

The Process Used by Family Surrogate Decision Makers to Withdraw Life-Sustaining
Treatments in the Blood and Marrow Transplant Population

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Bethany Joy Gerdin

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Cynthia Peden-McAlpine, PhD, ACNS, BC, Advisor
Joan Liaschenko, PhD, RN, FAAN, Co-Advisor

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Dedication

This thesis is dedicated to blood and marrow transplant patients, their families, and the healthcare professionals who care for them.

Abstract

Background: There is limited information about the experience of family surrogate decision makers who make the decision to withdraw life-sustaining treatments (LST) from an individual, and nothing is published about this experience in the blood and marrow transplant (BMT) population.

Objective: The purpose of this study was to describe the experience of surrogates who have participated in the decision making process of withdrawing LST from a BMT patient.

Method: This study used a phenomenological perspective, using van Manen's (1990) approach to guide the data analysis. In depth, unstructured interviews were conducted with 10 family surrogate decision makers, two to 12 months after the patient's death. van Manen's selective approach was used to identify units of meaning, clusters, themes, and categories that emerged from the data.

Findings: The essential themes were: knowing the patient as a person; working through the information, receiving support through trusting relationships; recognizing reality; making the decision; and living with the decision.

Conclusion: The results of this study will inform nurses and other health care team members about the experience of surrogates who have chosen to withdraw LST from a BMT patient. Future studies will use this understanding to develop and test interventions for health care providers aimed to decrease the burden of surrogate decision makers. This will promote a peaceful experience for these families and patients, and decrease

professional burden of the health care team, who currently does not have evidence based guidelines for these patient/family situations.

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Chapter 1: Introduction to the Study

“Today I know I am making the best decision. But I’m so afraid of the weeks and months ahead, when I know I will doubt myself” (Anonymous, personal communication, September 2008). Nearly seven years later, I vividly remember my patient’s wife saying this to me shortly before LST were withdrawn from her husband. My patient underwent a BMT, had complications, and had been reliant on LST for approximately one month. As a fairly new registered nurse, I could see the fear and uncertainty in my patient’s wife, and I had little more than common sense and deep compassion to guide me in my care for this woman. I wanted to be better prepared for the inevitable next time. I talked to my coworkers and reviewed the literature. These methods, however, did not reveal any research-based nursing interventions that would improve this process for families: there was nothing in the literature, and while there were certainly nurses with more experience and subsequently increased confidence in these situations, this did not help new graduates like myself. Thus, I recognized the need for research – to learn more about the family surrogate decision maker’s process of withdrawing LST from a patient after a BMT.

Having a role in determining when LST should be stopped for a critically ill family member is a formidable decision that healthcare staff must better understand and support. An increasing number of patients are able to survive due to medical advances such as mechanical ventilation, hemodialysis, and invasive artificial nutrition and hydration. As a result, when a patient is no longer able to participate in his or her own decisions, the healthcare team and the patient’s family must make difficult decisions about how long to continue LST, and to what extent. These situations are becoming

increasingly common. According to Angus et al. (2004), one in five Americans die using ICU services. Additionally, Prendergast and Luce (1997) found that 90% of deaths that occur in the intensive care unit are a result of decisions to limit or withdraw LST, compared to 51% in the late 1980s. Additionally, studies have found that family members who are involved in end of life decisions often experience great distress, to the extreme of developing post-traumatic stress disorder (Azoulay et al., 2005). Thus, it is critical to understand the family's decision making process to withdraw LST.

Specific Aims and Research Question

The goal of this study was to understand the family surrogate decision maker's process to withdraw LST from an adult BMT patient in the ICU when the patient is unconscious or unable to speak for him/herself. This knowledge will contribute to the moral, ethical, financial, and practical implications of end of life decision making, and can be used to provide health care providers with better knowledge of how to care for families making end of life decisions in an understudied and unique population, decreasing the stress, guilt, and doubt these families often experience (Wendler & Rid, 2011). Since little is known about this decision making experience in the BMT population, a qualitative phenomenological method was used. This study has one aim:

Interpret the meaning that family surrogate decision makers ascribe to the decision making process of withdrawing life-sustaining treatments from an adult blood and marrow transplant patient.

Using a phenomenological perspective, this study sought to answer the research question: What was your experience during the time surrounding your loved one's death, and what

were the circumstances that preceded and culminated in the decision to withdraw life-sustaining treatments from your loved one?

The results of this study will inform nurses and other health care team members about the process of family surrogate decision makers who have chosen to withdraw LST from a BMT patient. This research will have the potential to make this process more peaceful for family members so that individuals, such as my patient's wife at the beginning of this paper, will not need to fear the doubt and guilt they may experience after making such a decision. Future studies will use this understanding to develop and test interventions for health care providers aimed to decrease the burden, stress, guilt, and doubt of surrogate decision makers. This has the potential to promote a peaceful experience for these families and patients, and decrease professional burden of the health care team, who currently does not have evidence based guidelines for these patient/family situations.

Background

Changing healthcare environment. The United States' health care environment in hospitals has changed in two major ways. First, significant advances in life-sustaining medical technology and treatments have been developed. Moses III and Martin (2011) outlined the advances in medical technology since the National Institute of Health was created in 1948. Examples include: the polio vaccine, antibiotics, and antipsychotics in the 1950s; cardiopulmonary bypass, organ transplantation, and hemodialysis in the 1960s; and new treatments for diseases such as Acquired Immune Deficiency Syndrome (AIDS) and many cancers in the 1990s which allowed such diseases previously

considered fatal to be considered chronic. The shift from fatality to chronicity has changed the American mentality: many more people are dying in hospitals, attempting to prolong their life through medical technology.

The second major change in the current healthcare environment is a shift from physician paternalism to patient autonomy. Previously, the American Medical Association (1847) supported complete paternalism, stating patients should exhibit complete and unquestioned obedience to their physicians. By 1990, however, the American Medical Association began to emphasize patients' rights to education and informed decision making. This focus on patient autonomy and recent political movements warning of death panels (Nyhan, 2010) have caused many physicians to be hesitant to recommend withdrawal of LST. As a result, physicians increasingly rely (and place pressure) on family members of patients who are unable to make decisions for themselves. The combination of increased patient/family autonomy, decreased physician paternalism, and the increased number of deaths that occur after withdrawal of LST demonstrates an obvious need for the health care team to be better prepared to assist families during this decision making process.

Surrogate decision making and advance directives. Surrogate decision making is an attempt to assure patients who are unable to make decisions for themselves that they will receive the medical care they would choose for themselves if they were able. The Patient Self Determination Act (1990) was one of the driving forces initiated to assure that an individual's end of life wishes were granted. The Act required hospitals, nursing homes, and hospices to provide patients with information about advance directives,

document whether or not patients had an advance directive, implement advance directive policies, and educate staff and communities about advance directives (La Puma, Orentlicher, & Moss, 1991).

As a result of the increased emphasis on advance directives, considerable research has been conducted in this area. Despite the theoretical benefits of advance directives, especially in maintaining an incapacitated patient's autonomy, this research has found multiple limitations of advance directives. Torke, Alexander, and Lantos (2008) delineated three areas of research that highlight the disadvantages of advance directives and surrogate decision making. First, a number of studies have investigated whether and to what extent individuals change their preferences over time (Carmel & Mutran, 1999; Danis, Garrett, Harris, & Patrick, 1994; Edwards, 2002; Houts, Smucker, Jacobson, Ditto, & Danks, 2002). These studies revealed that the majority of patients' preferences for end of life care change from the time they made the advance directive to the time they are sick and hospitalized. Second, research has addressed families' and physicians' ability to predict a patient's wishes (Seckler, Meier, Mulvihill, & Cammer-Paris, 1991; Sulmasy et al., 1998; Uhlmann, Pearlman, & Cain, 1989), and found that the predictions are often severely limited. Third, research has focused on individuals' wishes for their advance directives to be the sole guide for decisions in their care (Kim & Kjervik, 2005). Generally, individuals do not want their advance directive to be the only means of communicating their wishes.

Another drawback of advance directives was discussed by Welie (2001), who argued that "A patient's living will [advance directive] generally is based on the patient's

imaginary reconstruction of what life would be like in the never before experienced X,” (p. 173). Welie explained that this is problematic for several reasons. First, patients cannot predict future facts or foresee the precise nature of their future health condition. Second, an individual is not able to truly understand what it would be like to live in specific health states (such as a permanent vegetative state). The individual making the advance directive is only able to have an “outsider” understanding of this. This finding is of particular relevance because when families withdraw LST, they often make statements that indicate the patient never could have imagined his/her current health state and, if s/he would have known of this state, s/he would not have chosen to live like this. Families are left feeling that the advance directive does not accurately represent the patient’s true wishes.

As a result of these problems, even when patients have an advance directive – a tool that is designed to decrease the burden of surrogate decision making by assuring the patient’s wishes are known and fulfilled – surrogates still experience distress. Wendler and Rid (2011) summarized the effects on surrogate decision makers after making treatment decisions for incapacitated adults, which was based on 40 studies that included 2854 surrogate decision makers. More than half of the surrogates were family members of the patient, and the majority of the decisions regarded end of life treatment options. Wendler and Rid found that most of the studies reported negative emotional outcomes for surrogate decision makers, including stress, guilt over the decisions they made, and doubt that they made the best decision. Additionally, many of the negative effects lasted for months or years after the decision was made. Azoulay et al. (2005) found that post-

traumatic stress reaction, with a high risk of post-traumatic stress disorder, is common in surrogate decisions makers who were involved in end of life decisions. Members of the healthcare team can only decrease this burden after gaining a thorough understanding of this process; however, little is known about this experience.

Current State of the Science

A small set of literature limited in scope. There are a small number of studies that explore the decision making experience of individuals who choose to withdraw LST from a loved one who was previously able to make decisions independently (Hayes, 2003; Limerick, 2007; Meeker & Jezewski, 2009; Swigart, Lidz, Butterworth, & Arnold, 1996; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999; Wiegand, 2008; Long, Clark, & Cook, 2011; Wilson, 2011). Chapter Two will discuss these studies in depth; however, in summary, they demonstrate that families who had made decisions regarding withdrawing LST went through a process, not an event, that included: understanding the severity of the illness; the need for clinical information; recognition of futility; and consideration of the patient, the family, and the surrogate decision maker after the decision. While this research certainly offers enlightenment to the experience of family decision makers who choose to withdraw LST, none of the studies included BMT patients and their families, which has left a gap in a unique population.

