstly, patients and families relied on healthcare professionals to know and understand their treatment options, with their choices largely depending on what was offered to them. In Norton and colleagues' (2019) study, because a patient preferred "*to always try*" and to "*do something"* he "*stopped active cancer treatment only when he was told that there were no other cancer treatments available"* (p. 672); *"they said that he had three choices: try another chemo treatment, discontinue treatment, or try experimental. And he, without even hesitating, said I am gonna try the new chemo"* (pp. 671-672). Commonly, on their own, patients "*had not realized that stopping [potentially life-sustaining treatment] was an option"* (Sellars et al., 2018, p. 218). As Norton and colleagues (2019) noted;

> *"Caregivers did not recall discussions about prognosis or times when a possible transition to comfort-oriented care was discussed. As one caregiver said: '[…] It wasn't being communicated that you are not doing well. You know, so maybe you might want to just lay up on the chemo and let you enjoy your life. There was never that option there. It was like, come back in 3 weeks'"* (p. 672).

Other times, seemingly due to lack of explanation from healthcare professionals, families simply did not realize that they had made a choice to continue potentially life-sustaining treatment. On their own, "*surrogates were not aware that each successive treatment decision was a decision to*

continue support, because to them, it was simply a discrete continuation of interventions needed as the patient's condition changed" (Long et al., 2011, p. 210). Patients and families also relied on healthcare professionals to understand the potential outcomes of treatment; *"although the families prepared for the deaths of their parents, they were confused by the information presented by the physicians. '[…] I asked them if my mother would recover, and they said, 'the possibility is not zero'"* (Maura et al., 2019, p.5). Recurrently, families referred to the inevitable outcome of death, and the reality that potentially life-sustaining treatments would, eventually, not be able to sustain life as "*unexpected*", "*overwhelming*" and "*shocking*" (Liu et al., 2014; Lord et al., 2020; Norton et al., 2019). Lord and colleagues (2020) suggest that this may be due to "*desensitization*" to acute deteriorations as "*parents may adjust to their child surviving against the odds each time, resulting in a feeling of shock when the child ultimately does not survive"* (p. 8). However, study findings frequently suggested that patients and families heavily relied on information and guidance from healthcare professionals to understand that treatments would not allow patients to live indefinitely; *"I thought the diet, the drugs and the kidney dialysis were adequate to keep her alive for an indefinite period but the [ACP nurse] said that everyone on dialysis has a much shorter lifespan and you need to plan"* (Sellars et al., 2018, p. 220). It was only after receiving information from the ACP nurse that this family member became aware of the limits of potentially life-sustaining treatment.

Secondly, patients and families relied on healthcare professionals to create space for their wishes to be heard and incorporated in decision making. Frequently, patients and families had formulated preferences about their future care, usually triggered by a diagnosis or exacerbation of illness, but relied on healthcare professionals to solicit these preferences (Seah et al., 2013;

Zaal-Schuller et al., 2016). Most notably, a patient who "*hated*" dialysis did not voice their desire to stop treatment until they were explicitly asked about their wishes;

> *"I hated dialysis so badly, you've got no idea. So when [the ACP nurse] came to me and said, 'You can choose', I thought, 'Fantastic!' So I chose [to withdraw from dialysis]. It felt fantastic, and I mean it. Fantastic"* (Sellars et al., 2018, p. 220).

Sometimes, although patients and families were technically asked their preferences, the treatment option was presented in a way that made families feel "*there was no other choice but to accept*" the treatment course proposed by healthcare professionals (Maura et al., 2019, p. 6) (whether it be to continue or stop treatment). On a few occasions in Githaiga and colleagues' (2017) study, though healthcare professionals asked the family 'what they want,' the directive way in which the option was presented creates doubt that the families actually felt able to decline the physician's proposition;

> "*He [the doctor] called me and said 'Mrs Fikira I want you to sign here. If your husband deteriorates at night I want you to give us consent that we don't take him to ICU. If he was my father that's what I would have done' […] 'because he is going to be on a life machine and this doesn't help. But just tell me what you want'"* (p. 5).

Indeed, patients noted that they were often not given the chance to refuse proposed treatment courses and felt they had to "*succumb to the medical powers*" (Romo et al., 2017);

> "*Patients were generally reluctant to question medical recommendations. One participant recalled that her non-English-speaking mother was comfortable expressing her treatment preferences to her family yet lacked the confidence to voice these to her treating team: 'If a doctor or nurse approached her with something (through an interpreter)… she felt that she had to play by the rules*" (Moon et al., 2021, p. 4).

Colclough and colleagues (2014) explained that patients and families did not realize that they had a "*right to choose*" and thus "*followed whatever the physician said to them with or without understanding"* (p. 508), partially because "*culturally questioning to the authority figure was not an option*" (p. 509), but also because healthcare professionals did not create two-way communication. Families who were not given space to be included (and who wanted to be included in decisions) felt "*robbed*" of the decision and experienced "*feelings of powerlessness and injustice"* (Moon et al., 2021, p. 5). Feeling excluded also led to feelings of defensiveness and created tension in the relationship with healthcare professionals;

> "*Families often were acutely aware of the power imbalance between themselves and the physicians and attempted to assert their decision-making rights: 'I listened to what they had to say and then I took out my MPOA (Medical Power Of Attorney) and the doctor looked a little worried and I know why because it's a proper certified one through a lawyer so they can't overrule…Well they can, but they would have to take me to court"* (Moon et al., 2021, p. 4).

Fournier and colleagues (2017) also found; "*parents who had the worst feelings were those who experienced WANH as a procedure that was imposed upon them without their support"* (p.368). Thus, being excluded from decisions about potentially life-sustaining treatment at end of life, when the decision makers wanted to be included, negatively affected relationships and experiences.

Thirdly, patients and families relied on information and guidance from healthcare professionals to develop a "*comprehensive view*" of the patient's health (Wilson, 1993, p. 304) and to be able to recognize health decline or the "*conditions common to the terminal stages"* of the disease (Sarabia-Cobo et al., 2016, p. e8). The information about patients' health and

prognosis that patients and families had access to, truly depended on what was shared by healthcare professionals;

> "'*They (nurses) were very interested in the oxygen measurement… the saturation…all the time. I felt they were hung up on that screen. And then it was kind of like that was what they answered about when I asked how he was, either when I was there or on the phone in the evening.' The uncertainty in the patient's situation was thus under-communicated and limited to objective results of measurements"* (Lind et al., 2012, p. 670).

Not only this, but "s*everal informants [described] a form of socialisation that occurred, where they learned which measurable parameters the nurses emphasised and later they themselves became interested in these"* (Lind et al., 2012, p. 670). This suggests that the information shared by healthcare professionals also guided patients and families own focus toward specific (and limited) aspects of the patient's health. When the "uncertainty in the patient's condition was under-communicated," patients and families were left feeling "*hopeful*" and "*unprepared*" for the patient's decline and "'*blindsided' by the nearness of death and what an imminently dying patient might look like"* (Norton et al., 2019, p. 673). Thus, receiving honest information was fundamental not only for relational closeness, but also to understand the patient's health and prognosis; "*We were hearing from the oncologists – there was so much hope. She [the patient] goes to the emergency room and this doctor just basically said 'you're gonna die'. And the [ER] doctor also said 'oncologists generally won't admit that'*" (Norton et al., 2019, p. 672);

> *"I was a bit shocked when [the ACP nurse] said that everyone here has a much shorter lifespan and you need to plan for it. No one had said that to us in the last three years. The*

> *nephrologist had certainly never spoken in any sense at all about life expectancy"* (Sellars et al., 2018, p. 221).

Lack of preparedness for the patient's decline meant families were also unprepared for the decisions that came with progression of the disease (because no one had foretold them);

> "*The event of total dysphagia was sudden and unexpected for the daughter. It would appear that total dysphagia was also, unaccountably, not expected by the healthcare professionals involved. No advanced preparations for complete dysphagia or sudden death were made prior to tube feeding"* (Wilson, 1993, p. 306).

Thus, families relied on guidance from healthcare professionals to know what to expect in terms of disease progression and decision making.

When information and guidance from healthcare professionals was insufficient, patients and families worked to supplement what was received, by reading articles and books (Maura et al., 2019), looking to past experiences (Colclough et al., 2014), and the Internet or family and friends with a medical background (Zaal-Schuller et al., 2016). When patients and families had to do this, and "*acquire the necessary information themselves"* or "*be the one to ask for information"* they described it as a "*big effort*" "and *"huge responsibility"* (Lind et al., 2012, p. 671), and experienced "*even more difficult"* decisions (Sarabia-Cobo et al., 2016, p. e9). Norton and colleagues' (2019) found, that when no explicit end of life discussions occurred, caregivers described a "*difficult dying process"* and experienced much distress. These caregivers "*reported having experienced trauma, distress, anxiety, panic, uncertainty, and self-blame and felt angry, frustrated, deceived, and abandoned by the oncology team for providing insufficient information and no guidance"* (Norton et al., 2019, p. 671). This distress sometimes persisted, even after the patient's death, with the families in Moon and colleagues' (2021) study seeking answers at the

study interview; "*families sought answers following patients' death, which was demonstrated in how they analyzed discharge summaries during the interview, and [they] suffered unresolved distress and confusion"* (p. 6). On the other hand, when patients and families were able to rely on healthcare professionals' expertise, patients and families felt prepared, supported and satisfied; *"It was a lot to take, as parents, and I feel that they [healthcare professionals] really did take the time to walk us through it, and just to show some compassion, which was really nice"* (Lord et al., 2020, p. 6). In Norton and colleagues' (2019) study, when the oncologist was "*clear all along from day one*" that chemotherapy would only "*buy time,*" the authors found that "*clear decisions and seamless transitions*" to comfort care occurred (p. 671).Open communication (along with shared deliberation and decisions) also led to the "*least caregiver distress and greater satisfaction with care*" (Norton et al., 2019, p. 673).

Nurses were regularly referred to as an important source of information, guidance and support, that patients and families could rely on;

> *"All 10 surrogates described the essential role ICU nurses played in helping them understand what was happening to their patients. These nurses explained the medications they gave to patients and the implications of the data conveyed by vital sign and intracranial pressure monitors. One surrogate said she valued the nurse who would explain things to her 'after I felt (the physicians) had just kind of thrown up on me'"* (Long et al., 2011, p. 209).

These authors also suggested that an advanced practice nurse could be a resource to patients and families "*with the technical knowledge to answer questions and help the surrogates understand the patient's condition and the time to spend with them while they were in the process of making decisions"* (Long et al., 2011, p. 209). Sarabia-Cobo and colleagues (2016) also suggested that

"*good communication by a qualified professional, such as a nurse, could ease the translation of medical information, disease language, and the exploration of values and goals"* (p. e9). These citations highlight ways in which patients and families can and did rely on nurses for support and information when making decisions about potentially life-sustaining treatment at end of life.

Reliance on Family. Patients and families also relied on each other for guidance and practical help, especially for assistance with decision making. When advanced illness resulted "*in an inability of the person to make decisions, the responsibility often [fell] on the families"* (Sarabia-Cobo et al., 2016, p. e7). The same was true for patients with significant intellectual disability who "lacked decision-making capacity" (Zaal-Schuller et al., 2016). Relying on and including significant others in decision making was often "*seen positively*" (Colclough et al., 2014) and was especially necessary "*in the absence of explicit dying wills"* (Githaiga et al., 2017, p. 5). However, even when a record of patients' preferences existed, patients relied on *"'like-minded' and capable surrogates, either caregivers or clinicians, who would advocate for their wishes"* should their wishes be "*challenged or overruled*" at end of life (Sellars et al., 2018, p. 219). Other times, patients who were capable of making their own decisions still relied on their loved ones for treatment decisions (Needle et al., 2020, Romo et al., 2017). The patients in Romo and colleagues' (2017) study explained that delegating the decision to a person they trusted allowed them to "maintain a sense of control" and also relieved them from "*the distressful aspects of contemplating mortality"* (p. e74);

> *"Participants relied on family because they believed family would make appropriate choices and it alleviated burden of deciding: "I'm more comfortable with my daughter [making decisions]. I mean, I know she wouldn't steer me wrong."; "My poor daughter*

> *has to do all the heavy grunt work, and it's just a burden. I'm sorry, but God, I'm glad she's there"* (p. e73).

These authors explain that "*delegating decisions can be an exercise in autonomy"* (Romo et al., 2017, p. e74) and that *"people do not always want to make explicit decisions"* (p. e75).