Differences in the BMT population. BMT is a treatment option for extremely aggressive forms of cancer, especially when the patient has not responded well to more traditional treatments. These patients must choose to undergo a BMT or accept the fatality of their disease. By choosing to have a BMT, therefore, these patients have

declared themselves as fighters, desperately hoping to survive the transplant and live cancer-free – something that happens for only an estimated 30% of these patients. This statistic, moreover, is optimistic because it does not include patients who do become cancer-free but die as a result of complications of the BMT. Thus, BMT can be considered an extreme treatment option - these are not patients who are passively going through a routine treatment process – they are fighting to what may be the bitter end.

Patients who have a BMT do not have a chronic disease; they have an aggressive cancer that is attacking their body at a rapid pace. Without a transplant they will die. A BMT, therefore, could be considered a form of LST. Nor do these patients have an acute illness, and they have not experienced a sudden or debilitating accident. They generally do not exceed the age of 65, and are thus not classified as a geriatric population. They do not have dementia. In fact, prior to having a BMT, patients must have generally good overall health and have relatively few comorbidities. In summary, despite their aggressive cancer, BMT patients are healthy and have a relatively high quality of life. These are the reasons that patients who have BMTs likely cannot fit into the previous research findings on this topic. Rather than family members making decisions to withdraw LST for someone who is elderly, frail, dealing with a debilitating chronic illness, or dementia, they are making the decision whether or not to withdraw LST for someone in the prime of life. Many BMT patients have young children, new spouses, and flourishing careers, attributes that are highly valued by society. It is likely that the decision making process to withdraw LST would be different for this type of patient, and thus this research was conducted.

Additionally, BMT patients can survive on LST for extended periods of time, often several months. While these patients rarely show improvement, they do not show a steady decline, either. The patient is in a medical limbo. After initiating LST, therefore, it is very difficult to end treatments, as the patient is not clinically different after one month of relying on LST than he/she was after one week of these treatments. Beauchamp and Childress (2009) argued that once LST have been initiated, it is much more difficult to decide to stop these treatments than choosing not to initiate them when first needed. Thus, families of BMT patients arguably have a more difficult time withdrawing LST than families of other patients, since in one sense, a BMT itself can be considered a life-sustaining treatment.

Prendergast and Puntillo (2002) discussed a case of an individual that highlighted situations of critical patients who do not recover or die quickly, similar to those reliant on LST after a BMT. These patients are “not improving nor acutely dying, alive but with a dwindling capacity to recover from their injury or illness” (Prendergast & Puntillo, 2002, p. 2732). The authors discussed the questions that these situations evoke, such as whether to continue treatment. Prendergast and Puntillo (2002) focused on communication in these situations, and argued that “effective communication includes sharing the burden of decision making with family members” (p. 2732). If, however, health care providers do not understand this experience, query the effectiveness of this communication.

Significance and Innovation

The changing health care environment demonstrates the significance of this research – increased deaths in critical care units after the decision has been made to withdraw LST and a decrease in the paternalistic medical model of years past. Furthermore, surrogate decision maker distress and the limitations of advance directives highlight the need to better understand the decision making experience of individuals who choose to withdraw LST from a family member. The differences of the BMT population have been explained to demonstrate why family members of these patients need to be studied as a unique population. Finally, in order to emphasize the significant need for this research, it is helpful to consider the prevalence of withdrawal of LST in the BMT population. Although national statistics of this event do not exist, in one major adult BMT center with 22 beds, six patients died in a 30-day period. Family members chose to withdraw LST for three of these patients, and the other three died after being transitioned to hospice.

Contribution to Nursing

This study is innovative because little research has been conducted in the BMT population, and none has been done regarding the experiences of individuals who have chosen to withdraw LST from a family member who had a BMT. Thus, the findings from this study will advance the healthcare field by informing the clinical practice paradigm of reliance on BMT family surrogate decision makers.

This study contributes to the healthcare field, particularly nursing, in a number of ways. By providing an understanding of the family's experience, this study can be used to

propose interventions for nurses to assist families during this time. Currently, there is not sufficient research available to guide nurses in these situations. Nurses are left to “follow their instincts,” drawing on lessons in therapeutic communication, common sense, and an awareness of how the nurse herself would like to be treated in a similar situation. While these strategies are helpful, they are not adequate. Nurses are deeply involved with families during this time, and the stress of not feeling adequately prepared to support a family can be intense. As a result of this study, and the knowledge gained to guide interventions, the discipline of nursing will be further enhanced in two ways.

First, these interventions will contribute to the discipline of nursing by assisting nurses in fostering as peaceful an environment as possible for families during withdrawal of LST. The decision to withdraw LST from a family member has been found to be stressful, emotional, and a demanding experience for families, causing extreme levels of stress, doubt, and guilt. The discipline of nursing focuses on holistic patient and family centered care. In order to provide this type of care, the experience of these families must be understood. Wojnar and Swanson (2007) explained:

Investigators seeking to develop knowledge that embraces ideals of holistic nursing are challenged to understand human experiences in health and illness and identify caring needs of nurses and patients who come together in contemporary health care settings. The interactions inherent in holistic nurse-patient transactions may be explored through phenomenological inquiry (p. 172).

Ideally, this research will provide evidence for interventions that make this goal possible for nurses to achieve and thereby lessen the negative effects of these situations on families.

Second, these interventions will assist in better preparing nurses to support families during this difficult process. It will also decrease the stress nurses currently experience due to the inadequate amount of research and available interventions . This may reduce caregiver burnout common in the discipline of nursing and give nurses the confidence that their interventions are indeed helpful for families.

Finally, in a caring discipline such as nursing, it is crucial to understand the experience of a patient, which includes the family. This allows nurses to be more empathetic and provide more sensitive, appropriate care. Since there is not currently any research that shows what these families experience, this research is innovative and will be instrumental in providing nurses with information regarding the family's experience.

Organization of Dissertation

This dissertation is organized into five chapters. The first chapter provides an introduction to the dissertation and its research aim. Chapter 2 consists of a review of the related literature – the process used by family surrogate decision makers to withdraw LST from a critically ill patient. Chapter 3 describes the methodology of the dissertation. Chapter 4 explains the analysis of the research findings. Finally, Chapter 5 discusses the contributions of the research, relates the findings to the literature review, the recommendations of the research participants, and the implications for research, practice, and education.

Chapter 2: Review of the Related Literature

As described in Chapter 1, the health care environment in the United States hospitals has changed in two major ways: significant advances in life-sustaining medical technologies and treatments and a shift from physician paternalism to patient autonomy. The first major change has caused a shift in the American mentality: many more people are dying in hospitals, attempting to prolong their life through medical technology.

Kuiper (2012) summarized this shift:

During the 20th century we have seen a change where dying was removed from our houses and was brought to the hospital, lured by augmented possibilities of treatment and cure that medical science brought us. We have forgotten the constant closeness of death known to former generations of our families. As we all know, the increase in medical knowledge and technological and pharmacologic advancement gave us many good things; it did not bring us eternal life (p. 316).

The second major change is the shift from physician paternalism to patient autonomy. This shift has caused the medical team to rely more heavily on patients and their families to make their own decisions for their healthcare, especially at the end of life. The implementation of the Patient Self Determination Act (1990), for example, was an effort to improve surrogate decision making. Despite some authors (McCoy, 2008) finding that, at times, physicians do still force treatment on patients, there is also an opposite phenomenon that occurs in the patient/physician relationship. Physicians rely

more on patients and their families to decide if and when LST should be limited or withdrawn. This increases pressure on family members of patients who are unable to make decisions for themselves. The combination of increased patient/family autonomy, decreased physician paternalism, and the increased number of deaths that occur after withdrawal of LST demonstrate a time-sensitive need for the health care team to be better prepared to assist families during this decision making process. This is especially true since surrogate decision makers often experience distress. As described in Chapter 1, Wendler and Rid (2011) found that the vast majority of the studies in their systematic review reported negative emotional outcomes for surrogate decision makers that lasted for months and even years after the decision was made. The findings of Azoulay et al. (2005) regarding the incident of post-traumatic stress disorder in family members after making end of life decisions support this review. Members of the healthcare team, therefore, must better understand the burden of surrogate decision makers, particularly those who are involved in end of life decisions, in order to decrease their burden.

Aims

The aim of this systematic review was to synthesize the process, or lived experiences, of family surrogate decision makers who have made decisions about withholding or withdrawing LST from a critically ill family member who was previously able to make decisions independently. Findings were synthesized according to the various themes found in the studies. These include: understanding the illness severity; the need for clinical information; recognition of futility; consideration of the patient; consideration of the family; the surrogate decision maker – after the decision; and process, not event.

Design

This chapter is a systematic literature review of peer-reviewed research articles investigating the experiences and processes used by family surrogate decision makers who made decisions about withdrawing and withholding life-sustaining treatments for critically ill family members. *Conducting Research Literature Reviews: From the Internet to Paper* (Fink, 2010) guided the method for conducting this review.

Search Methods and Practical Screen

An expert librarian in the health sciences was consulted throughout the data search and retrieval process. The software OvidSP was used to search the databases MEDLINE (1946-2012), PsychINFO (1806-2012), and CINAHL (1982-2012). All databases were searched from the dates of their inception.

All three databases were searched using the following keywords: “ethanasia, passive”, “withholding treatment”, “process”, “decision making”, and “family”. First, “withholding treatment” and “process” were combined with the Boolean operator ‘AND’ with “decision making” and “family”, the latter of which were combined with the Boolean operator ‘OR’. Next, a search was conducted combining “ethanasia, passive” with “decision making” and “family”, the latter of which were combined with the Boolean operator ‘OR’. All searches were limited to include only articles about humans printed in the English language. Additionally, articles about infants (birth to 23 months) were excluded. Each of the three databases were searched separately.

Article abstracts in peer-reviewed journals were reviewed for inclusion or exclusion criteria. Studies were screened to include those where the experience of making decisions regarding withholding and withdrawing life-sustaining treatments took place in the hospital

setting, and those in which the patients were previously competent/capacitated/independent adults. Studies were excluded if the patients were neonatal, pediatric, or previously incapacitated decision makers (those with mental illness, dementia, or Alzheimer 's disease). There were no limitations for research design, sampling methods, date of publication, date of data collection, duration of data collection, or source of financial support.

Finally, an attempt to locate articles that may have been missed in the database searches was made by conducting ancestry and dependency searches. This was done by using the search engines Web of Science and Google Scholar to search for articles that had cited relevant articles from the databases (dependency). Additionally, the reference lists of each relevant article were also screened for inclusion criteria (ancestry).