Given this need (and sometimes desire) to rely on others for decision making at the end of life, family members (or healthcare professionals), in turn, "*relied on prior conversations with the patient"* (Long et al., 2011, p. 207) to guide decisions about potentially life-sustaining treatment. Across studies, being able to rely on "*crystal clear*" previously stated wishes could "*ease the stress of making life or death decisions*", "*helped a great deal*" in the process (Schenker et al., 2012, pp. 1661-62), and allowed families to know and follow the patient's plan (Sellars et al., 2018). Alternatively, "*when the [patients'] desires were unknown, their families experienced significant conflict regarding the decision to accept life-prolonging treatment"* (Maura et al., 2019, p. 6). These surrogates "*struggled with whether they were doing the right thing"* (Long et al., 2011, p. 207) and noted that, had the patient's wishes been known, the decision "*would have been a lot easier"* (Wilson, 1993, p. 306). Given all this, Needle and colleagues (2020) pointed to the importance of facilitating discussions about end of life so that patients and families could "*develop a better mutual understanding of important treatment considerations"* (p. 288). In addition to the above, families who were called on to make decisions for others also relied on the rest of their family, on friends and their faith for support and guidance in the decision making process; "*Surrogates spoke of how their faith in God supported them through their experiences of being a surrogate and the role it played in forming their decisions"* (Long et al., 2011, p. 208); "*Drew's family strongly relied on faith during*

Drew's illness and in their decision-making" (Needle et al., 2020, p. 284). Thus, families relied on others for support and guidance during the decision making process.

Patients with advanced illness also relied on others (often family members) for care, support and assistance. As Norton and colleagues (2019) write;

> "*Family caregivers play an important role in providing physical and emotional care and support to patients with advanced cancer, especially as a patient's condition worsens. They traverse the health care system with patients, are often present when oncologists share prognostic information, and frequently serve as the providers of care during patients' last weeks of life"* (p. 670).

Relying on family members for care was especially common in resource limited settings (Githaiga et al., 2017) or in areas where formal home care was "*underdeveloped*" (Foley et al., 2014). In these places, patients commonly lived with and depended on their families for care. Relying on others for care especially occurred for illnesses which, when advanced, would "*lead to dependence in activities of daily living [and] a bedridden lifestyle"* (Sarabia-Cobo et al., 2016, p. e7), such as dementia and ALS. Patients with such illnesses or with disabilities that affected their ability to verbally communicate were also reliant on their close relationships for assistance with communication and *"to translate their […] non-verbal signals for the physician"* (Zaal-Schuller et al., 2016, p. 291). Similarly, in Foley and colleagues' (2014) study, patients with dysarthia (due to their advanced ALS) relied on their significant others to help them communicate with the study's authors; *"their carers or significant others communicated with the first author on their behalf"* (p. 69). Other times, patients relied on their family's support to comprehend the information received from healthcare professionals; *"As patients' ability to understand complex information may be compromised by illness and medication, they depend on*

their families to understand and interpret medical information" (Moon et al., 2021, p. 5). Finally, families and patients also relied on one another for financial support, which impacted end of life preparations. A patient in Githaiga and colleagues' (2017) study prepared his family saying; "*Mum cannot afford the rent. Now, she's going to look for a smaller house [] And the little money which I'm going to leave will educate the ones who are in school'"* (p. 3).

Patients and families considered their reliance on others and others' reliance on them when making decisions about potentially life-sustaining treatment at end of life (a notion described in more detail in the theme "sense of responsibility" below). Participants in Maura and colleague's (2019) study who were providing care to their parents "*were aware of the limits of care that they could provide"* (p. 4) and considered their own exhaustion when contemplating potentially life-sustaining treatments. These families also recognized that they relied on healthcare facilities for care and thus considered the facilities' policies about treatment when making treatment decisions; "*The families understood that it would be difficult to keep their parents hospitalized if they refused treatment"* (Maura et al., 2019, p. 5). In addition, patients and families who had young children generally considered their children's reliance on them when making treatment decisions (Foley et al., 2014; Schenker et al., 2012).

The concept "reliance on relationships" was related to the concept of "closeness in relationships" in a few ways. Recurrently, "closeness in relationships" made patients and families more willing and able to rely on another. Patients who viewed their physicians as experts, and trusted them, were "*happy to go along with whatever the doctors said"* (Moon et al., 2021, p. 3). As well, nurses' physical and relational closeness made relying on them for information and support feasible; "*The ICU nurses were an important resource to help the surrogates become better informed because of their availability to answer questions"* (Long et

al., 2011, p. 210). Indeed, proximity to nurses was noted as being helpful in acquiring information; "*The nurses have been so kind and good to me…they answered any questions I had and would help me whenever I needed help"* (Seah et al., 2013, p. 1025-26); "*the relatives described receiving most of their information from nurses, who were considered closer and more approachable for questions*" (Sarabia-Cobo et al., 2016, p. e8). On the other hand, when medical staff was "*inaccessible*" both physically and otherwise, families were left "*feeling like they had inadequate information to use in their decision making"* (Long et al., 2011, p. 209) because of the infrequent opportunity to discuss the patient's case.

There was also a connection between the theme "reliance on relationships" and "identity and quality of life in relationships." Recurrently, lack of independence was described as undesirable and seen as decreasing quality of life; "*If they undergo gastric feeding, they would just spend their days confined to bed. I doubt if you could call it 'living'. I wouldn't want it for me or my mother"* (Maura et al., 2019, p.4). Likewise, some patients with ALS were more accepting of death before "old age" because;

> *"They no longer felt worried about the possibility of living to an age that they associated with loss of independence. Indeed, one participant suspected that her quality of life would be unacceptably low if she were to reach "old age." '[…] it would be much harder to maintain your independence in your nineties'"* (Foley et al., 2014, p. 71).

Some studies pointed to the possibility that relying on others impacted one's personhood and relationships and, together, this would impact one's identity, which was undesirable;

> *"The physical and mental changes such as incontinence, falls, multiple fractures, loss of mobility, inability to live alone, getting lost, violent behaviour, inability to recognize*

> *family, and an inability to feed oneself […] led the family to view the patient as being the "living dead"* (Sarabia-Cobo et al., 2016, p. e8).

Needle and colleagues' (2020) suggested that serious illness may encumber the independence that is characteristic of adolescence; "*Adolescence is characterized by the establishment of individual identity, a sense of self, independence and autonomy from parents, and the importance of peer relationships. Serious illness may lead to a loss of identity"* (p. 282). Thus, adolescents' independence, and consequently their sense of identity, could be impacted when advanced illness caused reliance on their relationships.

Sense of Responsibility: "My life belongs to me, but also to everyone else"[9]

Patients and families experienced a sense of responsibility to others (their loved ones and sometimes, society) when making decisions about potentially life-sustaining treatment at end of life. This greatly impacted their experiences and decision making process. Patients and families experienced a sense of responsibility to respect and protect their loved ones' wishes and well-being. When it was not possible to satisfy their sense of responsibility to their loved ones (e.g. when patients' wishes conflicted with another family members' wishes), feelings such as fear, burden and guilt transpired.

When family members were contemplating potentially life-sustaining treatment for patients at end of life, they took the task seriously and felt a responsibility to uncover, consider and respect the patient's wishes, values and beliefs. This occurred even when patients had trouble communicating at end of life; "*The doctor [asked] if I wished to receive life-prolonging treatment. I asked her [patient] 'Yes' or 'No' in writing, and she pointed to 'No' […] and I told the doctor not to give life-prolonging treatment"* (Maura et al., 2019, p. 6). When deciding to

[9] Seah et al., 2013, p. 1023

forgo CPR, the mother of an adolescent patient shared that her son's expressed wishes moved her to agree to sign a DNR for him;

> "*I remember one day he asked me to hold him. He brought up the topic and told me 'Mom […] I do not want to hold on anymore.' He expressed his point very clearly. He wanted me to give up any aggressive treatment. I signed [the DNR] on the day he died"* (Liu et al., 2014, p. 31).

Families' sense of responsibility to respect patients' wishes meant that they were willing to endorse patients' treatment preferences despite "not liking it"; "*I didn't want him to die but it's his life, his decision. I didn't like it but I agreed with it"* (Sellars et al., 2018, p. 221). When patients' wishes were known and followed, families expressed feeling "*encouraged*", "*relieved*" and "*grateful*" and that the "*correct decision*" had been made; "*although it was difficult, the caregiver felt satisfied that he or she had made the correct decision"* (Sellars et al., 2018, p. 219); *"…her wishes were followed… I was relieved"* (Moon et al., 2021, p. 4). Additionally, Wilson (1993) found that this sense of responsibility to respect patients' wishes persisted for some time after a decision had been made;

> *"This sense of responsibility does not stop when the decision is made. The daughter was still concerned over the decision she had made one and one half years before. She continued to hope that it was the decision her mother would have made for herself had she been competent"* (p. 306).

Overall, as in Schenker and colleagues' (2012) study, families "*described the importance of considering their loved ones' [the patient's] values or acting in their interest*" (p. 1659).

Decision makers' sense of responsibility to consider and respect their loved ones' wishes extended to other family members' wishes (not just patient wishes). Patients and families making

these decisions recognized that persons they had a relationship with (e.g. other family members not included in the decision making process) would be impacted by the decisions they made, and thus felt a sense of responsibility to consider the thoughts and preferences of these individuals. For this reason, patients often "*sought validation*" (Long et al., 2011) from their families and aimed to make decisions that their families "*endorsed*" (Foley et al., 2014). In Seah and colleagues' (2013) study, the patients indicated that once they made the decision to forego dialysis, they sought their family's views saying; *"my life belongs to me, but also to everyone else, so I discussed it with them"* (p. 1023). The adolescents and young adults in Needle and colleagues' (2020) study also put great importance on their parents' desires;

> *"Their decisions were rooted in their relationship with their parents. Participants recognized that their parents had to live with the decisions they made: 'It would depend on them, not me, because at the end of the day, they're the ones that have to live on. Like, if they wanted me to continue living, and I didn't want to, and so the doctors valued what I said and pulled the plug, then they have to live with the fact'"* (p. 286).

In general, as in this study; "*participants deliberated on how to balance their own individual desires with those of their families"* (Needle et al., 2020, p. 285) and "*participants were willing to consider sacrificing their own preferences for those of their [families]"* (p. 286). Conversely, in Sellars and colleagues' (2018) study, patients' sense of responsibility to consider their families' wishes was experienced as "*pressure*" to continue treatment. A patient expressed that they "*would have discontinued therapy much 'earlier' but lacked support from caregivers to withdraw"* (Sellars et al., 2018, p. 219). Patients and families' sense of responsibility to consider their loved ones' thoughts about treatment was largely related to their sense of responsibility to protect well-being; they sought family opinions in order to preserve "*family well-being and*

harmony" (Seah et al., 2013), to "*keep a happy medium*" and prevent "*resentment*" (Schenker et al., 2012). Families involved in the decision also wanted healthcare professionals to recognize the importance of including other family members' in the decision making process and were distressed when key family members were not included in care discussions. As one mother explained;

> "*For decisions that were made for her quality of life, and her end-of-life care and all of that, I felt very uncomfortable that I was approached by myself. Some of the talks should not have happened without my husband present"* (Lord et al., 2020, p. 6).

Likewise, a patient's wife wished that the physician had included her daughter in the decision about CPR; "*I signed and after the doctor had gone my daughter cried, sobbed, 'mummy how can you do that? [] I wish he had told me before so that I consult the members of the family"* (Githaiga et al., 2017, p. 5). There was also evidence that patients considered their families' wishes beyond decisions about potentially life-sustaining treatment. During recruitment in Seah and colleagues' (2013) study, two patients who declined to participate "*expressed concerns that family members may not be comfortable with the interviewer coming into their house"* (p. 1021).

Patients and families' sense of responsibility to protect each others' well-being manifested, in part, as a willingness or reluctance to discuss and prepare for end of life. Most frequently, speaking about end of life was avoided and death was referred to as "*taboo*" (i.e. a topic that is banned because of risk) (Liu et al., 2014; Sellars et al., 2018). Indigenous peoples believed in the "*power of words*" (Colclough et al., 2014), and others believed that "*speaking about death implies summoning it*" (Githaiga et al., 2017, p. 4). As such, patients and families often avoided "*death talk*" to sidestep "*stirring up emotional distress, […] to keep hope alive through engaging in positive conversations"* and ultimately to protect each others' well-being

(Githaiga et al., 2017, p. 1). In some instances, this aversion occurred both ways. In Taiwan, some parents chose not to disclose their child's diagnosis/prognosis to their child so as to protect them and in turn, their child tried "*to pretend not knowing their condition in order to protect [their] parent"* (Liu et al., 2014, p. 34).

On the other hand, for some, this sense of responsibility to protect their loved ones' well-being was apparent in their desire to talk about end of life and prepare them for the future;

> *"For me, I think what helped us as a family is being prepared. […] when I heard you [Baraka] talk, I was thinking your mum hid so much. She didn't want to see you in pain and sometimes for a woman it's harder. For a man I think he's feeling like 'if I leave my family like this everything will be, you know, in disarray'"* (Githaiga et al., 2017, p. 3).

The patients in Sellars and colleagues' (2018) study shared that, the fact that ACP would relieve their families from having to make a decision was "*more important than whether their specific ACP treatment and care wishes were adhered to at end of life*" (p. 218); "*I don't think [my partner] is the sort of guy that can handle [end-of-life decision-making]. So, I thought I'll just get what I want down on paper and he can follow it"* (Sellars et al., 2018, p. 221). When disagreements occurred within a family as to whether engaging in discussions about end of life was helpful or "taboo," tension and conflict arose;

> *"'They thought I was an enemy. At one point they just told me 'you want your mother to die' which is not the case' […] Baraka sought to initiate end-of-life discussions with her sisters in an effort to support her mother by facilitating what she deemed a dignified death. This yielded dissonance between cultural beliefs regarding speaking about death being perceived as a death wish versus the reality of impending death"* (Githaiga et al., 2017, p. 4).

A wife in Australia shared she had done the same with her husband, who had tried to discuss end of life with her; "*I said, 'Look stop talking about this, don't think about dying. You're going to live until you're in your 80s.' I was optimistic and I think he was trying to warn me but I just refused to listen"* (Sellars et al., 2018, p. 220). This further highlights how a difference in values (here, whether it is important to discuss end of life or not), can lead to disagreements.

Families' sense a responsibility to protect their loved ones from harm also manifested as wanting to make decisions that would maintain or shield their loved one's (the patient's) well-being;

> *"Once parents realized that their child was less likely to recover and more medical treatment could only hurt their child and cause pain, they signed the DNR form. […] 'I saw her rescued every half an hour. My wife and I cried when we saw the medicine injected. Her little tummy was shivering intermittently. Her whole body's color changed. I felt she was "living death." We were torturing her. I thought signing the DNR form would be better for her...'"* (Liu et al., 2014, p. 31).

A sense of responsibility to protect patients' well-being meant that families' were inclined to choose the option that was presented as being "better" for the patient;

> *"He told us […] 'there're two things – you take him home or we take care of him in hospital: which one do you choose? Many people would like to see their person go [die] at home and even when they go home sometimes they get better.' So we chose for him to come home"* (Githaiga et al., 2017, p. 5).

On the other hand, sometimes families chose to pursue potentially life-sustaining treatment at the patient's end of life in an attempt to protect the patient from anguish, especially if treatment was presented as the means to achieve this. In Maura and colleagues' (2019) study, at first caregivers

thought they should decline potentially life-sustaining treatment for their parents, to "*preserve their parents' joy*" and to "*allow their parents to die naturally without pain"* (p. 5). However, the physicians explained that their parents would "*experience pain if allowed to die naturally*;"

> *"I told the doctor that I was not going to change the batteries of my mother's pacemaker. I created a written agreement with my brothers. …The doctor said that she would suffer severely when the batteries died. So … we decided to change them because we didn't want her to suffer … I was given lots of confusing information … but I bet she wouldn't have suffered that much, right?"* (Maura et al., 2019, p. 5).

Similarly, the parents in a neonatal intensive care unit were conflicted about withdrawing artificial hydration/nutrition (WANH) for their critically ill newborn, because of their sense of responsibility to provide their child with nutrition and care, and protect them from starvation;

> *"By its very nature, WANH challenges the deepest parental layers of the psyche. […] A mother said: 'We owe it to our children to feed them; that's the first thing a mother does.' And one father: 'I wondered what she must have thought of the fact that I was not feeding her.' Indeed, it was usually terribly painful for parents to cope with the psychological violence WANH inevitably entailed for them"* (Fournier et al., 2017, p. 368).

Ultimately, families experienced a sense of responsibility to make decisions that would alleviate suffering and allow for a "peaceful death." The daughter in Wilson's (1993) article chose tube feeding so that her mother would not "*starve to death*" which she believed would be "*a painful and lingering type of death*" (p. 303).When families felt their decision had allowed their loved one to experience a "*peaceful death*" they felt that they had made "*the right decision*"; *"It really was a peaceful death, so I was convinced it was the right decision"* (Maura et al., 2019, p. 6).

Alternatively, the sense of responsibility to protect patients' from harm sometimes took the form of wanting to protect patients from death, which fostered a desire to pursue potentially life-sustaining treatments and any chance of recovery. Most family members in Schenker and colleagues' (2012) study wanted to "*pursue any chance of recovery*" and deemed not doing so "*the wrong decision*"; *"the wrong decision for me would be to not give her a chance… to recover to get better"* (p. 1661). Families wanted to try "*everything*" and make sure that they had done "*enough*" to protect their loved one's life (Liu et al., 2014; Maura et al., 2019). This meant that, despite agreeing to DNR, the parents in Liu and colleagues' (2014) study would consider pursuing any additional treatment offered, no matter how small the chance of survival;

> *"They still hoped for a miracle that their child might survive even after they signed the DNR form. A's mother said, 'But if the doctor mentioned there might be a new treatment, we would still try even just having faint hope'"* (p. 32).

Given their sense of responsibility to protect the patients' lives, families were often reluctant to decline potentially life-sustaining treatments, or make decisions that could bring about the patient's death. The daughter in Wilson's (1993) study felt that if she did not choose tube feeding, her mother would "*starve to death*" which left her feeling as though "*there was only one decision she could make*" (p. 303) – to pursue tube feeding. The daughter explained her sense of responsibility to protect her mother;

> "*They were saying 'Should we just make your mom comfortable here at the hospital' and basically let her die. They were going to let her starve to death ... and I couldn't do that. I wouldn't want her kept alive by extraordinary means; anything beyond that, but basic feeding […] I just felt terrible. But I had to do what I thought was the best. I just couldn't make the decision to starve her to death. There was no choice"* (Wilson, 1993, p. 306).

Similarly, regarding the withdrawal of artificial hydration/nutrition, a parent in Fournier and colleagues' (2017) study remarked that "*the intentions are not as neutral as they say. To allow death to happen, you have to want it to happen"* (p. 370). These findings begin to reveal that decision makers experienced potentially conflicting responsibilities – to protect patients from suffering, but also to protect them from death. Moon and colleagues (2021) articulated the fact that some families wanted to "*fight for*" and protect their loved one's life, while some wanted to protect their loved one from "*invasive interventions*";

> *"Families' desire for active therapies reflected respect for the value of their loved one's life and a commitment to the patient: 'I've done what I need to do as a daughter because I have to fight for the last minute of her breath…'* '*Fighting' often involved appeals for further active treatment, such as antibiotics or dialysis. In other cases, families sought to protect a loved one from seemingly futile and invasive interventions"* (p. 4).

Sarabia-Cobo and colleagues (2016) summarized this notion by describing families as being "*torn between the two faces of death*" – "*first, death was felt as a loss of their loved one, but otherwise it was a relief, a release and a break because of the cruelty of the disease"* (p. e8). Thus, families experienced tension between their sense of responsibility to protect their loved one from harm and their sense of responsibility to protect their loved one from death.

Patients and families also felt a responsibility to consider how pursuing or declining treatment would "burden" or affect others (e.g. other family members, their friends, society) – financially, physically, temporally and emotionally. For the patients in Seah and colleagues' (2013) study, their family's financial well-being was a priority when making decisions about dialysis; *"I did not want to be a great burden to my children… my children will still be burdened financially"* (p. 1024). These patients considered how their treatment options would create

"*financial stress*" on their families (Seah et al., 2013, p. 1021). As well, a young adult in Needle and colleagues (2020) study refused potentially life-sustaining treatment that would extend life by 2-3 months saying; "*it makes no sense to make family members go through that for another two to three months and cause more of a rack up on bills with that [treatment]"* (p. 285). Sellars and colleagues' (2018) study revealed that patients also considered how their treatment choices would financially burden society, with some saying *"'government [shouldn't] spend millions to keep [patients] alive once [they] can't do things' because 'if the brain doesn't work there's no use wasting money'"* (p. 218). Patients and families also took into account how the decision to pursue or withdraw/withhold potentially life-sustaining treatment would physically and temporally burden their family members. In Long and colleagues' (2011) study, as families contemplated life support, they weighed the "*expected burden to the family of caring for a person with long-term effects of severe traumatic brain injury*" (p. 207). Similarly, a patient in Sellars and colleagues' (2018) study shared; "*The more important thing is to take that burden off my family. If I'm on life support, what is the point in dragging it out for the family? They'd probably come every day*" (p. 220). Patients and families also sought to protect their loved ones' emotional well-being with the decisions they made. Many adolescents/young adults in Needle and colleagues' (2020) study took into account how discontinuing potentially life-sustaining treatment would emotionally impact their families. Their "*desire to avoid suffering and maintain an acceptable quality of life was often in competition with [their] concern over the perceived negative impact a decision to discontinue treatment, with resulting death, would have on their families"* (Needle et al., 2020, p. 287). In general, as Seah and colleagues (2013) articulate here about patients contemplating dialysis, a sense of responsibility to protect family well-being was pivotal for patients making decisions about potentially life-sustaining treatment at end of life;

> "*The exigencies of dialysis were evaluated not solely against gains/burden to the individual but most importantly after consideration of family well-being. […] Decisions are taken by the individual but [were] driven by a strong sense of being beholden to family"* (p. 1027).

This quote from a patient's husband summarizes the above well; "*How terrified I would be to lose her and have her die. But I'm also terrified of, what if she lives? I mean, ultimately, what…at what emotional, physical, economic cost to the family?"* (Schenker et al., 2012, p. 1660). This further highlights the tension that families experienced between their many senses of responsibility (here, between their sense of responsibility to protect the patient from death and their sense of responsibility to protect the rest of their family from emotional, physical and financial burden).

All of this combined – the sense of responsibility to respect patient and family wishes, to protect patient and family well-being and patients' lives – meant that decision makers often felt like there was a "*right decision*" to make, and experienced feelings of "*burden,*" "*stress"* and "*doubt*" as they tried to find it (Sarabia-Cobo et al., 2016; Schenker et al., 2012; Wilson, 1993). Long and colleagues (2011) explained;

> "*Surrogates make their decisions in a psychological environment marked by insecurity about making the 'right' decision, putting the patient's needs before their own, maintaining a holistic view of the patient, and a desire to keep the patient's identity and dignity intact"* (p. 205).

When it became challenging to satisfy all the ways in which patients and families felt responsible to each other and others, feelings of burden and guilt occurred. Despite feeling a duty to respect patients' wishes, it was sometimes difficult to do so, either because wishes were unknown or

because patients' wishes were incompatible with protecting another's well-being. In Schenker and colleagues' (2012) study, surrogates considering life support "*clearly conceptualized their role as enacting their loved ones' wishes, yet found adherence to this approach was difficult in light of their own or the family's emotional needs"* (p. 1663). Difficulty adhering to patient's wishes led to feelings of "*guilt*", "*struggle*" and "*tension*" as families making these decisions tried to balance what was best for everyone (Sarabia-Cobo et al., 2016; Schenker et al., 2012);

> "*I know she would want me to make this decision…to just take charge and just say '…that's enough, just let her go' . . . that might be the part that bothers me: that I'm kind of holding back…I gotta look at if I'm being selfish…it goes through my head every day"*" (Schenker et al., 2012, p. 1661).

On the other hand, despite their good intentions (to relieve suffering) when withholding/ withdrawing treatment, families blamed themselves and experienced profound guilt if they felt their decisions had precipitated the patient's death. Liu and colleagues (2014) found;

> "*Once they signed the DNR form, parents described how they felt pressure or like an 'executioner' who had given up on their own child. They blamed themselves, feeling that they were not being good guardians of their child by signing the DNR form"* (p. 32).

Another mother who agreed to DNR shared, *"I felt it was like throwing my child into water but he could not swim and was going to drown. I really could not stand this"* (Liu et al., 2014, p. 32). In this study and in Schenker and colleagues (2012) study, the act of signing a document seemed to fortify families' feelings that they were responsible for the patient's death; "*But just knowing like, that I might be signing her death sentence, more or less, you know… that's what's hard"* (p. 1660). In other cases, patients' deterioration after treatment withdrawal led to feelings of guilt and feeling responsible for their loved one's death. For parents who chose to withdraw artificial

hydration/nutrition for their newborn, if death took more than 3-4 days to occur and the child's physical appearance began to deteriorate;

> *"They wonder if their infant not rather dies from starvation than from her disease, what is absolutely unbearable for them as parents. They feel profoundly guilty not having been able to protect their little one against a supplementary and so aggressive ordeal"* (Fournier et al., 2017, p. 369).

These feelings of guilt transpired even when the decision makers believed that treatment withdrawal was the "appropriate" choice;

> *"Often when physicians proposed withdrawal of active treatment, families felt they were being asked to terminate a loved one's life even if they intellectually recognized the cessation of acute care was appropriate: 'I felt guilty, guilty, guilty! I felt I was pressing the button for her life to end'"* (Moon et al., 2021, p. 5).

Other times, families simply could not enact their sense of responsibility to protect patients' wishes and well-being, as they had been excluded from the decision, which led to more feelings of "*grief and guilt*";

> "*The ability to advocate was an integral component of [surrogates'] relationship with the patient and an expression of love and commitment. Feelings of grief and guilt surfaced during bereavement if families perceived physicians disregarded their advocacy, and therefore they had failed to protect their loved one"* (Moon et al., 2021, p. 4).