Search Outcome

In the first phase of the search, the database Ovid MEDLINE yielded 145 articles, which were then screened for inclusion criteria, resulting in four eligible articles. The database PsychINFO yielded 15 articles. One article was eligible, but was a duplicate from the MEDLINE search. The database CINAHL yielded 18 articles. Three were eligible: one was a duplicate from MEDLINE, but two were unique. Thus, six articles were selected from the three database searches. During phase two, the original six articles were searched for ancestry and dependency results. This resulted in two new articles. During phase three, the same process was applied to the two new articles. No additional articles were found. The confidence that all relevant articles were found was increased due to the extensive amount of duplications during the three phases of screening.

Results

Understanding the illness severity. All eight of the articles either directly or indirectly discussed the need for surrogate decision makers to understand the severity of the illness. Four of the articles found that it was necessary for surrogates to “work” through understanding the illness before they had the ability to make decisions regarding withholding or withdrawing LST. Understanding the illness severity meant that surrogates had a preoccupation with the disease and how to understand the physiological problem that had occurred, the means by which it was being treated, the mechanisms of deterioration, the consequences of the deterioration, and the reasons the deterioration could not be stopped.

After surrogates saw consistent signs of deterioration, they often came to a new understanding or belief about the patient’s ability to recover, which resulted in a fundamental change in perception (Limerick, 2007 and Meeker & Jezewski, 2009). Authors of two articles spoke extensively of how this process took varying amounts of time. For instance, even when surrogates were told early in the process of the critical nature of the patient’s illness, it took time for them to understand and believe it. Four articles presented the ways that chronic versus acute events/illnesses influenced the amount of time it took surrogates to understand the illness severity. When the illness or injury was considered acute, it was very shocking for families to see such a drastic and sudden change in the health of their family member. It took extra work for families to reconcile the recently healthy individual with the prognosis clinicians were telling them – that the patient was not going to improve. One participant in the study by Wiegand

(2008) explained that it was too difficult to believe his family member who had made Thanksgiving dinner just days ago wouldn't recover. In contrast, when the illness was chronic, surrogate decision makers generally had less work to do – they had a shorter process of understanding and accepting the illness severity – because recognition had started long before the current hospitalization.

The need for clinical information. In order for surrogates to understand the severity of the illness, they required clinical information. This included information relating to the illness/injury, prognosis, and treatment options. Five of the eight articles specifically discussed that surrogate decision makers wanted as much information as possible. In all of the articles, the primary source of clinical information was healthcare providers. Surrogates went through extensive efforts to seek explanations from clinicians, even when this required “chasing doctors” (Limerick, 2007) in order to have conversations regarding the patient's prognosis. The articles also consistently identified the need for surrogates to have more than one source of information, which allowed them to corroborate and confirm data from various sources. These other sources included their own observations and assessments of the patient's condition, statistics from the internet, and observations and interpretations of clinicians' nonverbal communications, behaviors, and other subtle cues in order to fill in gaps in their understanding.

Two closely related subthemes regarding clinical information were prevalent in the data: communication with and trust in clinicians. All eight articles highlighted that when there was inadequate communication between the clinicians and surrogates, surrogates had a difficult time trusting the clinicians. The reverse was also true – when

surrogates were satisfied with the communication they received from physicians, they were more apt to trust them. In general, clinicians were seen as facilitators to making withdrawing and withholding decisions when they offered supportive communication, guided surrogates through treatment options, and supported the surrogates' decision once it was made. In contrast, clinicians acted as barriers when they had poor communication, resulting in conflict and confusion.

Surrogates needed communication to be timely, thorough, clear, understandable, forthright, and honest. In general, surrogates in the studies felt that clinicians acted with tact and sensitivity. Criticisms centered on clinicians being too tentative and circumspect in their communication and prognostic information. In fact, in one study (Hayes, 2003), surrogates reported that even when clinicians were unsure about the patient's prognosis, communicating that uncertainty to the surrogates increased the level of trust. It was common for surrogates to need prognostic information multiple times, and when clinicians did not fulfill this need or did not give surrogates enough time to process the information, surrogate stress was increased and decisions about treatment were delayed. Additionally, surrogates expressed increased stress when clinicians used technical words and jargon that they could not understand.

A common concern with communication was that surrogates had a difficult time feeling like they had a consistent source of information. This created difficulty in obtaining a clear clinical picture, which was especially the case when surrogates were given contradictory information. This greatly increased the stress and confusion level of

the surrogates, conflicts within families, and the time required to understand the critical nature of the illness because they did not know which clinician to trust.

An additional concern regarding communication was the limited availability of clinicians to surrogates. Limerick (2007) called this “chasing doctors,” which surrogates felt the need to do if they did not feel satisfied with the amount of communication they were receiving from clinicians. A common way to ensure that communication did occur was for meetings to be scheduled between families and clinicians. The timing of these meetings was very important. Families were only willing and able to discuss withdrawing LST after they came to understand and accept the critical nature of the patient’s illness/injury. If meetings occurred before this point, families felt that clinicians were giving up on their family member. This resulted in surrogates questioning the credibility of the clinicians, becoming angry, and losing trust with the health care team. Similarly, when families felt pressured to make the decision to withdraw LST (which occurred when the topic was broached prior to understanding), they became protective, defensive, and more insistent that all LST should continue.

Trusting relationships between surrogates and clinicians were necessary before surrogates could make the decision to withdraw or withhold LST. A consistency of providers fostered trusting relationships because then surrogates had increased confidence that the clinicians truly knew them and the patient. Surrogates felt strongly that they needed to be listened to, respected, and included in clinical conversations. When these needs were not met, conflicts arose, resulting in an increase of negative outcomes for both the patient and surrogate.

Recognition of futility. Once surrogates felt they had received adequate information through satisfactory communication and had a trusting relationship with clinicians, they were able to truly understand the nature of the illness/injury and began to recognize futility of LST. Three articles discussed the necessary step of recognizing futility before the decision to withdraw LST could occur. Similar to understanding the illness severity, recognizing futility occurred at varying times for members within a family. Once recognized, it was important for families to avoid prolonging the death, and the decision to withdraw and the subsequent withdrawal happened a short time later. Tilden, Tolle, Nelson, Thompson, and Eggman (1999) found that this generally happened within 24 hours. For the majority of participants in the studies, recognition of futility was gradual, steady, and progressive.

There were several barriers to recognizing futility. These included a sense of hope that the patient would “rally” and start to improve. This was seen in several studies when the patient had a chronic illness and had made multiple improvements in the past despite clinicians giving a grim prognosis. This was also a common experience when the patient had required life-sustaining measures emergently. Surrogates needed time to see whether or not their family member would respond to the treatments. Denial was also a barrier and led to delays in terminating treatment. An additional barrier in one of the articles (Tilden et al., 1999) was issues with the meaning of futility. While clinicians report futility to have an ambiguous meaning, family members used the term consistently to mean that there was no or an extremely low probability of the patient being able to return to a minimally acceptable level of functioning or quality of life. Faith and a belief in an

afterlife facilitated the recognition of futility and the decision to withdraw because it allowed surrogates to believe the patient's death would relieve his/her suffering. Faith and a belief in the afterlife, however, could also serve as a barrier to recognizing futility when spiritual beliefs fueled hope for a miracle.

Once futility was recognized, it was very important for surrogates to relieve their family member's suffering. In one study (Wilson, 2011), all participants wanted good pain control for the patient regardless of what treatment options were chosen. Thus, when the surrogate believed the patient to be in continuous pain and/or suffering, they were much more likely to withdraw and withhold LST.

Consideration of the patient. As discussed, surrogates needed clinical information in order to understand the severity of the illness/injury before they could accept their role as surrogate and make decisions regarding withholding and withdrawing LST. Once this role was accepted and decisions needed to be made, surrogates relied on a different source of information – patient information. This was just as critical to surrogates as clinical information. Patient information included three subcategories: the patient as a person, advance directives, and quality of life.

Patient as a person. Seven of the eight included articles discussed the importance of thinking of the patient as a person. In order to utilize information about the patient as a person, surrogates spent time remembering and thinking about the patient's values, previous conversations, and how the patient responded to similar situations. Surrogates did work to resolve issues about the meaning and course of the patient's life, and what the patient would have valued in their current situation. In order to do this, families

worked through personifying their family member as a critically ill patient, thinking of the critical illness as part of the patient's life story, and beginning to see closure of the patient's life story. During this time, close family members of the patient used narrative review of the patient's life to put together pieces of the patient's "life puzzle," remembering and explaining the patient's life experiences, discussing the values and preferences of the patient, his/her personality and character, and confirming that forgoing LST was consistent or not consistent with what the patient would want. These narratives centered around the patient's physical and emotional responses to previous health problems, knowing his/her feelings about death, and knowing what gave his/her life meaning. Surrogates then reconciled the patient's life narrative with the prognostic information given by clinicians to define their situations and options.

Constructing a narrative of the patient's life and values increased the surrogates' and families' confidence in the decisions they made. This allowed them to make decisions they believed represented the patient's wishes, not merely based on a clinical balance of harms and benefits. Participants in several studies stated that this knowledge of the patient as a person made withholding and withdrawing treatment decisions more straightforward. Additionally, this gave surrogates more confidence and the ability to defend their decisions to clinicians and other family members.

In contrast, when the patient was estranged from the family, and surrogates had little information about the patient as a person, they had little information on which to base decisions. Thus, instead of being able to focus on the patient's recent lifestyle and preferences, or even hypothesized preferences, surrogates tended to focus on issues

relating to the opinions of other family members. As a result, when surrogates had little or no indication regarding the patient's values, wishes, and treatment preferences, they struggled with whether or not they were making the right decision, experienced more uncertainty, and had more problems with guilt and fear.

Advance directives. Four of the eight articles included in this review discussed how advance directives influenced surrogates. Namely, specific knowledge of what the patient wanted was used to provide a sense of clarity and resolution. This knowledge allowed surrogates the liberty of choosing what the patient wanted, and removed a large amount of the doubt and guilt experienced by surrogates. One study found that advance directives provided the most security to the family in coming to terms with their decision. Advance directives were also beneficial because they facilitated discussions with family members and clinicians. As a result of these discussions, the surrogate decision makers were able to extrapolate substituted judgment statements, again increasing their ability to make a decision they believed the patient would have made for him/herself. Interestingly, however, Meeker and Jezewski (2009) found in their metasynthesis that even when advance directives were available, surrogates relied more on prior discussions with the patient about his/her wishes than they relied on the information provided in the advance directive.