The inability to advocate for their loved one "*galvanized families' distress*" and left families feeling like they "*didn't do enough*"; "*My thoughts at that time were – still are – that I didn't do enough"* (Moon et al., 2021, p. 4).

Healthcare professionals could help alleviate some of this burden experienced by decision makers. Firstly, Moon and colleagues (2021) explained that healthcare professionals could facilitate "transitions to end of life" by "*acknowledging a family's expertise of the patient as a person and understanding families' need to advocate on patients' behalf"* (p. 6). Long and colleagues (2011) found that nurses can help reassure families experiencing doubt;

> "*I'm talking out loud to this nurse going 'Oh my God, I don't know if I did the right thing, I'm just not sure what I'm doing.' She turned to me and she goes, 'You made the right choice, because look, he is going now on his own.' He was kind of like telling me, 'know you did the right thing'"* (p. 208).

Decision makers were also reassured and felt "*peace*" when healthcare professionals reframed the patient's death as due to their disease and not the treatment withdrawal decision (Long et al., 2011; Moon et al., 2021). Sellars and colleagues (2018) found that having a clinician present whose role was to mediate and facilitate end of life discussions helped patients feel more comfortable discussing "*topics that would have otherwise been avoided"* (p. 219) which highlights how nurses can help with the distress associated with preparing for end of life.

"Sense of responsibility" was related to the concept of "reliance on relationships" in a few ways. Patients considered having to rely on others as being equivalent to "being a burden" and felt a sense of responsibility to protect their families from such dependence. One woman with ALS recalled how difficult it was for her to care for her mother who had died of a motor neuron disease, which prompted her to refuse ventilation, so as to avoid becoming dependent on, and "burdensome" to her own family;

> *"So I'd love to just go [die] quick. I would hate to have to depend on everyone having to do everything for me. . . . All the pain and anguish and the anger and everything that I went through, and I'd hate to inflict that on them"* (Foley et al., 2014, p. 72).

On the other hand, patients and families were aware of how their families relied on them, and felt a sense of responsibility to consider this reliance when making decisions. Many of the participants who had young, dependent children considered their "*sense of duty toward their children*" when making decisions about potentially life-sustaining treatment at end of life (Foley et al., 2014, p. 73). A patient with end stage kidney disease decided to pursue dialysis because his wife urged him to go for their children; "*You've got to go, come on, the kids are only young"* (Sellars et al., 2018, p. 221). In contrast to this, patients who had no partner or young, dependent children felt they had "*more freedom*" to decide as they pleased, with one participant who chose to decline ventilation saying, "*You see, I don't feel I have the need to hang on at any cost. If I had a husband, wife, children, it might be different"* (Foley et al., 2014, p. 72). When contemplating potentially life-sustaining treatment that may cause significant disability, one adolescent shared that if their family "was not around," they might choose differently;

> "*It would depend on how it would affect my family in that situation. Like, if they would, like, want me alive or what." Mother: "What if I wasn't around and it was going to be a nurse [caring for you], you know?" Pt: "Then I would want to die, so the second option"* (Needle et al., 2020, p. 286).

Patients whose illness would necessarily create a reliance on others (e.g. ALS) were often conflicted – they felt a sense of responsibility to avoid choosing treatments that would create a reliance on their loved ones, but also felt a sense of responsibility to "*be there*" for their families;

> "*'(P): I want to be here for as long as I can, yeah. Interviewer (I): So then you might choose them [life-sustaining interventions] to help you stay alive? (P): Oh yeah, but without being too much of a burden on (spouse)…"* (Foley et al., 2014, p. 72).

On the other hand, patients and families were sometimes eager to rely on others (e.g. other family members, God) during the decision making process so as to share the responsibility of the decision and alleviate their feelings of burden and worry. Reliance on and belief in God alleviated the burden of the decision for some decision makers (Liu et al., 2014; Schenker et al., 2012). In Schenker and colleagues' study (2012), the majority of participants "*spoke of prayer as a source of hope, solace and community"* and for some, "*involving God in decision making relieved the weight of responsibility they bore and helped them to feel less alone"* (p. 1663). Families also sought to "*share the burden of decision making*" with other family members which eased their fears of later being "*blamed for a patient's death or disability*" (Schenker et al., 2012, p. 1662). When decision makers were not able to rely on family and share the responsibility during the decision making process, "*the decision became more frightening and difficult as a result"* (Wilson, 1993, p. 303) –"*it was sort of on me, by myself"* (p. 305).

"Sense of responsibility" was also related to the concept of "closeness in relationships." A close relationship with the patient amplified families' sense of responsibility to the patient when making decisions about potentially life sustaining treatment at end of life;

> "*I've always dreaded being in a situation like this, where you do have to take responsibility for decisions you make about somebody else… and that somebody else is… it's not somebody else, it's my mother, someone I love, I hold dear…it's […] it's just…it's tough, it's tough*" (Schenker et al., 2012, p. 1660).

Another participant in this study wanted to respect their mother's wishes, but had trouble agreeing to withhold treatment because it was "his mom"; "*It's just, um…you know, like… it's your mom, you want her around for…ever, if you could have her around forever"* (Schenker et al., 2012, p. 1660). Quotes such as these also served as a reminder that decision makers were not making these decisions for a stranger, but rather for someone that they loved, dearly.

Normative Discourses: "Tube feeding does not improve nutritional status"[10]

The findings above outlined how the experiences of patients and families' making decisions about potentially life-sustaining treatment at end of life affected, and were affected by the relationships involved. In this section, I look more closely at the normative discourses reflected in my sample, prompted by my consideration of how the healthcare philosophies described in Chapter 2 impacted authors' study and portrayal of the above experiences. Despite the fact that the studies in my sample advanced the ideas above (e.g. about the importance of relational connections in decision making at end of life), there were many instances of normative discourses within authors' writing. Here I describe how, through their tone and language, authors supported and endorsed notions of objectivity and individual autonomy in decision making, and discouraged the occurrence of what they deemed false hope.

Encouraging Objectivity. Authors often suggested that decisions about potentially life-sustaining treatment ought to be based on empirical research and objective clinical results. Authors maintained that this objective data was required to make "informed decisions" and expressed concern when decisions about potentially life-sustaining treatment were based on subjective, uncertain, or emotional data. For example, Seah and colleagues (2013) seemed troubled when patients based their decision to decline dialysis on subjective "*hearsay*" and "*lay*"

[10] Maura et al., 2019, p. 1.

stories rather than "*information provided in the context of medical consultations"* (p. 1026). These authors seemed concerned that these subjective stories would lead to "*misunderstandings about dialysis fuelled by biased information"* (Seah et al., 2013, p. 1027). Some authors suggested that receiving information and making decisions should not occur in an emotional state, as emotions were perceived as affecting the understanding and use of objective information and thus, as hindering the decision making process. Colclough and colleagues (2014) listed "*a belief in healing*" and emotional experiences such as "*being in denial or a depression stage*" as "*barriers*" to understanding and accepting patients' diagnoses and prognoses (p. 508). These authors explained that "*without rational reasoning or adequate knowledge, decision making and quality of life would not be optimized"* (Colclough et al., 2014, p. 509). Recurrently, authors referred to basing decisions on anything other than objective, scientific data as "unfortunate"; "*unfortunately, the most influential factors in decision-making were: […] lack of knowledge over what tube feeding involved, and the belief that tube feeding would not prolong her mother's life* (Wilson, 1993, p. 299). This is not to suggest that adequate understandings of illness and treatment options are not important for decision making, but rather serves to highlight the type of understanding and information (i.e. objective and scientific) that tended to be upheld.

Authors also supported treatments that were 'objectively' indicated or 'objectively' in the patient's best interest and discouraged treatment choices that were, as per objective data, contraindicated. For instance, Maura and colleagues (2019) called the use of tube feeding in patients with advanced dementia "*controversial*" since objectively; "*tube feeding does not improve nutritional status, prevent aspiration pneumonitis, or improve quality of life and vital signs in patients with severe dementia"* (pp. 1-2). Authors also seemed to question when patients or families chose to pursue treatment which, 'objectively,' might not benefit the patient; "*despite*

[receiving] data on limited effectiveness, patients requested chemotherapy" (Norton et al., 2019, p. 671). In Zaal-Schuller and colleagues (2016) study, there was evidence that this emphasis on objectivity also influences legislation, as the Dutch Medical Treatment Act promotes treatment that is 'objectively' indicated and discourages treatment that is 'objectively' contraindicated;

> "*In children who lack decision-making capacity, informed consent from their parents is needed before treatment can be started. However, if a parent refuses to allow treatment but there is no question that this treatment is obviously necessary, the physician is allowed to treat the child without parental consent. In cases in which treatment clearly will not be beneficial to the patient, physicians are not obligated to provide treatment, even when parents request it"* (p. 284).

To note, although the principles of beneficence and non-malificence likely also influenced these citations, the notion that treatments can (and should) be 'objectively' indicated is apparent.

Encouraging Individual Autonomy. As described in the themes above, authors' studies revealed that patients and families frequently and importantly considered their relationships in their decision making. Nonetheless, authors' often endorsed decisions that were based on patients' individual preferences and that respected individual autonomy. Authors recurrently suggested that patient preferences should guide decision making above all else. Lind and colleagues (2012) wrote that end of life decisions "*should be based on the patient's wishes"* (p. 667) and Sarabia-Cobo and colleagues (2016) reiterated that "*the wishes and preferences of patients with dementia should inform the decisions made about their future care"* (p. e6). Authors promoted individual autonomy in their writing by pointing to the benefits of respecting autonomy; "*it is through autonomy that people exert control over decision making"* (Romo et al., 2017, p. e70) and by advocating for procedures such as the completion of an advanced directive

which is "*a step beyond informed consent in that it provides context and respect for patient autonomy"* (p. e6). Authors also demonstrated disapproval when patients' preferences and autonomy did not guide the decision; *"It must be noted that the primary factors that should have influenced this decision were the values and preferences of the mother"* (Wilson, 1993, p. 307); "*Patient autonomy, reported to be the current guiding principle behind life-support decisions, was a theoretical and not practical principle in this case"* (p. 308). Ultimately, authors discouraged treatments that were undesired by patients. As Needle and colleagues (2020) wrote; "*emerging literature demonstrates the benefits of adolescent and young adult advance care planning, including the avoidance of unnecessary or undesired treatments"* (p. 282). Sarabia-Cobo and colleagues (2016) expressed similar thoughts; "*given the lack of residents' cognitive capacity and the low prevalence of advance directives, this population is especially vulnerable to either over- or under-treatment at the end of life"* (p. e7). Thus, authors' writing created an overall tone suggesting that treatment choices should, above all else, respect patients' individual wishes.

Discouraging False Hope. Authors' articles recurrently presented a compelling critique of the good death discourse (e.g. by recognizing that some families desired to pursue potentially life-sustaining treatment at end of life in order to 'fight' for their loved one's life) (Moon et al., 2021). Despite this, authors' writing nonetheless reinforced (and was perhaps influenced by) the notion that a 'hyper medicalized' death would be harmful and that preventing "*timely and appropriate transitions to end of life care"* would "prolong patient suffering" and "result in conflict" (Moon et al., 2021, p. 2). Liu and colleagues (2014) wrote;

> "*The introduction of increasingly invasive medical interventions and technologies has made an impact on this [dying] process, so that children with life threatening conditions*

> *who previously would have experienced a more immediate, natural death, are spending increasing lengths of time in a prolonged state of postponed death"* (p. 29).

Thus, authors endorsed less 'hyper medicalized' deaths, with many authors expressing concern that "*only*" a minority of patient deaths occurred in hospice (Norton et al., 2019; Sellars et al., 2018). Githaiga and colleagues (2017) question "*why some families kept their relatives in hospital despite their knowledge that their illness was terminal; nine out of 13 patients died in hospital"* (p.6). Indeed, when illness was advanced and death was foreseeable, authors tended to encourage decisions to withhold/withdraw potentially life-sustaining treatments. Norton and colleagues (2019) referred to the discontinuation of chemotherapy when patients were in the terminal stage (and unable to tolerate more chemotherapy) as "*the obvious and sensible (albeit unwelcome) next step"* (p. 671). Seah and colleagues (2013) also suggested that when there is "*worse co-morbid loads and poor general condition*" as well as "*uncertainty on survival benefits,*" recommending dialysis becomes a "*dilemma*" (p. 1019). Fournier and colleagues (2017) wrote at length about our "duty" to create a good and "*merciful death*" –even if that required a palliative 'medicalization.' They found that 3-4 days after withdrawing artificial hydration/nutrition, changes in the child's appearance made parents feel that they were "*starving*" their child to death so, to protect them from such an ordeal, the authors suggest that; "*healthcare professionals have a duty to control the timing of death, even though this might be incompatible with the worry to avoid the intention of hastening the baby's death"* (Fournier et al., 2017, p. 365). They suggest that our main concern should be *"how [death] can be assisted in the least painful way possible; that is to say, in the most 'humane' way possible"* (Fournier et al., 2017, p. 371).

Authors advocated for an acceptance of the patient's impending death to protect patients and families from the conflicts and issues that they attributed to a lack of acceptance;

> "*Their level of support for the patient reflected their level of acceptance of the patient's illness as those who could not accept the patient's illness took non-supportive actions or self-destructive behaviours. 'Well, of course, right at first it was really a shock, and I was angry at the doctors and the hospital. And I was even angry with her for not letting me know ...'"* (Colclough et al., 2014, p. 508).

Sellars and colleagues' (2018) seemed to advocate for acceptance of poor prognosis, since they found that "denial" delayed end of life planning; "*some participants who refused ACP were unable to accept that the patient was 'really that sick'"* (p. 218). Liu and colleagues (2014) suggested that parents' "false hope" that their child could survive should be "mitigated" seemingly out of an aspiration to protect parents from disappointment;

> *"Many of the parents in this study retained some hope for their child, even though they signed the DNR form. It supported our impression that most parents had difficulty facing the real possibility that their child might die young, looking for a miracle to occur. Parents need to be encouraged to express their inner conflicts to help mitigate false hope"* (p. 33).

Thus, despite finding that decisions about potentially life-sustaining treatment at end of life can be based on subjective, emotional data, that patients and families often consider their relational ties in decision making, and that a desire to 'fight' sometimes occurs at end of life, authors' writing tended to reflect normative discourses, namely that decisions should be based on objective data, respect patient's individual (rather than relational) autonomy, and that false hope should be mitigated.

Chapter 5: Discussion

This thesis described a metasynthesis of qualitative research about patients and families' experiences of making decisions about potentially life-sustaining treatments at end of life. Guided by relational ethics, I conducted this metasynthesis with the aim of gaining insight into the inter-subjective nature of patients and families' experiences (i.e. how their relationships impacted and were impacted by these experiences and decisions). I also sought to explore how healthcare philosophies (namely the biomedical approach, the palliative approach, shared decision making approach and notions of a good death) influenced authors' study and portrayal of these experiences. In this chapter, I will begin by summarizing the findings uncovered by this metasynthesis and then, I will discuss how these findings relate to the theoretical underpinnings of this study and existing literature. Then, I will outline the implications that these findings have for nursing practice, education and research, followed by the limitations of this study. This chapter will conclude with my reflections about how this thesis has impacted my practice as a clinical nurse.

Summary of Findings

The themes presented in Chapter 4 (Findings) shed light on the ways in which patients and families' relationships impacted their experiences of making decisions about potentially life-sustaining treatment at end of life. Healthcare professionals' relational approaches, particularly their openness, honesty and empathy, impacted not only patients and families' emotional experiences but also their comprehension and use of any information provided. Without honesty and empathy from healthcare professionals, patients and families reported feelings of anger and shock, as well as an overall poor understanding of the prognosis and options available. Healthcare professionals' relational approaches (their openness, honesty, empathy) thus affected

access to information and care, as well as patients and families' inclusion (or exclusion) in the decision making process. Relationships with family members considerably impacted patients' sense of identity and quality of life. Even if advanced illness was present, when relational ability and relational closeness were present, patients' sense of identity and quality of life was maintained. Patients and families relied on the persons they had a close relationship with for practical help and support throughout the decision making process. Personal relationships also created a sense of responsibility to the other; a sense of responsibility to ensure that their loved ones' well-being and wishes were protected in the decision making process. Behind the scenes, tensions often arose between families' senses of responsibility (e.g. to protect patients from death but also to prevent further suffering with treatment), which led to a difficult deliberation process and feelings of burden and guilt.

Studies in this sample offered a critique of normative discourses. For example, given that authors' findings suggested that decision makers considered their relationships when making decisions, authors offered a critique of the importance placed on individual autonomy and created a case for relational autonomy. However, despite critiques of normative discourses in their study findings, authors' writing nonetheless reflected normative discourses, in some instances. In a number of authors' texts, the importance of objectivity, respecting individual autonomy and mitigating false hope was reinforced. Authors endorsed decisions that were based on scientific, objective data, and that respected patients' individual autonomy, above all else. They suggested false hope should be mitigated in most circumstances.

Theoretical and Empirical Perspectives

The following section will relate my study findings (detailed in Chapter 4) to existing literature and the theoretical underpinnings of this study (detailed in Chapter 3), namely

relational ethics and relational autonomy, the biomedical approach, notions of a good death, and the palliative approach and shared decision making approach.

Relationality in Decisions about Potentially Life-Sustaining Treatment

The findings of this metasynthesis outline the importance and impact of relationships on patients and families' experiences of decisions about potentially life-sustaining treatment at end of life. Recall that relational ethics asserts that an ethical interaction is characterized by mutual respect, engagement, embodiment, environment and uncertainty. My study findings (Chapter 4) illuminate the ways in which patients and families enacted these tenets in their relationships with each other, and the ways in which these tenets tended not to occur in their interactions with healthcare professionals. I will describe these occurrences in this section.

Patient-Family Relations. I begin with the theme "sense of responsibility" because it represents the epitome of relational ethics; that relationships are the center of morality and that relationship fosters a sense of responsibility to others (Bergum, 2013; Pollard, 2015). Patients and families experienced a sense of responsibility to protect their loved ones' wishes and well-being with their decisions and the decision making process. Decision makers experienced a sense of responsibility to engage with, consider and respect their environments (i.e. their family members and society) when making decisions about potentially life sustaining treatments at end of life. They sought to respect decisions and preferences that were different than their own and tried to work with each other to come to a decision. Similar to relational ethics and relational autonomy, the theme "sense of responsibility" highlights the fact that we are socially embedded, interrelated beings, and thus respecting and understanding our environments (e.g. social contexts and obligations) necessarily occurs when making decisions (Killackey et al., 2019; Wright & Brajtman, 2011). Indeed, patients and families seemed to adopt a relational approach to

autonomy. They sought to uphold individual wishes but were also aware that decisions occurred within the context of relationships, and would impact more than their own future or well-being. Families' consideration of their relationships when making decisions about potentially life-sustaining treatment at end of life is a finding articulated earlier by Meeker and Jezewski (2008), in their metasynthesis.

Tensions existed between the different responsibilities patients and families sensed during decision making (e.g. the sense of responsibility to protect patients' wishes sometimes conflicted with their sense of responsibility to protect the rest of their family's wishes), which created difficulty in decision making. The theme "sense of responsibility" thus suggests that patients and families may hesitate with decisions about potentially life-sustaining treatment at end of life given all that they consider, and the tensions between all that they consider, and not necessarily because they misunderstand how poor prognosis is, or the implications of treatment. The difficulty of navigating these tensions also offers insight as to why decision makers are eager to rely on others during the decision making process, and emphasizes the importance of healthcare professionals' engagement and support. The findings of this metasynthesis also suggest that these difficulties occurred behind the scenes, as these considerations seemed to happen in interactions among family members, not with healthcare professionals.

In their relationships with one another, patients and families demonstrated mutual respect. As mentioned, they attempted to account for others' wishes, to consider how decisions would impact others, and were willing to bracket their own preferences to protect the wishes or well-being of another. Recall, relational ethics also holds that mutual respect involves considering and respecting the personhood of individuals at all times, no matter their physical state (Pollard, 2015; Upasen, 2018). The theme "identity and quality of life in relationships"

demonstrates ways in which families exercised this notion. Although families sometimes considered that their loved one was 'no longer there' due to their deteriorated ability to interact with others, more frequently, families explained how they felt their loved one was 'still with them' despite their advanced illness. When making decisions about potentially life-sustaining treatment, families took their loved one's personhood into account and often concluded that, despite severe illness, their loved one's life was still worth living and saving, which impacted their decisions. This is not to suggest that choosing to withdraw or withhold treatment would necessarily be disrespectful of a patient's personhood. Rather, what would be disrespectful would be to disregard it, assume it is not present, or to give it no weight in decision making.

My study findings also highlight the presence and importance of embodiment in patients and families' experiences. Recall that the daughter in Wilson's (1993) case study shared that, through physical contact with her mother's body, she perceived her mother's identity to be maintained. This supports the premise of embodiment; that the sense of self is "inexorably linked" to one's body, since it was interactions with her mother's body that created a sense of identity for her mother (Wright & Brajtman, 2011, p. 25). Additionally, patients and families' desire to be physically close to one another (e.g. families' desires to be able to touch their loved ones once treatments were withdrawn) further supports the notion that we are embodied beings, that our bodies are part of what connects us to others and that our bodies are the means by which we experience the world (Bergum, 2013; Wright & Brajtman, 2011).

Patient/Family-Healthcare Professional Relations. The themes "closeness in relationships" and "reliance on relationships" underline the fact that patients and families longed for (and required) engagement with healthcare professionals when making decisions about potentially life-sustaining treatment at end of life. My study findings suggest that it was often

due to the lack of engagement from healthcare professionals that left patients and families feeling angry, confused, shocked and alone in their experiences. In the studies in my sample, without engagement and information from healthcare professionals, families were often unaware of patients' guarded prognosis; they relied on healthcare professionals' engagement to understand the patient's health and illness trajectory. My findings also suggest that this lack of engagement (and the subsequent lack of information regarding the patient's illness and prognosis) may be contributing to the prolonged distress that occurs after patients' deaths. Poor engagement and information exchange left families wondering 'what happened,' after the patient had died. This is in contrast to the instances in my sample where healthcare professionals did engage with patients and families, by providing honest information and being available, which led to feeling prepared, supported and satisfied. In their metasynthesis, Meeker and Jezewski (2008) also found that lack of honest and thorough information from healthcare professionals could cause families to experience guilt over decisions about potentially life-sustaining treatment that were made without this information.

Patients and families depended on engaged healthcare professionals to adequately understand patients' health and treatment options, including that patients were dying or that palliative care was an option. Recall that the literature tends to suggest that patients and families do not choose to withhold or withdraw treatment at end of life because they are in denial or have misunderstood the patient's prognosis (Blumenthal-Barby & Ubel, 2018). My study findings suggest, however, that this hesitation to withhold or withdraw treatment may instead be because they are not aware that doing so is an option, or they did not receive honest information from healthcare professionals to suggest that the patient may be dying. Only some authors recognized that misunderstandings were, at least partially due to lack of guidance and engagement from

healthcare professionals. For example Wilson (1993) called the fact that healthcare professionals did not inform the patient's daughter that complete dysphagia would eventually occur as an 'unaccountable' oversight. To note, I am not suggesting that denial does not occur or that every instance of hesitation or misunderstanding is due to healthcare professionals' lack of engagement. I am suggesting that, as my findings imply, we must recognize that patients and families are dependent on our expertise and knowledge, and that honesty (with empathy) is paramount. As well, rather than simply blame patients and families for 'not getting it,' we healthcare professionals should instead accept some responsibility, and consider whether we've been engaged, honest, clear and available to the patients and families we care for.

As well, patients and families longed for healthcare professionals to move towards them, work with them, and create space for them in the decision making process (albeit, not always). As explained in Chapter 3, engagement entails nurturing persons' individuality and giving space to their voices. Often times however, as my findings affirm, patients and families' voices or preferences were not solicited until late into the illness, if at all. On many occasions, it was not considered or accepted that individuals' preferences may differ, or that persons may not wish to pursue potentially life-sustaining treatments deemed indicated. Thus, it seems patients and families' choices were not always met with 'mutual respect' which, recall, entails being reflexive about our assumptions and being open to views that may be different than our own. Instead, patients and families often felt they could not refuse the treatment course proposed. Not feeling heard or as though they had no choice led to feelings of defensiveness, a loss of sense of control and a desire to move away from healthcare professionals. However, some patients and families were happy to entrust their decisions to a healthcare professional who they had an engaged relationship with, and whom they trusted.

The above suggests that patients and families approached decisions about potentially life-sustaining treatment differently than healthcare professionals, and placed value or importance on different considerations during the decision making process, compared to healthcare professionals. Patients and families approached these decisions in a relational manner. They engaged with their loved ones, considered others' preferences and sought to respect wishes that were different than their own. Healthcare professionals, on the other hand, tended to approach these decisions in a more scientific manner; they assessed which path seemed empirically best, based on biomedical knowledge, and sought to follow it.