Quality of life. The final theme of gaining patient information was the work of combining the knowledge of the patient as a person, the knowledge gained from advance directives, and clinical information to evaluate the patient's quality of life should they survive. Five of the eight articles discussed surrogate evaluation of quality of life. In

order to do this, surrogates considered both the patient's past and future quality of life. Personal knowledge of the patient's quality of life prior to the current hospitalization influenced the future decision making process. The surrogates went through a process of moving between the knowledge of the patient's preferences and evaluation of his/her likely future quality of life. This process was similar to the reframing reality process previously discussed. During this process, surrogates weighed the likely future quality of life and its acceptability to the patient and the burden of treatment and potential recovery.

Consideration of the family. Throughout the surrogates' experience of fulfilling their needs for clinical information, patient information, understanding of the illness severity, and recognition of futility, there was also a prominent consideration of the family. Half of the articles in the review discussed the work of seeking family consensus. For the majority of families in these studies, the surrogates sought agreement about decisions among close family members. Since individual readiness to withdraw LST occurred prior to family readiness, it was common for withdrawal to be delayed until other family members were "on board." Surrogates felt that reaching this consensus offered them a degree of "protection" from future problems and questions concerning the decision to withdraw the treatments. Consensus was also considered an important factor in "protecting the family." In order to maintain a close and functioning family, surrogates were unwilling to make withdrawal decisions prior to family support. The importance of consensus is demonstrated in Meeker and Jezewski's (2009) study – when the family was unable to agree upon treatment options, the family experienced negative experiences and a greater level of conflict.

Related to reaching a consensus, communication between family members was of great importance. Typically, one member of the family – either the person most closely related, in the most intimate relationship, or legally named as the patient’s surrogate – became the “leader” of the family. During this role, he/she acted as spokesperson and collected and disseminated information. This role of primary communicator took place before, during, and after the decision making process. It was done in person and virtually. This allowed the surrogate and the rest of the family to remain in close contact. It allowed family members to interact and explore each other’s rights, ideas, and patient knowledge with one another. Similar to the findings that negative experiences and increased conflict occurred when consensus about decisions was not reached, less open communication also resulted in negative consequences.

Finally, a common theme in this set of articles was the consideration of how treatment decisions would affect the family in the future. There was general consensus within the articles that the decision making experience affected the entire family, not just the legal surrogate. Thus, it was important for families to create a situation they believed would allow them to continue functioning as a family in a healthy way. One way to ensure this was to achieve consensus; another was to have the belief they had made the best possible decision under the circumstances. This is why it was critical for families to communicate about the patient as a person, what his/her values were, and the severity and prognosis of the illness.

In some cases, decisions were made based on the emotional well-being of the surrogate decision maker and the rest of the family. In these cases, the potential harm to

the patient was balanced in the family's mind by the future benefits the family would experience. Families anticipated what the decisions meant to the family, and in cases when LST were withdrawn, the family began the process of anticipatory grieving. Thus, even when the patient was still alive, the rest of the family began the work of adjusting to changing roles, responsibilities, and relationships that would result after the patient's death.

The surrogate decision maker: after the decision. Participants in the study by Wiegand (2008) described decisions to withhold or withdraw life-sustaining measures as the hardest decision they'd ever made, "horrific and cosmic" (p. 1119). In general, the majority of the articles explained that accepting the responsibility of the surrogate role was the hardest, most difficult, intense, painful, overwhelming, devastating, and traumatic experience of their lives. This burden was decreased when surrogates felt a sense of duty and pride in fulfilling this role – this subset of surrogates described the experience as fulfilling a family obligation that left them enriched from the experience.

Tilden et al. (1999) found that six months after making the decision, surrogates felt more positive about the experience if they felt certain they had acted in their family member's best interest. Other studies found that surrogates experienced more positive outcomes when they believed their decisions were made according to what the patient would have wanted, that nothing could have been done to create a different outcome, and that there was no possibility of recovery.

In contrast, surrogates suffered more negative consequences when they believed too much time had elapsed between making the decision to withdraw LST and when the

decision was actually implemented. This occurred when time was required for family members who were not present to come and spend time with the patient or the surrogate waited to get family consensus. Negative experiences were also the result of surrogates' feelings that they had failed to honor the patient's wishes.

It was important for surrogates, similar to families, to have the feeling they could "go on" after the decision was made to withdraw LST and the patient's death. For many surrogates, surrogates who had spiritual beliefs and faith in something outside of themselves, such as prayer, a belief in an afterlife, and that their family member was in a "better place," increased this feeling. Often, the ability to "go on" began when surrogates were able to integrate their experience into their present and future life. This occurred when surrogates began planning rituals surrounding death, such as wakes and funerals. Surrogates also had an easier time continuing their lives when family relationships were strengthened during the decision making experience. For instance, when families were able to connect, accept the impending death, and had time to resolve previous wrongs in the family, surrogates experienced more positive outcomes. In contrast, without family support, surrogates had increased stress levels and long-term strain in family relationships. Thus, surrogates used discretion when sharing the experience with others. The majority of surrogates withheld parts of their decisions from people for different reasons – guilt, feeling the experience was too personal and painful, and the fear of misunderstanding and judgment.

A process, not an event. Finally, all eight of the articles included in this review emphasize that the experience of making decisions to withdraw or withhold LST from

critically ill family members is a process, not an event. This process took varying amounts of times for all families in all studies; it did not happen at one point in time. Rather, families went through various stages, both linear and circular, before making the ultimate decision. In order to arrive at a place where surrogates were able to make these decisions, they went through a process that involved understanding the illness severity, gaining clinical information, recognizing futility, gaining patient information, considering relationships and effects of the rest of the family, and how the decision would affect them as a person.

Strengths and Limitations of the Evidence and Review

The inclusion criteria for this critical literature review were specific. Only articles that focused on the process of making decisions regarding withdrawing and withholding LST were included. This limitation excluded studies that focused on issues such as which factors caused increased stress for surrogate decision makers or looked at only one time point of the decision making experience. Additionally, articles were not included if the study sample consisted of critically ill patients who were children, only older adults, or adults who were not previously competent and independent in decision-making. This limitation excluded a number of studies that focused on whether or not surrogate decision makers decided to pursue treatments for family members who lived in nursing homes, such as whether or not to hospitalize them for aggressive treatments. These strict limitations were specifically chosen to hone in on decision-making processes for a specific sub-type of patient. Based on practice experience and familiarity with the literature, this reviewer believes that the many elements of varied populations have the

potential to substantially change the process for decision makers. For example, it is likely the decision making process may be different for a group of elderly patients in a nursing home suffering from dementia, young children whose parents make all of their decisions, and the sample in the current study – previously competent, healthy, adults.

These limitations resulted in a small set of included articles – a total of eight. A small sample set results in a number of strengths and limitations. A strength of this review is that the set of articles are recent. The oldest article, published in 1996, is less than 20 years old, and two articles were published in the last four years. This indicates a current and relevant set of research. Thus, there is increased confidence that the findings from these studies reflect the actual decision making process of the patients and families seen in our practice today.

The strict inclusion criteria also ensures that we are truly learning about the experiences of a specific sub-group of people. The results are not confounded by the experiences of surrogate decision makers who made treatment decisions for a wide array of patients. While this is certainly a strength, it is also a limitation since the articles do not inform about other types of patients and surrogate decision makers and how their decision making processes may differ. Thus, the generalizability of this review is limited to a specific subtype of surrogate decisions makers. Nevertheless, the eight studies in this review had study samples representative of different education levels, ethnicity, and socioeconomic status, which functions to increase the generalizability of the findings.

All eight of the studies included in the review used qualitative methods. There were no mixed method studies or quantitative research. Since inclusion criteria focused

on *process*, this is a natural result. Indeed, as in any research, the nature of the research question needs to determine the research method used. Thus, while it would typically be seen as a limitation to have only qualitative research included in a review, due to the phenomenon being reviewed, a *process*, it is natural that quantitative studies were not included. A further strength of this set of the eight qualitative studies included in this review is the diverse use of qualitative methods used. The articles made use of grounded theory, interpretive phenomenology, descriptive phenomenology, and metasynthesis.

Seven of the eight articles had no major quality concerns. The results of one study (Long et al., 2011), however, need to be interpreted with caution, as the level of analysis was not deep, the concepts and ideas are only shallowly developed and linked to each other, and the findings do not offer new insights to the phenomenon. This last point is evidenced that there were no original ideas in this article. Since this article did not offer any original ideas that were not discussed in the other seven articles, rather than adding new insight that should be considered cautiously, it essentially offers no insight.

The findings of these studies do not contradict each other. While each study obtained slightly different results, the findings were complimentary and served to augment the overall understanding of this experience. The negative cases presented in multiple studies further strengthen the findings. Each study was unique and focused on slightly different aspects of the decision making process. Together, these studies provide a thick and rich understanding of the process of surrogate decision makers making decisions regarding withholding and withdrawing LST for critically sick patients.

A final limitation of this review is that it was conducted by a single person. This has the potential to decrease reliability in the literature search, data abstraction, and quality appraisal.

Conclusion

The results of this literature review indicate that family surrogate decision makers go through a several-stage process when they make decisions about withholding or withdrawing LST for critically ill family members. The literature indicates that they have a need to understand the illness severity through obtaining clinical information. It is only at this point that families are able to recognize futility. After reviewing and remembering relevant information from the patient such as who they are as a person, their advance directives, and predicted quality of life, the surrogate is able to make a decision. This decision is made in the context of the family and how the family and surrogate will be able to “go on” after the decision. Finally, it is clear that this is not a single event, but rather a process that has varying times for families as well as individuals within the family.

Chapter 3: Methodology

Research Strategy and Theoretical Orientation

A phenomenological research method was used to meet the aim of this study: interpret the meaning that family surrogate decision maker's ascribe to the decision making process of withdrawing LST from an adult BMT patient. Phenomenology is important in nursing research because of its emphasis on human subjectivity. Giorgi (2005) explained that phenomenology was a break away from positivism. It allowed researchers to better understand the human condition by decreasing the priority of objectivity; making it possible to blend science and unique humanness, thus moving from prevalent reductionist tendencies; and moving away from quantitative methods in social and human sciences to qualitative methods, which have achieved rigor and legitimacy. An important aspect of phenomenology is that the philosophy focuses on consciousness, human existence, or the very nature of being itself (Giorgi, 2005, pp. 75-76).