Influence of the Biomedical Approach

My study findings underscore the effects and dominance of the biomedical approach within relationships and decision making at the end of life. Recall, the biomedical approach reduces the body into parts and focuses on that which is material, visible and objectively measurable, (Chan et al., 2009; Feo & Kitson, 2016), thereby creating a split between the mind and body, as it views objective and subjective as opposites (Wade & Halligan, 2004). This approach also holds that health is the absence of disease, that illness experiences are universal, and thus, that there is a single, universal truth about how to return to a state of health in any given circumstance, which does not require consideration of individuals' social and cultural contexts (Chan et al., 2009; Wade & Halligan, 2004). In this section, and using my study findings, I hope to illuminate some of the ways in which these assumptions of the biomedical approach impacted relationships between patients/families and healthcare professionals as well as patients and families' experiences of making decisions about potentially life-sustaining treatment at end of life. I will also explain the parallels that exist between the notions of a good death and the biomedical approach.

The prevalence of this approach can explain, at least in part, the relational distance that often occurred between patients/families and healthcare professionals. The biomedical approach focuses on the 'physical, visible and objectively measurable,' and gives less importance to that which is intangible and subjective (e.g. relationships and personal experiences) (Feo & Kitson, 2016). Thus, within the biomedical approach, the focus is "on the patient as a body to do things to, rather than a person to engage with" (Feo & Kitson, 2016, p. 5). This risks making the patient, as a person, "invisible" (Mazzotta, 2016, p. 97) and results in unengaged relationships as interactions would be focused on physical, measurable parameters, such as vital signs, rather than the relationship or person. This would explain why in Lind and colleagues (2012) study, for example, the nurses were fixated on the patient's oxygen measurements and focused on this measurable parameter during their interactions with families, which limited their engagement. This may also explain why, when patients' treatment plans focus on comfort (e.g. Emma's case in Chapter 1), we engage less with them and their families, and spend less time in their rooms, since there are less 'objectively measurable' parameters to focus on.

On a larger scale, authors have explained that the biomedical approach's focus on the physical and measurable has impacted the structure and priorities of our healthcare system as a whole. As a result of the prioritization of such parameters, the efficiency of healthcare professionals and institutions is being calculated in terms of physical, objectively measureable parameters (e.g. rates of discharge) (Feo & Kitson, 2016; Mazzotta, 2016). Our healthcare institutions are thus set up in a manner (e.g. in terms of staffing) that optimizes and prioritizes efficiency and measurable deliverables, and creates little time for us to focus on engagement and relationships or to provide care beyond biomedical tasks (Feo & Kitson, 2016; Mazzotta, 2016). The result is "a model of care that is depersonalised, mechanistic, and transactional, where the

focus is on patient throughput and output […] at the expense of a relational model focused on engaging meaningfully with people to deliver personalised care" (Feo & Kitson, 2016, p. 5). In addition to making it difficult for us to engage with the persons we care for, placing primary importance on measurable parameters and efficiency can create notions like the one expressed by a participant in Sellars and colleagues' (2018) study; that the "government [shouldn't] spend millions to keep [patients] alive once [they] can't do things' because 'if the brain doesn't work there's no use wasting money'" (p. 218). Thus, cost-saving discourses have become so strong that we have allowed them to influence our ethical calculus around death and dying.

In addition to its focus on the physical and measurable, the biomedical approach has a reductionist view of individuals and separates persons into parts, so as to more efficiently treat disease (Chan et al., 2009; Feo & Kitson, 2016). Together, these assumptions mean that the biomedical approach focuses mainly on the body and its measurable parameters, and has difficulty viewing persons as whole, interconnected beings (Chan et al., 2009), especially when disease is present (Wade & Halligan, 2004). The biomedical approach asserts that health is the absence of disease, that disease is the occurrence of a measureable, abnormal pathology and that health cannot exist when disease is present (Wade & Halligan, 2004).Thus, the biomedical approach seems to suggest that health is another entity that can be objectively measured and, based on what is visible and measurable, is or is not present, regardless of a person's experience of the abnormal pathology (Wade & Halligan, 2004). It would therefore follow that this model cannot uphold the notion that health and wholeness can exist amid disease; and especially not amid advanced, severe disease. This may explain, at least in part, why, across my sample and other literature, withholding and withdrawing potentially life-sustaining treatment seemed more permissible and acceptable when disease was severe or when disability or advanced age were

present. When measurable ‘abnormal pathologies’ are as numerous as they are in these individuals, the biomedical approach suggests that health and wholeness can absolutely not be present. For example, this may be why the daughter in Wilson’s (1993) case study was encouraged to withhold artificial nutrition for her “severely debilitated” mother; because the biomedical approach holds that well-being cannot exist in her mother’s case. The reality is, of course, that despite many ‘pathological abnormalities,’ patients with advanced illness were able to lead meaningful lives. I acknowledge that the meaningfulness of her mother’s life was assessed by the daughter in Wilson’s (1993) case study, and not the mother herself. Nonetheless I wonder who would be better positioned to assess her mother’s quality of life – healthcare professionals who barely know her, or her daughter who has an intimate relationship with her.

Underlined by a realist ontology, the biomedical approach claims that medical knowledge is “objectively ‘true’ and ‘real’” and thus that, within healthcare decisions, there is a single, universal answer, or truth, that is applicable, regardless of an individual’s contexts and experiences (Chan et al., 2009, p. 118). In fact, recall that biomedicine suggests that “phenomena are better understood outside their context, separated from related people or objects and the emotions and meaning that patients associate with them” (Chan et al., 2009, p. 118). Given its assumption of single truths, and its omission of individual contexts, the biomedical approach seeks a ‘one-size fits all’ answer to situations (and asserts that this is best) and does not support individualized care (Chan et al., 2009; Feo & Kitson, 2016). As Wade and Halligan (2004) have explained, within a biomedical approach, “the patient is a passive recipient of treatment” (p. 1398). This means their input has little impact or importance in decision making, since medical knowledge has already uncovered the best course to be followed (Feo & Kitson, 2016). This may further explain why healthcare professionals tended not to engage with patients and families or

create space for them in the decision making process. The best way forward was uncovered by medical knowledge and did not require any or much information from them. The reality, though, is that patients and families have a social context and unique needs and preferences that ought to be considered in decision making. This will be expanded on in the next section, below.

Given its view of health and disease, it would follow that the biomedical approach seeks to resolve any abnormal pathologies to return to what it considers a state of health (i.e. the absence of abnormal pathologies). In addition, Chan and colleagues (2009) explain that the biomedical approach "understands competence to mean doing everything possible to save lives and avoid the 'failure' of death" (p. 122). Thus, within the biomedical approach, the norm and goal would be to save lives, avoid death, treat abnormal pathologies, and do so according to the 'universal truth' of how to accomplish this (Chan et al., 2009; Wade & Halligan, 2004). Together, this may be contributing to the general apprehension of death and palliative care, the view that pursuing potentially life-sustaining treatments when illness strikes is the expectation or that choosing not to pursue biomedical treatment is equivalent to 'giving up.' The biomedical approach sets these (aversion of death and the use of potentially life-sustaining treatments when 'abnormal pathology' occurs) as the standard, and what we are expected to do. Recall in Norton and colleagues' (2019) study, a patient's wife shared that the oncologist asked if they wanted to "try another chemo treatment, discontinue treatment, or try experimental" (pp. 671-672). This implies that the options were biomedical treatment or nothing, which reinforces the notion that potentially life-sustaining treatments are the standard. In their qualitative interview study that explored parents' treatment decision making process for their children with cancer, Badarau and colleagues (2017) also found that parents felt their options were "between having and not having treatment" (p. 24). To note, I am not suggesting that we should not offer potentially life-

sustaining treatments or not aim to save patients' lives. I am suggesting we should not assume that every patient and family desires this course, and that we create space for other treatment courses within healthcare. Indeed, within my sample, there were individuals who preferred not to pursue the scientifically recommended potentially life-sustaining treatment for their illness (Seah et al., 2013; Sellars et al., 2018).

My study findings suggest that patients and families placed less importance on the biomedical approach than some authors and healthcare professionals. While some authors advocated for decisions based on empirical, measureable data, patients and families were willing to base decisions on lay stories or uncertain, emotional data and approached decisions more relationally (as described above). The different importance placed on the biomedical approach may partially explain the disagreements about treatment course that occurred between patients/families and healthcare professionals within the studies of my sample. This may have also contributed to the tensions patients and families experienced during decision making (described in the theme "sense of responsibility") as they tried to balance their relational ethical approach with the opposing assumptions of the biomedical approach. The findings in Chapter 4 reveal that patients and families considered their relationships, but also considered what was objectively indicated, and experienced tension or difficulty as they tried to balance these. However, this tension is not necessarily something that ought to be removed. Recall, relational ethics asserts that it is important to hold space for tension between differing values. What ought to occur, however is an acknowledgment of the existence and emotional impact of this tension.

All of the above has brought me to the conclusion that the predominant "notions of a good death" have many parallels with the biomedical approach. Firstly, similar to the 'one-size fits all' approach of the biomedical approach, the good death discourse leads us to believe that

there is one right way to die. Secondly, (and related to the above), both the biomedical approach and notions of a good death suggest that individual contexts would not impact the best course of action, and need not be considered. Lastly, the good death discourse tends to encourage basing treatment choices on objective parameters (e.g. when data suggests potentially life-sustaining treatments are no longer effective, such treatment should be withheld or withdrawn), which is similar to the biomedical approach's focus on these parameters.

The biomedical approach is so prevalent and extends into philosophies of knowledge creation that, despite my reservations about its dominance, I find myself wanting to quantify the impact of healthcare professionals' relational approaches, or provide measurable evidence to justify the importance of this study and of patients and families' experiences. I feel the need to present objective measurements that show that engagement, honesty and empathy leads to improved decision making, or that relational experiences are associated with improved patient outcomes. Feo & Kitson (2016) explain that the biomedical approach tends not to value relational, psychosocial experiences or outcomes, as these are not physical, visible or measureable. Of course, the findings of this study do show that relational approaches are impactful. An unengaged, dishonest, unsupportive approach can lead to feelings of shock, confusion, anger, and loneliness. This study also shows that overall experiences are important as well; distressing experiences can have a lasting impact, even after the patient has died. I simply cannot quantify the impact of these approaches and experiences, which, although the biomedical approach suggests is problematic, I disagree.

Moving Towards Person-Centered Care

It became clear as I completed this metasynthesis that much of what is missing in healthcare professionals' interactions with patients and families (e.g. honesty, empathy, and

engagement) could be addressed by approaching care in a more person-centered way. Indeed, many authors advocate for a movement away from the biomedical approach, and a move towards a more holistic, relativist approach to care, where the patient as a whole person is the focus of our care (Chan et al., 2009; Feo & Kitson, 2016; Mazzotta, 2016). Chan and colleagues (2009) have asserted that "there is a need to subscribe to a more relativist approach to knowledge, one that recognizes several possible truths" (p. 119). They explain; "if we subscribe solely to a realist view of biomedical knowledge […] we invalidate other ways of knowing and understanding experiences of illness, death and dying, therefore invalidating end-of-life experience of many people" (Chan et al., 2009, p. 119). A more holistic approach to care would urge us to see the persons we care for not merely as patients with a disease, but "as *persons* with unique circumstances that impact their illness and recovery" (Feo & Kitson, 2016, added emphasis, p. 5). Importantly, as Mazzotta (2016) explains, the goal is not to view biomedicine or technology as a hindrance to holistic care but rather to see "diverse nursing knowledge including technology, equipment, and lifesaving measures as part of holistic care" (p. 94). This is why I advocate here for a "move towards" holistic care and not an elimination of the biomedical approach.

As described in Chapter 2, person-centered care is an important tenet of the palliative approach and, as I will clarify throughout this section, an important aspect of shared decision making. Therefore, I discuss my findings in relation to person-centered care rather than the palliative approach and shared decision making approach, because it is this aspect (person-centeredness) of these approaches that is responsive to the difficulties explained above. My choice of 'person-centered' as opposed to 'patient-centered' is also intentional, as the former emphasizes the personhood of individuals, whereas the latter can obscure personhood by focusing on illness (Slater, 2006). In fact, as described in Chapter 1, I was tempted to refer to

patients as ‘persons’ throughout this thesis, but decided to use the term ‘patients’ for the sake of clarity (that I discuss persons in a healthcare context).

The CNA and colleagues (2015) explain that person-centered care means that “all aspects of care are provided in a manner that is sensitive to the person’s and family’s personal, cultural, and religious values, beliefs and practices, their developmental state and preparedness to deal with the dying process” and is founded upon “healing relationships grounded in strong communication and trust” (p. 9). In their concept analysis, Morgan and Yoder (2012) define person-centered care as:

> “a holistic (bio-psychosocial-spiritual) approach to delivering care that is respectful and individualized, allowing negotiation of care, and offering choice through a therapeutic relationship where persons are empowered to be involved in health decisions at whatever level is desired by that individual who is receiving the care” (p. 3).

Thus, person-centered care is individualized, holistic, respectful and empowering. It recognizes and is respectful of persons’ individuality, of their wholeness and seeks to empower patients and their families in healthcare decisions (Morgan & Yoder, 2012).

By recognizing that patients and families are individuals with unique values, concerns, ideas, expectations and feelings (McCance et al., 2011), person-centered care holds that there cannot be an assumption of ‘universal truths’ or a ‘one-size fits all’ approach in healthcare (Morgan & Yoder, 2012). Indeed, the findings of my study highlight patients and families’ individuality; some family members preferred to ‘be the one’ to make the final decision, while others preferred to defer decisions to persons they trusted. Some families preferred to discuss and prepare for end of life while others believed discussing end of life should not occur. Some patients and families wanted to pursue potentially life-sustaining treatment at end of life, while

others wanted to withhold or withdraw such treatment (which affirms the individuality of desirable end of life care or notions of a good death). Unlike the biomedical approach, person-centered care purports that we ought not to assume a 'universal truth' is applicable, and instead engage with the persons we provide care to so as to uncover and respond to their individual needs and preferences (including their preferences for level of participation in decision making) (McCance et al., 2011; Morgan & Yoder, 2012). In these ways, a person-centered approach reminds us that patients and families' view of what is best or preferred may be different than what the biomedical approach suggests is 'universal truth'.

Given the above, person-centered care discourages standardized or routine care (e.g. patient order sets) since these would overlook individual patient and family preferences (Morgan & Yoder, 2012). Although one might argue that standardization of care or a 'one size fits all approach' may be more efficient or time-saving as it circumvents the time it would take to explore each person's unique preferences, I would argue that, in the long run, lack of engagement is more problematic. As my study findings show, lack of engagement causes distrust in healthcare professionals, confusion about the patient's state, and emotional distress, all of which might require even more time to rectify after they have occurred. Additionally, embracing individuality would save the time we might spend trying to convince patients and families that they must pursue the treatment course set out by the biomedical approach, since embracing individuality would involve accepting the fact that patients and families may not wish to pursue this path. As well, and importantly, person-centered care does not disregard biomedical knowledge, instead, this approach entails suggesting to patients and families what empirical data recommends is best, and then assessing whether this option is acceptable to them (and, importantly, being open to the fact that it might not be) (Feo & Kitson, 2016).

Person-centered care is also holistic and respectful in that it "recognizes and *values whole* persons" and appreciates the interdependence of persons' "biological, social, psychological and spiritual aspects" (Morgan & Yoder, 2012, emphasis added, p. 3). This approach therefore reminds us that we are caring for *people*, with a unique social, psychological, and spiritual environment that ought to be valued and considered in decision making (further emphasizing the importance of mutual respect, environment and engagement) (Morgan & Yoder, 2012). Indeed, the theme "sense of responsibility" shows that patients and families do consider the multidimensional aspects of a person in their decision making. With its focus on wholeness, person-centered care moves away from the disease-oriented and fragmented ethos of the biomedical approach, and recognizes that persons are more than their biology or disease (McCance et al., 2011). If we limit ourselves to this fragmented ethos, and do not consider all of the aspects that make up a person (e.g. social, psychological, spiritual) or focus only on biology (as the biomedical approach does), it can be easy to forget that persons with abnormal pathologies are whole and valuable. Person-centered care, on the other hand, affirms that all persons possess considerable qualities and strengths, and thus, even persons living with advanced illness or disability, for example, are whole and valuable (Morgan & Yoder, 2012). As Slater (2006) explains, person-centered care maintains that "even persons with dementia, who may no longer present their original persona; they still have positive attitudes and strengths that can be incorporated" (p. 140). Thus, similar to relational ethics, person-centered care holds that all individuals (including those with an advanced illness) can, and should be valued, and viewed as whole, interconnected persons who deserve respect and engagement.

Related to the concept of holism is the concept of personhood which, like wholeness, outlines how we define ourselves conceptually as persons (i.e. what it means to be a person)

(Sofronas et al., 2018). Sofronas and colleagues (2018) explain that person-centered care prompts nurses to "align their care with the personhood of their patients, that is, their patients' need to be understood, their need for emotional and physical security, and their need for a sense of place and belonging" (p. 410). Personhood is socially constructed, is maintained through meaningful interactions with others, and thus is "not a static concept and could change according to one's situation" (Sofronas et al., 2018, p. 409); studies in my sample offer examples of this (Foley et al., 2014; Wilson, 1993). By holding a fluid conceptualization of wholeness and personhood, we can more easily recognize that worth, and even quality of life, can exist with advanced disease, disability or old age (Sofronas et al., 2018). As these authors write; "quality of life can be either enhanced with a fluid, subjective conception of personhood, or dismissed with rigid assumptions about such issues as disability, and what constitutes a life worth living" (Sofronas et al., 2018, p. 412). The findings of my study (Chapter 4) offer many examples of what can happen if we fail to recognize that disease does not lessen our worth or abolish the qualities that make us a whole person (regardless of what the biomedical approach suggests). Without appreciating that persons' wholeness and value is derived from more than their biology, we risk assuming that older individuals have a poorer quality of life or that they are like old cars that belong in "the scrap yard" (Foley et al., 2014, p. 71), or risk thinking that caring for persons whose "brain doesn't work" would be like "wasting money" (Sellars et al., 2018) or that persons with a "very debilitated condition" "should be left to die" (Wilson, 1993, p. 303). The reality is that these individuals can still live a life 'worth living,' hold meaningful relationships, be loved and be important to someone.

Together, patients and families' individuality and wholeness, as well as the findings of this study, demand that healthcare professionals foster engaged relationships (i.e. move towards

and work with) the persons they care for. Engagement is required to understand and create space for patients and families' individual preferences (and needs, feelings, hopes, etc.) and to become aware of the biological, social, psychological and spiritual aspects that patients and families place importance on when making decisions. Through the engagement that it endorses, person-centered care seeks to share the decision making power and responsibility with patients and families, as a sign of respect (McCance et al., 2011; Slater, 2006). Morgan & Yoder (2012) explain that "offering choices in care recognizes and respects the inherent value of each individual" (p. 4). Daly and colleagues (2018) have affirmed that shared decision making is an essential aspect of person-centered care. These authors suggested that even patients who have impaired cognition or dementia are not automatically incapable of making a decision, and can possibly be included in decisions, to the extent that the wish (Daly et al., 2018). Morgan & Yoder (2012) explained that if we offer information, engage in effective communication, bracket our assumptions (e.g. of what constitutes a good death) and support individuals' choices, then patients and families will feel genuinely empowered to be involved in healthcare decisions. Inclusion in decision-making to the extent that patients and/or families prefer can also increase self-esteem and quality of life (Daly et al., 2018). Recall however that person-centered care recognizes individuality and that, as my findings affirm, not every patient and family want to partake in decision making. Thus, this approach supports shared decision making as conceptualized by Makoul & Clayman (2006) wherein patients and families' preferences for participation is assessed as part of the shared decision making process.

In addition to empowering patients and families and upholding and respecting their individuality and wholeness, person-centered care preserves dignity and is therapeutic (Chochinov et al., 2015; McCance et al., 2011). Effective person-centered care can increase

satisfaction with care, feelings of well-being and foster empathy and trust in relationships, which is protective for patient safety as trust endorses frank patient disclosures (Chochinov et al., 2015; McCance et al., 2011). As Chochinov and colleagues (2015) explain, person-centered care allows patients to feel known for who they are, rather than only in terms of their disease, which is dignifying. Thus, although we tend to suggest that potentially life-sustaining treatments ought to be withheld or withdrawn at end of life so as to preserve dignity (Baumrucker et al., 2018; Johnson et al., 2018); it may be more dignifying to recognize that patients and their families are persons with worth/value, and to treat them as such.

Implications for Nursing

The findings of my metasynthesis have implications for nursing practice, education and research. This section presents these implications and recommendations.

Implications for Practice

My study findings reveal practical ways that nurses can and do impact and facilitate patients and families' experiences of making decisions about potentially life-sustaining treatment at end of life. The theme "closeness in relationships" highlights the importance of attending to the quality of our relationships with patients and families and suggests that we ought to engage in open, empathetic dialogue and move towards patients and families. This would not only positively impact their emotional experiences (e.g. by decreasing loneliness), but would also facilitate their access to information and their inclusion in the decision making process, at whatever extent is desired. Open communication can ease the difficulty of discussing arduous conversations (Ibanez-Masero et al., 2019) and, as my findings show, honesty is imperative to building trust. Trust in turn facilitates end of life discussions (Bellamy, 2017; Dunbrack, 2006), and further facilitates access to information, as families are more likely to approach a healthcare

professional they trust. Indeed, Adams and colleagues (2011) found in their literature review that "when family members developed trusting relationships with nurses, they could ask nurses questions, trust that they would get the truth, had a better understanding of the prognosis and were more prepared" (p. 12). In addition to fostering trust in their own relationships with patients and families by being honest and empathetic, my study findings also show that nurses can help foster intimacy between patients and their families by manipulating the healthcare environment in a way that allows for their closeness (e.g. by lowering the bed side rails).

Secondly, the theme "identity and quality of life in relationships" underscores the importance of recognizing that families' have an intimate knowledge of patients' identity and quality of life, and thus should be consulted in any assessments of these. This theme also highlights the enduring presence of personhood, and the impact that all relationships have on identity and quality of life –which further indicates that we ought to tend to the quality of our relationships with patients. These findings urge us to be empathetic and respectful of the inherent value of all human life and remind us that, just because quality of life (and identity) seem to have gone, does not mean that they have.

Thirdly, the theme "reliance on relationships" confirms that nurses are important sources of information for patients and families. Nurses provided information, but also explained medical information to patients and families after they felt physicians had "just kind of thrown up" on them with information (Long et al., 2011, p. 209). This is consistent with findings from other studies which have found that nurses were "information brokers" who helped clarify treatments and medical information for patients and families (Adams et al., 2011; Clabots, 2012). Importantly, the theme "closeness in relationships" underlines the merit of providing and explaining this information sensitively, with empathy. This theme also reminds us that patients

and families' understanding of patients' prognosis and treatment options is strongly dependent on the amount of truthful information healthcare professionals provide. Given that patients and families relied on healthcare professionals for information about prognosis and that families relied on their guidance to recognize when the patient might be dying, Ibanez-Masero and colleagues (2019) highlighted the importance of training healthcare professionals on how to recognize a dying patient and how to communicate this to families, sensitively.

Finally, the theme "sense of responsibility" urges us to appreciate all that patients and families consider when making decisions about potentially life-sustaining treatments at end of life. They consider the patient's wishes and well-being, their family's wishes and well-being and their responsibilities to their family members; and they attempt to balance all of these. This is not to suggest that the solution is to reduce or remove their senses of responsibility to their loved ones, but rather offers insight as to why patients and families may hesitate to make a decision about potentially life-sustaining treatments. Thus, I urge my fellow healthcare professionals to consider that patients and families may insist on pursuing potentially life-sustaining treatment at end of life, not because they are in denial of the patients' prognosis, or misunderstand what treatment entails, but rather, because they are trying to attend to their many responsibilities to their loved ones, and the tensions between these. Hardwig's (2005) recommendation thus seems particularly pertinent now – that rather than "vilify" decision makers who request treatment, healthcare professionals should instead sit with them, and have an open, honest, empathetic conversation about their motivations and emotions.

As discussed above in the section "moving towards person-centered care," together, the findings of this thesis pointed to a need to approach care in a more person-centered manner. Doing so would entail recognizing and respecting the wholeness, value and individuality of

patients and their families (e.g. that each family unit would have different preferences about whether or not to discuss end of life). Authors offer some practical ways that person-centered care can be enacted. Chochinov and colleagues (2015) suggest that asking patients "What do I need to know about you as a person to give you the best care possible?" and noting the answers on patients' charts can prompt healthcare professionals to consider patients as persons. Mazzotta (2016) suggests that, to help direct our attention towards the person, nurses can "remember that they care for the patient in the bed and not the equipment" and recall that technology "should supplement nursing care, not overpower it" (p. 97).

At an organizational level, my study findings endorse putting more focus on relationships and person-centered care. I suggest an organization-level shift because enacting person-centered care and being able to invest in quality relationships can be difficult in healthcare settings where efficiency and standardization are central (Morgan & Yoder, 2012). Indeed, "the health care environment (physical and cultural) dictates the parameters for nursing care and either fosters or stifles the ability for care to be individualized to each client" (Morgan & Yoder, 2012, p. 5). These authors suggest that a person-centered climate can be achieved by vision (and commitment to that vision), by the attitudes and behaviours of organizational leaders, and by sharing governance of organizations so that administrators are not the only ones making decisions about patient care (Morgan & Yoder, 2012). As Slater (2006) explained; "although health care systems attempt to enhance delivery of care by providing clinical/critical pathway documents to ensure all staff provide similar care, acknowledging the individual needs is important for planning care for the person, rather than the patient" (p. 139). Badarau and colleagues (2017) explain that standardization can cause families to feel as though they are confronted with a "choiceless choice," with the standard protocol being the only viable option (p.

21). They explained that rather than standard protocols, “communication, sharing of information, and engaging in discussions about preferences, values, and ultimately care goals should be decision making’s foundation” (Badarau et al., 2017, p. 21).