Furthermore, phenomenology focuses on the lived experience of an individual, and is thus appropriate for this research question. van Manen (1990) explained that the lived experience of an individual is the starting and ending point of the philosophical underpinning of the phenomenological research method. It aims to take the lived experience and transform it into text, expressing the essence of the experience. This results in a text that is a reflexive reliving of the experience, and the reader is able to take ownership of something meaningful (van Manen, 1990, p. 36). This research aims to discover exactly what these individuals experience during the time surrounding the decision to withdraw LST from a family member who underwent a BMT. Thus, using a

phenomenological approach to transform the lived experience and discover its essence is consistent with the aim of this study.

van Manen (1990) further described the essence of something as “a good description... construed so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way” (p. 39). Indeed, understanding the nature and significance of the family’s experience is a crucial aim of this study and necessary to inform future practice guidelines. It is not sufficient to recognize that people are having an experience – it must be understood. Thus, a phenomenological design is the most appropriate methodology for this research question since phenomenology focuses on the lived experience of the individual.

Interpretive phenomenology moves beyond mere description of an experience and attempts to find its meaning. In this tradition, humans are able to find significance and meaning in their own lives. Thus, this tradition goes beyond finding the universal essences of an experience. Universal essences are features that are common to everyone who has had a particular experience; they represent the true nature of the condition being studied. They are used to generalize, describing the one truth of an experience.

In contrast, context is very important in interpretive phenomenology; it influences choice and gives meaning. Additionally, interpretive phenomenologists emphasize the need to reflect on their own past experiences and biases relevant to the experience being studied. “It is the researcher’s knowledge base that leads to specific ideas about how the inquiry needs to proceed to produce useful knowledge” (Lopez & Willis, 2004, p. 730).

This leads to the concept of co-constitutionality, suggesting that “meanings that the researcher arrives at in interpretative research are a blend of the meanings articulated by both participant and researcher within the focus of the study” (Lopez & Willis, 2004, p. 730). Thus, the personal experience of the principal investigator in this patient population and in these situations greatly strengthens this research and the approach.

Since the research question for this study focuses on finding the meaning of what individuals experience during the decision making process of withdrawing LST from a family member, the interpretive phenomenology tradition is the most appropriate research strategy. This tradition aims to understand an individual’s experience, and in this study, this goal was obtained by conducting unstructured interviews with individual participants. These interviews served as a means to collect experiential descriptions of the time families were making the decision to withdraw life support from a BMT patient.

Approval for this study was obtained from the University of Minnesota Institutional Review Board (Appendices A and B) and the University of Minnesota Cancer Research Review Committee (Appendix C).

Procedure for Data Collection

Participants for this study were recruited with the assistance of the BMT nurse manager from an inpatient metropolitan BMT center. The nurse manager is routinely aware of the condition of BMT patients and whether or not they are reliant on LST. In situations where family members agreed to withdraw these treatments, the nurse manager sent a letter to the family member two to twelve months after the death of the patient, asking if he/she was willing to be approached by the researcher regarding this study

(Appendix D). The family member was given the option of sending a return letter to the nurse manager indicating he/she did not wish to be contacted by the researcher

(Appendix E). The nurse manager provided the primary investigator with the contact information for family members willing to be contacted. The primary investigator then made contact with the family member within two to twelve months of the patient's death.

Data collection was done through unstructured interviews. Unstructured interviews, which pose one main question (the grand tour question) provide a means of obtaining narrative data by listening to the interviewee's story in his/her own words without any preconceived ideas. Interviews were recorded on a digital recorder that was encrypted. Participants were allowed to choose an interview location with which they were comfortable. They were notified prior to the interview and told the grand tour question so they can begin to think about it in advance. This question was: "Tell me about the process, your experience, of the time surrounding your loved one's death, and things that led up to the decision to withdraw LST from your loved one." The aim of this question was to obtain narrative data, learning about the individual's experience from a temporal perspective – its beginning, middle, and end. The interview began with ice breakers in order to put the participant at ease and establish rapport. It was the belief of the primary investigator that having experience in this area would help establish rapport with participants, which is critical for the success of the interview and a significant limitation, if not achieved. This appeared to be the case as participants were eager to share their stories. Probes were used for clarification as needed. Specific probes were asked if participants did not naturally answer the following questions: What factors

seemed to contribute to the decision to withdraw life-support? What emotions did you experience during this time? Was there anything that the medical team did that was helpful? Not helpful? What were your various thought processes during this time? At the conclusion of the interview, the potential for follow-up was discussed with participants.

Sample – human subjects. The inclusion criteria for participation in this study were that the surrogate decision maker would speak and read English fluently and was involved in the decision to withdraw LST from an adult BMT patient. Interviews were conducted between two to twelve months after the death of the patient. Two to twelve months was chosen as an appropriate time frame based on time frames used in related literature, generally two to 24 months after the death. Two months is the minimum amount of time in order to allow the surrogate decision maker time to grieve and to avoid the potential of increased subject burden by discussing sensitive information so shortly after the family member's death. The standard of 24 months was shortened to 12 months to decrease variations in the data by having too broad of a time frame. There were no additional exclusion criteria. Children younger than 18 were not participants in this study because they are not legally allowed to be surrogate decision makers.

The sampling strategy is a purposeful sample, one that selects participants based on their knowledge of an experience. This is appropriate for the phenomenological nature of the study. Of note, the BMT center used to recruit participants in this study treats a diverse patient population. Thus, it was expected that women and minorities would be equally included in the sample. A sample size of 10 to 15 participants was the goal for this study. Recruitment continued until data saturation was reached. Thus, it is unlikely

the sample will consist of only one gender or ethnic group. The final sample size of this study was 10 participants.

Data and safety monitoring. Interviews were recorded on a digital recorder that was encrypted. Interviews, which did not include any personal identifiers, were uploaded onto the researcher's personal, password protected computer. These will be destroyed at the completion of the study. Interviewees chose a pseudonym which they used during the interview. No identifying information of the person or hospital were made. Interviews were transcribed verbatim, with the exception of all identifying information being removed. Transcripts will be kept for ten years for educational purposes and possible secondary analyses. Documents such as consents and participant contact information were kept in a locked file. They were used for any potential need to contact a participant during the study, and were destroyed at the completion of the study. Only the primary investigator will have access to these documents.

Participant risk. Consent was discussed at the point of initial contact by the researcher, and the consent form was signed prior to the interview (Appendix F). Although there was potential for participant risk because of the personal and sensitive information that was discussed during the interview, this risk was low. Participants discussed potentially sensitive material, but they were informed about what the nature of the study and agreed to participate prior to discussing this information. Additionally, they were told they were free to not answer any question they did not wish to, and they were allowed to withdraw from the study at any time with no consequences. At the conclusion of the interview, there was a "debriefing" due to the sensitive nature of the interview.

Additionally, participants would have been given a resource list if they found the interview to be upsetting or if concerns were raised during the interview; however, this was not needed. The anticipated benefits of this study outweigh the potential risks because the knowledge and understanding about these experiences will aid providers in better supporting surrogate decision makers and decreasing the sometimes severe burden and stress reaction of surrogate decision making.

Analysis of Data

After the interviews were conducted, they were transcribed verbatim and checked for accuracy against the original recordings. The text of each transcript was analyzed using the method described by van Manen (1990). The aim of phenomenological reflection is to determine and explicate the essential meaning of an experience. van Manen considered themes the structures that make up the experience. He explained that in order to interpret meaning, the phenomenon described in the text is thought of in terms of meaning units, structures of meaning, or themes. “Reflecting on lived experience then becomes reflectively analyzing the structural or thematic aspects of that experience” (van Manen, 1990, p. 78). Themes are the meaning and point of the experience, giving it shape. They are an attempt to provide a summary of the experience, even though such a summary is always inadequate. The themes are intransitive and describe an aspect of the experience.

The text for this research study was analyzed using the selective or highlighting approach. Using this approach, the researcher read the text several times, determining which statements and phrases seemed particularly essential and revealing of the

experience of families withdrawing LST from a loved one who had undergone a BMT. During these readings of the text, themes began to emerge. As the themes from individual texts emerged, the researcher noted that certain themes recurred as commonalities between texts. During analysis, these themes were retained by using appropriate phrases or statements that captured the main meaning of the theme. It was necessary to distinguish between incidental and essential themes. In other words, the resultant themes needed to be considered for uniqueness to the experience of withdrawing LST. This was done by “discover[ing] aspects or qualities that make a phenomenon what it is and without which the phenomenon could not be what it is” (van Manen, 1990, p. 107).

As essential themes were emerging from the data, the researcher wrote narratives about each emerging theme in an effort to make sense of and interpret the theme. In this study, the use of anecdotal narrative was used. According to van Manen (1990), writing cannot be separated from the research process, and the use of anecdotal narrative is a methodological device for making an elusive experience comprehensible (p. 116). Furthermore, anecdotes are “rather like a poetic narrative which describe a universal truth” (van Manen, 1990, p. 119), describing the universal truth in a particular manner, and thus engaging the reader in the story personally while simultaneously stirring the reader to reflect upon the universal truth being described. In conclusion, the textual analysis of this study was conducted by writing the narrative story of the essential themes used to interpret the lived meaning of withdrawing LST from a loved one.

Quality and Rigor

This study addressed rigor by using the primary criteria presented by Whittemore, Chase, and Mandle (2001). They argued that the unique blend of art and science in qualitative research must be balanced by what they called primary (credibility, authenticity, criticality, and integrity) and secondary (explicitness, vividness, creativity, thoroughness, congruence, and sensitivity) validity criteria. Primary criteria are necessary to all qualitative inquiry but are not sufficient in and of themselves. Secondary criteria augment the primary criteria and can be tailored to particular investigations (Whittemore, Chase, & Mandle, 2001).

Credibility is being faithful to the phenomenon. This was achieved by using quotes to show interpretation in the text, reflecting participants' experiences and context in a believable way. Authenticity is adequately representing the participants and the multiple realities of an experience. This was achieved by portraying an emic perspective, again using quotes and writing the findings as convincing and thoughtful thick descriptions of the participants' experiences. Criticality is providing evidence of following and mapping key decisions made during analysis. This was achieved by providing an audit trail of key decisions during text analysis. Integrity is ensuring the interpretations of the text are valid. This was accomplished by grounding the interpretations in the text and conferring with other researchers. Explicitness, or auditability, was addressed by once again providing an audit trail and the appropriateness of the research design.

As discussed, phenomenology is the most appropriate methodology for this research question. Vividness – compelling and evocative descriptions – was accomplished through thick descriptions which highlighted the essential themes of the phenomenon. Creativity, stretching the imagination to develop insightful interpretations, was accomplished by the innovativeness of this research question, and presenting the findings in an insightful and original way. Thoroughness, or comprehensiveness, was addressed by adequate sample size and interview duration, exploring the phenomenon until saturation is reached. Congruency between the research question, methodology, data collection, and analysis has been explained. After analysis, themes were assessed for coherence. Finally, sensitivity is assuring consideration of human, cultural, and social contexts. This was achieved by an ethical and respectful consideration for participants.