Implications for Education

Recurrently, authors suggested ‘communication skills training’ to facilitate healthcare professionals’ comfort with difficult conversations, and to increase the likelihood of discussing healthcare preferences in advance (Billings, 2012; Jimenez et al., 2018). In their overview of systematic reviews of ACP, Jimenez and colleagues (2018) found that communication skills training improved healthcare professionals’ skills, comfort, self-efficacy, preparedness and knowledge when it came to communicating with patients and families at end of life. Emphasis within nursing education on relational ethics and person-centered care would also likely help improve communication, as these approaches can increase empathy and encourage genuine engagement with patients and families (Chochinov et al., 2015; Upasen, 2018).

Nursing is a science that already appreciates the “fundamental distinctiveness of individual persons” (Wright & Brajtman, 2011, p. 22), and nursing theories currently inspire healthcare professionals to view patients as whole persons (Wright & Gros, 2012). However, an additional emphasis on what personhood, person-centered (vs. patient-centered), and whole person care actually mean, and ways to enact these approaches would benefit nursing practice and by extension patients and families’ experiences. Additionally, giving weight to relational ethics and relational autonomy in nursing education would encourage quality relationships within healthcare, and foster a respect for patients’ individuality and interconnectedness (Bergum, 2013; Delgado, 2019). Teaching about relational autonomy may help new nurses recognize that it is not patients’ vulnerability that risks impeding their autonomy, but rather, their

relationships (Delgado, 2019). As Wright and Brajtman (2011) highlight; nursing is more compatible with a paradigm of relation since "nursing is not performed exteriorly; it involves entering the world of the other, and understanding and responding to the calls of that world" (p. 23). Thus, relational ethics and relational autonomy would offer guidance as to how to do this (move towards/into the world of the other) in an ethical way.

Implications for Research

The results of this thesis clearly demonstrate the importance of relationships in patients and families' process of making decisions about potentially life-sustaining treatments at end of life, and the ways in which patients and families considered others in their decisions. The results also make it evident that, though one person may verbalize the final decision, the decision making process and deliberation rarely occurs in isolation of others. Recall also that a number of participants in the articles in my sample shared that they preferred their loved ones to be present for decision making discussions. However, only a minority of articles (in my sample and otherwise) interviewed more than one person per interview. Thus, I would recommend that future studies that investigate decision making experiences seek to interview patients and families together, to better capture the relational components of these experiences.

Patients and families' experiences of making decisions about potentially life-sustaining treatments at end of life also merits exploration from a strengths-based nursing or person-centered lens, whether it be for individual studies or a metasynthesis. Strengths-based nursing focuses on patients and families' inner and outer strengths (i.e. what they do that "best helps them deal with problems and minimize deficits") (Gottlieb, 2014, p. 24). Similarly, person-centeredness holds that all individuals possess qualities, strengths and can find a way to remedy difficulties (Morgan & Yoder, 2012). Thus, exploring this phenomenon with these theoretical

lenses could help further counter the existing, dominant narrative which suggests that patients and families tend to choose incorrectly, or often misunderstand when it comes to these decisions.

I have recommended a move towards person-centered care within healthcare practices. I would also recommend a move towards a person-centered approach within biomedical research. Though seeking to uncover scientific solutions to healthcare issues remains valid and useful, my thesis shows the importance of leaving space for patients' individuality. Thus, seeking to apply the findings of biomedical research in a 'one-size fits all' manner may not be a suitable goal.

Limitations

This metasynthesis sought to explore patients and families' experiences of making decisions about potentially life-sustaining treatments at end of life. A potential limitation of this study is that it did not include the perspectives of physicians or nurses in the data collection and analysis. Though this metasynthesis offers important insight as to how patients and families experienced these decisions, and their accounts offered some insight as to how healthcare professionals approached these decisions, healthcare professionals' actual views, approaches and experiences are not represented in this study.

Another limitation is related to the nature of a metasynthesis. A metasynthesis is an analysis of an analysis (Paterson et al., 2001). Thus, the quality of metasynthesis results is inherently dependent on the quality of each individual study, and on whether authors adequately represented the original participants' thoughts and experiences in their findings. The lack of access to the original participants interviewed means that there is no access to raw data or the persons behind the findings of each study, and thus no opportunity to seek clarification or additional knowledge from them. This can impact the truth value of metasynthesis results. However, I am reassured by the frequency of my results within my sample, as it is unlikely that

every author misrepresented the original participants' sentiments. Given that a metasynthesis is an analysis of an analysis, the raw data from primary studies is also subject to the influence of two authors' values, experiences and biases, which can also impact the accuracy of results. Recurrently, authors were not explicit about the theories or assumptions that influenced their research, which made considering the impact of their values, experiences and biases difficult.

Final Reflections

Undertaking this thesis has inspired me to reflect on my own nursing practice and the ways in which I tend to my relationships, engage with patients and families, recognize their wholeness and enact honesty. First, I can attest to the fact that, the conditions of nursing in a hospital setting can make it difficult to properly tend to relationships with patients and families. Even on the palliative care unit, I sometimes only have enough time to tend to physical or psychosocial emergencies. I have also noticed that I have become so accustomed to prioritizing biomedical tasks (e.g. administering medications) that on occasion, even when I do have time to sit and talk, I find myself feeling as though I ought to be doing something else.

Second, when it comes to engagement, I have particularly wondered how ACP documents (e.g. the level of care form described in Emma's case in Chapter 1 which is used in the hospital in which I work) impact the ways in which I, and other healthcare professionals engage with patients and families. I have found that, after decisions about level of care are made, engagement can become compromised. To illustrate this, I offer an example of how agreeing to 'level of intervention 4' can influence opioid recommendations and use. According to this document, once a patient and/or family have agreed to 'level of intervention 4,' it is understood by staff that this patient and/or their family has agreed to forgo any potentially life-sustaining treatment and focus on comfort. After a decision for comfort care measures only is made,

healthcare professionals often assume that these patients and/or their families consent to opioid use for pain or dyspnea. The reality is, however, that some do not want to receive opioids, whether related to a fear or misunderstanding of opioids or otherwise. I think engagement and person-centered care urges us to offer opioids in these scenarios, and explain their importance and, should a refusal occur, we can explore its motivation and try to address it. Regardless of the patient and family's ultimate choice, however, we must respect it. I must also acknowledge the value of an ACP document. For one, as I found in my study, families recurrently shared that knowing their loved one's end of life wishes was very helpful, as it offered some instruction as to how to decide. As well, given the usual time constraints in healthcare, I do not think it would be realistic to have an engaged, thorough conversation about every minor treatment decision. Indeed, ACP documents allow us to have one (or a few) major discussions that can guide treatment choices in a general way. Nonetheless, as this thesis has reminded me, what is important is to not allow an ACP document to put patients and families in a box, or assume that every patient and family who agrees to 'level of intervention 4' wants the same things.

Third, completing this thesis has inspired me to reflect on whether I view the patients I care for as persons. Especially in palliative care, when a patient is actively dying and their appearance, ability and consciousness begin to significantly change, it can be rather difficult to remember that they are persons, with a history and social network. Completing this thesis has reminded me though, of the importance of recognizing that the person I am caring for is more than a body, they are someone's loved one and we should always treat them as such.

Lastly, I would like to think that I am honest with my patients and families and answer truthfully when I am asked 'if a patient will ever wake up,' or 'how much time they have'. However, I have noticed that I sometimes hesitate to be honest. Upon reflection, I think this

hesitation occurs for the same reasons that healthcare professionals in the literature were not honest; I was not always certain of the answer and I did not want to burden the family with an answer that did not inspire hope, especially if I was wrong. Yet, I have noticed that being honest about a lack of certainty in prognosis is usually well received, especially if delivered empathetically. Completing this thesis has reassured me that, when combined with empathy, honesty never fails.

I wish to offer a final reflection on dualisms. There were many competing notions that came up as I completed this thesis, such as beneficence and autonomy, person-centered care and biomedicine, hyper medicalized and natural death, reductionism and holism, objectivity and subjectivity, and standardization and individuality. At times, I attempted to resolve which of each of these competing notions should 'win' and dominate in healthcare. However, the conclusion I have come to is that dichotomies are unnecessary, unhelpful and do not really exist. The goal should not be for any one of these notions to dominate its competing notion. Indeed, Mazzotta (2016) urges nurses not to accept dualisms, but to acknowledge them and work to 'blur the boundaries' that exist between them.

Conclusion

In conclusion, when making decisions about potentially life-sustaining treatment at end of life, patients and families longed for closeness in their relationships with each other and with healthcare professionals, which was fostered by honesty and empathy. Decision makers considered patients' identity and quality of life when contemplating these treatments and relationships had a significant bearing on these (identity and quality of life). When making these decisions, patients and families relied on healthcare professionals to create space for them in the decision making process, to the degree they desired, and relied on them for information to

understand the patients' prognosis and treatment options. They also relied on their family members and their faith for support and guidance as they deliberated these treatments. Finally, patients and families experienced a sense of responsibility to consider their loved ones' wishes and well-being when making decisions about potentially life-sustaining treatment at end of life, and experienced guilt and burden when tensions between their numerous responsibilities occurred. Authors' descriptions of these experiences reflected normative discourses, namely that objectivity and individual autonomy should be endorsed, and false hope should be mitigated. These findings suggest that healthcare can stand to move away from the biomedical approach and towards a person-centered approach to care. Doing so would recognize and respect patients and families' individuality and wholeness, the importance of engagement, and encourage us to approach decisions and interactions accordingly.

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Appendix A: Metasynthesis Search Terms

Table 2. Metasynthesis search terms

Databases	MEDLINE	CINAHL
MESH for DECISION MAKING (S1)	MH "Decision making" OR MH "advance care planning"	MH "Decision Making+"
Keywords for DECISION MAKING (S2)	Decision-making OR decision process	Decision-making OR decision process
MESH for TERMINAL CARE (S3)	MH "Life Support Care" OR MH "Terminal care" OR MH "Resuscitation Orders" OR MH "Hospice Care" OR MH "Withholding treatment" OR MH "Euthanasia, Passive" OR MH "Palliative care"	MH "Terminal Care" OR MH "Euthanasia, Passive" OR MH "Hospice Care" OR MH "Life support care" OR MH "Palliative care" OR MH "Advance Directives+"
Keywords for TERMINAL CARE (S4)	Terminal* OR palliat* OR life-sustaining* OR life-prolonging	Terminal* OR palliat* OR life-sustaining* OR life-prolonging
MESH for PATIENT, FAMILY OR SDM (S5)	MH "Family/px[Psychology]" OR MH "Family relations" OR MH "Professional-Family Relations" OR MH "Professional-Patient Relations" OR MH "Nurse-Patient Relations" OR MH "Physician-Patient Relations" OR MH "Terminally Ill"	MH "Critically Ill Patients" OR MH "Terminally Ill Patients+" OR MH "Family/PF" (family-Psychosocial factors)
Keywords for	Surrogate decision* OR	Surrogate decision* OR

PATIENT, FAMILY OR SDM (S6)	terminally ill patient OR family	terminally ill patient OR family
MESH for QUALITATIVE SUDIES (S7)	MH "Qualitative research" OR	MH "Qualitative studies+" OR
Keywords for QUALITATIVE STUDIES (S8)	Qualitative OR experience	Qualitative OR experience
SEARCH	(S1 OR S2) and (S3 OR S4) and (S5 OR S6) and (S7 OR S8)	(S1 OR S2) and (S3 OR S4) and (S5 OR S6) and (S7 OR S8)
Total	1276	1764

Appendix B: Analytical Questions

1) What are the methods used?
    a. What is the research question? What is the role of the researcher? Who did the authors choose to interview? How did they sample them? What are their procedures for data collection? What questions did they ask? How did they account for the impact of/on relationships? How did healthcare philosophies or decision making models come into play?

2) What theory guided the study (or seems to have guided it if not explicitly mentioned) or what theory does this study generate?
    a. What (if any) are the major cognitive paradigms or schools of thought represented in both the theoretical frameworks and emerging theory of this research? What kinds of articles do the authors cite? What language do they use? How does the theoretical framework/emerging theory account for the impact of/on relationships? How does it relate to healthcare philosophies or decision making models? If no theory is explicitly mentioned; which of the healthcare philosophies or decision making models seem to have guided it?

3) How did the authors analyze data?
    a. What are the underlying assumptions of the procedures used? How did they account for the impact of/on relationships? How did healthcare philosophies or decision making models come into play?

4) How did relationships (both individual and structural) impact the patient/SDM/family's experience and/or views of making the decision about potentially life-sustaining treatment at end of life? (Pay particular attention to mention and descriptions of the nurses' involvement). How did making decision(s) about potentially life-sustaining treatment affect these relationships? How was the experience impacted by the values at stake? How did the values at stake impact the experience? How did the relationships leave patients/families feeling?