Conclusion

In summary, since little is known about the experience of family surrogate decision makers who make the decision to withdraw LST from an individual, and nothing is known about this experience in the BMT population, this study sought to interpret the meaning of this experience for family surrogate decision makers of a family member who underwent a BMT. Using the interpretive phenomenological perspective, this study sought to answer the question: “Tell me about the process, your experience, of the time surrounding your loved one’s death, and things that led up to the decision to withdraw LST from your loved one.” van Manen’s (1990) phenomenological approach was used to guide the data analysis following unstructured interviews that took place two to twelve months after the patient’s death. van Manen’s selective approach was used to identify

units of meaning, clusters, themes, and categories as they emerged from the data.

Methodological rigor was achieved using the criteria presented by Whitemore, Chase, and Mandle (2001).

The results of this study will inform nurses and other health care team members about the experience of surrogate decision makers who have chosen to withdraw LST from a BMT patient. Future studies will use this understanding to develop and test interventions for health care providers aimed to decrease the burden, stress, guilt, and doubt of surrogate decision makers. This will promote a peaceful experience for these families and patients, and decrease professional burden of the health care team, who currently does not have evidence based guidelines for these patient/family situations.

Chapter 4: The Findings

This chapter presents the findings of this study and provides the demographics of the participants and a general description of the patient situation. A detailed description of the essential themes and subthemes of the experience will describe the experience of family surrogate decision makers who went through the process of making the decision to withdraw LST from a BMT patient. Narrative quotations support the findings. Additionally, a conceptual model, which visually depicts the relationships between the essential themes and subthemes will be presented.

Participant Demographics

The demographics of the participants are presented in Table 1.

| | |
|-------------------------|-------------------------------------|
| Ethnicity | Caucasian: 9 Somali: 1 |
| Age | 30-39: 2 40-49: 6 60-69: 2 |
| Gender | Male: 2 Female: 8 |
| Relationship to patient | Spouse: 5 Child: 4 Sibling: 1 |

Table 1. Characteristics of Surrogates

In this study, it is also important to consider characteristics of the patients in order to understand the broader context of the surrogate's decision. Table 2 shows these characteristics.

| | |
|--|--|
| Ethnicity | Caucasian: 7 Somali: 1 |
| Age | 30-39: 1 40-49: 3 60-69: 3 70-79: 1 |
| Gender | Male: 4 Female: 4 |
| Underlying diagnosis | Acute lymphocytic leukemia: 2 Acute myeloid leukemia: 2 Mantle cell leukemia: 1 Chronic lymphocytic leukemia: 1 Non-Hodgkin's lymphoma: 1 Myelodysplastic syndrome: 1 |
| Type of transplant | Double umbilical cord: 4 Two double umbilical cord: 1 Allogenic sibling donor: 2 Donor lymphocytic infusion: 1 |
| Length of time from diagnosis to death | 4-6 months: 2 10-11 months: 2 16-19 months: 2 Unknown: 2 |
| Length of time from BMT to death | 2 weeks: 1 1 month: 1 2-3 months: 3 5 months: 2 9 months: 1 |

Table 2. Characteristics of Patients

Overall Themes

The aim of this research was to describe and interpret the process used by family surrogate decision makers (from here they will be referred to as the surrogate) to withdraw LST from a family member who had received a BMT. Table 3 lists the essential themes and subthemes that emerged from the data, and Figure 1 shows how the themes relate to each other in a conceptual model. The themes are listed in the order in which they occurred, although differences to this order will be explained throughout this chapter. This chapter will demonstrate that, in contrast to the surrogates going through the process of withdrawing LST in the literature, these surrogates were more familiar

with the underlying disease process and the course of treatment because of the patient's history of illness. What was not familiar to them was the course of care in the intensive care unit (ICU) and the implications of that care. As a result, these surrogates' primary focus was on knowing the biographical life of the patient and the implications for that life.

| Essential Themes | Subthemes |
|--|--|
| - Knowing the patient as a person | - Considering the patient's advance directive - Telling stories and remembering the patient's goals |
| - Working through the information | - What information was needed - Piecing the information together - Navigating a sea of doctors: managing conflicting messages - The telephone game - Bridging the communication gap - Dancing between two hats - The stress of wearing the nurse hat - Putting on the family hat: an attitude of hope |
| - Receiving support through trusting relationships | - Caring for the person, not just a patient - Someone I know and trust - Time to build relationships - Sharing the burden |
| - Recognizing reality | - Problems stacking up - More harm than good - A new perspective on an extreme treatment - Seeing the changes - Listening to my gut - Accepting the change in prognosis - Toggle switch: helping them get better versus prolonging life |
| - Making the decision | - The importance of talking with the family - After the decision was made - Knowing what to expect - Sharing the moment and saying goodbye |
| - Living with the decision | - Trusted to do what's right - Second-guessing the BMT decision - Honoring and remembering the patient |

Table 3. Essential Themes and Subthemes

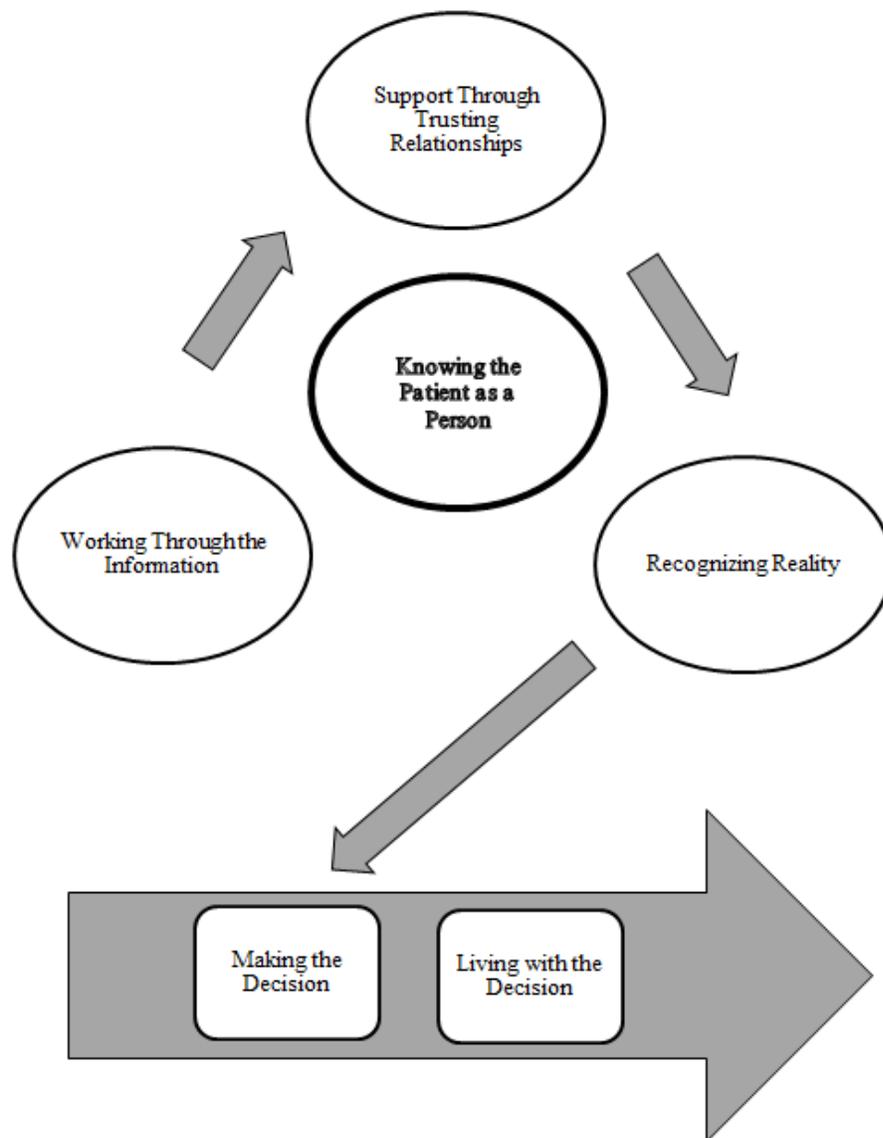


Figure 1. Conceptual Model of Essential Themes

Knowing the Patient as a Person

Knowing the patient as a person was primary and essential in the process of making the decision to withdraw LST. This consisted of knowing what was important to the patient and what his/her goals were for life after transplant. This was accomplished by considering the meaning of the advance directive in context of the patient's life, telling stories about the patient, and remembering the patient's goals.

Considering the patient's advance directive. The patient's advance directive was a starting point for surrogates in determining what decisions to make regarding withdrawing LST. BMT patients are strongly encouraged to complete an advance directive prior to undergoing the transplant, so the patient and the surrogate previously discussed much of the information typically found in an advance directive before the patient even had the BMT. This information included whether or not the patient wanted to be resuscitated, ventilated, or on a feeding tube. In the current study's group of surrogates, there were no instances of a patient having an advance directive, and the surrogates and close family members not being aware of the patient's wishes as expressed in the directive.

The majority of the patients in this study had completed an advance directive. Surrogates explained that having this information available to them once the patient could no longer make decisions for herself was extremely important and often helpful for them. Accordingly, they used the information in the advance directive when possible. For example, one surrogate explained that she looked at the documents her mother completed prior to her BMT, and said it was very clearly spelled out – her mother did not want any

life-sustaining measures, no artificial nutrition, hydration or “anything else like that.” She explained that her mother was very clear that she did not want to remain on life support, and so the surrogate decided she would not do anything “Terri Schiavo-like” – keeping her mother alive for an extended period of time for what would seem like no reason.

Another surrogate recalls that she and her sister had a very clear understanding of what the patient’s wishes were because the patient made an advance directive prior to undergoing the BMT. Thus, they felt that what the patient wanted was clearly spelled out.

The fact they make you do the living will ahead of time kind of forces you to discuss those options...That’s probably the biggest thing – knowing for a fact that is what the person wishes.

While surrogates considered it a gift from the patient to know what his/her wishes were as expressed in the advance directive, it was also necessary for surrogates to consider the advance directive within the context of the patient’s life. For instance, when patients stated in their advance directives that they didn’t want any extreme measures, some surrogates felt conflicted over this statement because they believed that the BMT itself was an extreme measure, and the patient had willingly chosen to do that. One daughter explains:

She indicated she didn’t want extreme measures to be taken. But a stem cell transplant itself is a pretty extreme measure, which she went into willingly and certainly making her own decision. You get into a funny place, because on the one hand, she is taking extraordinary measures to try and save her own life; but she took those steps believing she could come out the other side.

As the above quote alludes to, surrogates who experienced this struggle reconciled these apparent contradictions by considering the patient's quality of life after the BMT. For instance, even if the patient came through the transplant with lasting side effects, the surrogate considered this manageable for the patient so long as there were not significant chronic impacts on the patient's life. This was when the surrogates needed to remember conversations they'd had with the patient, stories from the patient's life, and consider what was most important for the patient in order to have an acceptable quality of life. For instance, physicians told the surrogate quoted above that if her mother survived, she would most likely need to be on a ventilator the rest of her life. The surrogate knew this was "definitely well outside of what she would have been happy to accept." Some surrogates referred to this as an "in-between life". The patient had the potential to live, but would be hooked up to machines and not living the independent, active life that was important to her.

I didn't want to put her in a situation where, if she recovered from the aspiration and recovered from the lung infection, she was still going to be on dialysis and compromised in other ways, unable to live the life that she would probably want to live...she was an extremely active person. There's no way she would tolerate an in-between life.

Another family member read the advance directive, and despite the patient saying that he did not want his wife to "pull the plug", he had also told her that he still wanted to be ambulatory; he wanted to know people; he wanted to exist. When she kept this request at

the forefront of her mind, she knew that quality of life was “more important than not pulling the plug” for her husband.

He liked life, and he lived it to the fullest, and that was going through my mind when we got to ICU: what kind of a life is he going to have?

Thus, although advance directives were a helpful tool for surrogates, it was always more important for them to remember the patient’s life – things the patient had said, done, and believed – when going through the process of deciding whether or not to withdraw LST.

Telling stories and remembering the patient’s goals. Regardless of whether or not the patient had an advance directive, it was important for surrogates to spend time talking with other family members, recalling stories about the patient, and reflecting on what the patient had told the surrogate about end of life wishes and goals for life after transplant. In this way, surrogates and other family members could combine their knowledge of the patient and what s/he wanted. For example, one surrogate explained talking to the patient’s parents:

She was very outdoorsy and it was hard to keep her home. She wanted to run and go hunting, fishing, and I know if she had had to carry around an [oxygen] tank or have limitations, she wouldn’t have enjoyed life the way she wanted to...She was a marathon runner – and they [the physicians] were talking that if she would have come out of the ARDS [acute respiratory distress syndrome], that she’d have either a trach or oxygen the rest of her life, and that she’d have so many issues that she’d be in and out of the hospital throughout the years...I just knew that she would have been mad if she would have woken up and that would have been the

case; she would have been mad that she went through that...So I would say, 'This is what she wants; this is what she told me. This is my view, this is what I believe.' And they would tell me what theirs was.

Surrogates used this information to help them determine whether or not to continue, start, or stop a treatment. For example, one surrogate considered the fact that the patient would not even take vitamins his whole life as she looked at the multiple intravenous (IV) poles and more than 10 IV bags going into the patient. This was a type of wake-up call that things had gone too far, that the patient would not desire to live like this. Another surrogate provided the following story:

Were his wishes to be like this in an ICU? No. No. He even told me, way before he got sick -- this is his humor -- but way before he got sick, he had a '69 Mustang that he rebuilt, and he's like, 'If I ever get sick, I want you to put me in that Mustang, hit the gas, and push me right over the canyon.' He just lived his life in a big way -- he was a big dreamer type person. I knew that. Where he was [in the ICU], it was totally not him.

Yet another surrogate reflected on the fact that his wife's transplant was delayed two days. He remembered that she was very disappointed in this delay because she just wanted to "get on with her life." He remembered that when she was initially diagnosed with cancer, she allowed herself a 10 minute pity party, then asked him to go and get the nurse to "get things rolling." When they had discussed the goals for treatment, he remembered her saying:

I just want my life back. I'm resigned to that, okay, for this period of time, while we go through the chemos and the bone marrows and stuff like that, I can't work. This is my life. I have to walk around with this PICC [peripherally inserted central catheter] in my arm. I have to do the chemos. I have to sometimes not feel the best. But I want my life back.

When this surrogate no longer believed his wife would get her life back, he was able to make the decision to withdraw LST. Other surrogates expressed experiencing a great fear that the patient would stay hooked up to machines, being fed through a tube, and never being able to return home. One surrogate thought this would be worse to the patient than anything else, and thus it caused her more fear than the thought of the patient's death.

Working Through the Information

Understanding the medical information surrounding the patient's condition enveloped the surrogates' need to understand who the patient was as a person. This process involved determining what information was needed; piecing the information together; navigating a sea of doctors; managing conflicting messages and the telephone game; bridging the communication gap; and dancing between the nurse hat and the family hat. Again, surrogates in this study were different than many in previous studies because of the amount of information they already knew. Since BMT patients are sick prior to a BMT and have often gone through different types of traditional cancer treatments and hospitalizations, most surrogates already understood the cancer diagnosis. They understood the course of a BMT and had some understanding of the associated risks. However, when the patient deteriorated to the point of needing LST, many

surrogates needed a new kind of information. The underlying cancer diagnosis was no longer the main threat for the patient – it was graft versus host disease, sepsis, pulmonary hemorrhage, and a host of other complications they knew little about, and nothing first hand. Thus, the surrogates in this study needed to learn this new information while also considering what they already knew regarding the underlying cancer diagnosis – all in light of what they understood of the patient as a person.

What information was needed. Surrogates felt the need to closely understand everything that was going on with the patient in order to make informed decisions. Much of the information the surrogates wanted, at least initially, during the experience of ICU care, was information regarding the patient’s treatment plan. Surrogates wanted to understand what problems the patient had and what was being done to fix those problems. For example, one surrogate explained how helpful it was when an ICU nurse explained to her the benefits of placing a tracheostomy. The surrogate had been very nervous about it, but the nurse helped her understand how it can actually be more comfortable for a patient than an endotracheal tube, which the patient currently had. Another surrogate talked about how phenomenal the nurses were at keeping her informed about the medications the patient was on. The surrogate remembers the patient having 16 IV bags hooked up to the patient at one point, plus the ventilator and the feeding tube. The nurses always explained what each of the medications was and what it was used for.

Besides needing information to have a clear picture of what was happening with the patient, there were several other reasons that surrogates needed to have information. One surrogate expressed that she felt she was the bridge between the medical team and

the patient. She felt that as family members, she and her sister looked for any clinical information they could so that they could try to communicate everything to the patient despite her sedation. They did this by touching her, talking to her, communicating in ways they felt the healthcare team maybe could not.

Constant information about the patient was also important so that surrogates could make comparisons. Were things with the patient better today than they were yesterday? Had there been a setback?

It was important to ask the doctors to compare things...yesterday how he was, and today how he is. Because when you compare things, you decide it's getting better, or it's getting worse. So that can give us ideas. It was important to compare things day to day.

Piecing the information together. One of the main ways surrogates received information was being present for the daily rounds by the medical teams. Surrogates explained that they would get to the hospital room early every day so they could be there when the doctors did the rounds. They wanted to hear the plan from each of the different disciplines caring for the patient, have a chance to ask questions, and ask different people for clarification about something they heard from someone else. In addition to being present for rounds, other surrogates explained that before anyone on the medical team left for the day, they would come into the patient's room to recap what was taking place, and they would ask the surrogates if they had any questions before leaving for the night. One participant described a resident as "taking her under his wing" and always stopping by

before leaving for the day to talk to her and inform her of what tests were done, what the results showed, and what the plan was.

Even if surrogates were not able to be at the hospital every day to get information from the healthcare team, it was still important for them to stay informed. This was accomplished by daily updates from the healthcare team. Sometimes surrogates received calls from multiple teams daily. For instance, one surrogate explained that the BMT physician assistant called him every day. Then, when the pulmonary team got involved in the patient's care, one of the residents on that team called to update him as well. When the healthcare team called with daily updates, this took some of the pressure off the surrogate because they did not have to worry about calling for information – they could just wait for the healthcare team to call. However, in order for surrogates to feel like they could leave the hospital and receive information through phone calls rather than being present at the hospital, a great deal of trust was necessary. One surrogate explains:

They called me every morning, so I'm like, okay, I'll trust that they'll call me if something changes... Usually it was the night nurse, I think, maybe, who would call before the morning. They would call and say 'here's what's going on,' and I was like, okay, they're letting me know... So that was really important, to keep updated, the whole communication thing.

In addition to rounds, surrogates discussed several other ways they learned to get information from the healthcare team. One of these ways was asking questions of every new person the surrogate met – anyone that could add additional information. For

example, when one patient started dialysis, the surrogate remembers asking many questions of the dialysis nurse.

I mean, even the first day we went down to do dialysis, I must have asked the guy 35 questions. What's this do and what's that do? How's this work and what is that? You know, just even how the equipment worked. I just have to know those things. It might have been as much for my sanity's sake as anything. Or to know how was this going to affect her? What could be the downside or what could be the negative or what could be the – you know.

Other surrogates went to family or relatives who had medical experience and asked them questions, or referred to the pamphlets they received in the BMT clinic prior to transplant. Still others went to the internet, explaining that there is so much information on the internet that it is harder to sort out what you want to look at versus what you do not. In contrast, other surrogates intentionally stayed away from the internet because it provided more much information than they could handle, especially because the information was not individualized to the patient.

There were so many different docs coming in and out. It was hard enough managing, in some cases, the different opinions of the different docs who were right there seeing this actual person with this actual set of symptoms, that I think I felt like trying to get generic information off the internet would have just added more noise to the din and wouldn't have necessarily been helpful.

The majority of surrogates in this study felt that every provider was informative and that anything they needed, any questions they had, were answered by someone. For

instance, if surrogates had questions when the medical team was not rounding, they most frequently asked the nurses. There was a consensus that even if the nurses didn't have the answer, they would either go find a physician to ask, or they would address it with the medical team during rounds. The availability of people to answer questions, the nurses explaining the interventions they were doing, and the medical team rounding and checking in with the surrogate before leaving gave surrogates a sense that they had a clear picture of what was happening with the patient.

I felt like I was getting a clear picture of things, I really did. I certainly felt like everybody, both the ICU team and the BMT team, I felt certainly like everyone was willing to talk and give us as much information as possible...yes, I do feel like I was able to get a clear picture.

Navigating a sea of doctors: managing conflicting messages. Although surrogates wanted as much information as they could get from the healthcare team, they could sometimes get lost in the "sea of doctors", or the many different disciplines involved in the patient's care. This could negatively affect surrogates because they were getting so many messages from so many different people and could create fragmented information and conflicting messages. For example, one surrogate recalls:

I'd talk to the lung docs, and they seemed very promising, especially towards the end, saying that she might come out of this. And then I'd talk to the BMT team, and it wasn't really looking too promising, so it was kind of conflicted... Then, after we made the decision [to withdraw LST], it kind of flipped. So I don't know if the lung docs were just trying to keep us uplifted, keep us in hope...because

after we said, 'Let's withdraw support,' the lung team kind of agreed that this was the way to go. Before that, they were saying, 'No, we still might have a chance.' I don't know if they were trying to keep our spirits up, which is cool, but it was hard because you got hope from the lung team, and then you got shot down from the BMT team.

Fragmented information and conflicting messages made it difficult for surrogates to know what to do with the information they were receiving. Many surrogates described finding a point person. Having a "go-to person" helped surrogates sort through the amount of information they received and prevented them from getting lost in the sea of doctors. This was necessary for the majority of surrogates because even when the overall message of the entire medical team was coherent, the manner in which it was presented varied greatly.

Ultimately, that's what I came to: looking to [the ICU team] more and more as my sounding board; because, again, you're getting information from so many different people that it's really hard, and at some point you really need to hone in on one person. I felt like that would have been a helpful thing to have in general, to have one person who was always, not necessarily 100% the messenger, but at least helping to direct the message, so that I wasn't going through these huge peaks and valleys based on different conversations. And the peaks and valleys weren't necessarily because things were changing that dramatically; it was more just the way different doctors looked at her, at where she was, and how they presented the options. So I did feel like, even though they weren't necessarily

presenting a coherent message, I was seeking it by looking to that one doc or team of docs to help me sort through.

When surrogates looked to one person or one team of people, they dealt with the different information and recommendations they were receiving by making sure that person or team was on board with what was going forward. They looked to the person/team and used them as a sounding board.

The telephone game. Another complication of the multiple disciplines and getting information from them was what one surrogate called "the telephone game". Information was told to one person, who told another person, who told another person. Surrogates, however, did not necessarily believe that this compromised the care the patient was receiving. For example, one surrogate described that the quality of care was not lacking but that communication was problematic. She believed that because the patient's diagnosis and her subsequent treatment was so complex and because so many people were involved in her care, communication was hindered. Thus, the multiple sources of information added complexity to the surrogates' role. For instance, in order to keep the family updated, the surrogate often felt she had to write everything down.

We as family members couldn't be there 24/7, so we were doing that same telephone game ourselves. We had a spiral-bound notebook that we would write down every day what the update was, and that was so that the next person could come and look back and see what had transpired through the week and what was needed.

Another surrogate explained that the doctors joked with her because she had a note pad in the patient's room and she wrote down everything. She said the reason she did this was so that the information would not be a blur when she called the rest of the family to update them.

When the surrogate could not be at the hospital, she relied on other family members to continue writing things down. When the other family members did not do this, however, it added stress for the surrogate. The surrogate felt like she could not leave the patient's bedside or she would miss out on valuable information. Indeed, some surrogates felt as though they could not leave the patient's bedside, at least not during the hours the medical team might round, for fear of missing something and potentially receiving information secondhand. Surrogates would make a point to be present when the physicians did round on the patient so the surrogate could hear firsthand the updates and plans for the patient. They wanted to be present to make sure that the reports they received from the different disciplines were consistent. Many surrogates felt the stories they were hearing were consistent, which made the surrogates believe the different disciplines were consulting outside of the room. Surrogates appreciated this because it prevented them from needing to put the different pieces of information together, reconcile different messages, and be the communicator between teams.

However, when the different disciplines had different methods of providing the information or different messages, this increased stress for the surrogate.

Just when they came in on their rounds, BMT would come in and say, 'She's not looking good,' and then pulmonary would come in and say, 'You know, if we did

this for three months, she could make it out of it.' You know what I mean? So it was just, you didn't know which way to go, you know?

Consistent nursing care helped to counteract the fragmented information and mixed messages surrogates were receiving. Since patients would have the same nurse for an entire day, usually several days in a row, nurses were able to help surrogates piece the information together, creating a coherent, whole picture of the patient's situation. One surrogate explained:

I wrote down that basically the ICU nurses became our lifeline just because, again, there was that continuity of care and that development of relationship, with us and with [patient] – more so even than the doctors.

Bridging the communication gap. Even when surrogates had a point person to help them sort through the information, they experienced additional stressors when more people were involved in the patient's treatment. For instance, some surrogates did not think the BMT staff were able to communicate with the ICU doctors or the nurses adequately. As a result, surrogates felt this became an additional role for them to perform. One surrogate explained that with the complexity of her mother's treatment, there were so many people involved in her care that the BMT staff were not necessarily communicating with the ICU staff. Thus, she felt that as the family member, she was the one who was trying to bridge that communication gap. She explained that the BMT doctors were only doing rounds once or twice a week, whereas the ICU doctors were doing rounds on a daily basis. She felt that she had more contact and relied more heavily upon the ICU doctors, even though they were not specialized in BMT. She felt they were

more familiar and in touch with her mother's care and immediate needs because they were more present. In other cases, when the BMT team did round daily, the surrogates gravitated more toward them. Thus, the family felt the need to bridge the communication gap between the multiple disciplines and were generally more inclined to align themselves with the team they felt was more present.

Surrogates also looked to nurses to help bridge the gap of care and communication. One surrogate recalls how she relied on the nurses during her mother's hospitalization.

The nurses in the ICU were extraordinary people who often bridged the gap in both information and humanity between the patients and family members and the doctors. When my mom was first admitted [to the ICU] a nurse was assigned to her 24 hours a day (1 to 1 nursing). That was an amazing thing and extremely helpful for me. Just having another person who was with her as much as I was made me feel so much less alone. Even when mom no longer needed a dedicated nurse, the nurse who cared for her was very present and available.

Dancing between two hats. Two of the ten surrogates in this study were registered nurses. These two nurses' experiences of working through the information was different than that of the other eight surrogates. These two surrogates experienced the subtheme of "dancing between two hats," especially during the time they were balancing making sense of the clinical information from the healthcare team and communicating to the rest of the family. The two hats these participants wore during this time were the nurse hat and the family hat. When wearing the nurse hat, nurse surrogates described

their main role as “advocating for the patient.” When wearing the family member hat, nurse surrogates described their main role as being a “supportive daughter/sister.” Wearing these two hats meant doing a dance – switching between focusing on the situation as a medical professional and focusing on the situation as a family member. The nurse surrogates in this study described their primary "hat" as a family member. However, they did not believe there was anyone else who would be able to speak for the patient in the same way they could. Therefore, they were forced to dance between wearing the family member hat to support the patient and putting on the nurse hat to advocate for him instead. This dance increased the amount of stress for the nurse surrogates.

The stress of wearing the nurse hat. Nurse surrogates perceived that their families relied on them to interpret information from the medical team because the families trusted that the nurse surrogate not only had knowledge about the medical situation, but also personal knowledge of the patient that the medical team did not have. A nurse surrogate who was a nurse in an ICU for eight years explained:

Everyone kept looking to me to explain what was going on, offer what some other possible interventions could be. And yes, that is a medical team's job, absolutely, and that is absolutely what they're there to do, but there's something different about hearing it coming from a family member who knows [the patient].

This was extremely difficult for nurse surrogates, and made the experience leading up to the decision to withdraw LST more stressful. Although they felt the family was emotionally supportive, they felt an extra burden because the rest of the family could not

understand the scientific depth of the situation and, as a result, looked to the nurse surrogate to interpret the information. One surrogate remembers when the physician's assistant brought up the option of changing the patient to a do not resuscitate (DNR) order. The surrogate simultaneously had to grapple with this decision while also making sure everyone in the family had a good understanding of what it meant to be DNR.

I think when people hear, especially if they're not medical, if they don't do CPR [cardiopulmonary resuscitation], it's like, 'You're letting him die.' But it's like, 'If they do CPR, ribs could break. It hurts. We can't necessarily be with him.' I had to tell them all of the things that go along with that...I had to try and reinforce, 'She said this, so that means this.'

Another nurse surrogate recounted a family member who kept telling her, "I found such and such on the internet." The nurse surrogate tried to gently remind the family member that while the information may be interesting, it was not individualized to the patient and was not always from a reliable source. This was an additional stress for nurse surrogates wearing the nurse hat because it added yet another responsibility to their role.

Wearing the nurse hat also added a different element to some decisions. For example, one nurse surrogate had a very difficult time when there were conversations about deciding whether or not to insert a feeding tube into the patient. It was her belief, based on her professional experience, that once a feeding tube was placed, it was harder to stop. She had seen families struggle greatly with the experience of choosing to withdraw artificial nutrition. Her experience told her that families had a harder time stopping basic nutrition versus stopping medications and ventilations. Thus, her

professional experience shaped her personal decision-making, and when the option to insert a feeding tube into her brother was presented, she had a very difficult time deciding what to do.

I don't know for sure, because I've never been down that road before, but hearing things in the news...and from my experience...it seems like tube feedings or that kind of stuff is harder to stop, because I think it's a basic -- you should at least try and feed people, give them nutrition.

Wearing the nurse hat gave nurse surrogates the background knowledge and confidence to know that as a family, they could say “no”. When physicians would come into the patient’s room and say "here's our next plan; here's what we're going to try next", the family had the right to say no. She had learned, through her professional experience, that the family had a choice, that the family did not need to decide to go ahead with whatever the medical team proposed next. Nurse surrogates explained that their experience was rewarding because they were able to come into the experience without blinders or cold feet. They did not have blinders because they knew that family members could say no to what physicians presented; they didn’t have cold feet because they had a solid knowledge base and relevant skills. Thus, they knew what questions to ask and how to interpret the information for themselves and their family.

Putting on the family hat: an attitude of hope. Nurse surrogates had a very difficult time removing the nurse hat because their background experience and knowledge were always present in their thoughts, emotions, and conversations. When nurse surrogates did take off the nurse hat and replace it with the family hat, they allowed

themselves to have more hope about the patient's condition. For example, one nurse surrogate stated that during the first week the patient was in the ICU, she had thoughts that he would not make it. She was thinking like a nurse and leaning toward the patient not surviving because she could see further down the road than the rest of the family. She said that when she would stop thinking like a nurse, when she would ignore what she had learned and knew from her professional experience, she was able to have an attitude of hope. Even nurse surrogates who had specific nursing knowledge of the medical extensiveness and seriousness of a BMT allowed themselves to have hope when wearing their family hat. When one nurse surrogate looked at her brother, saw that his hair had come back after his initial chemo, she allowed herself to think:

‘Oh, gee, this is going to be great.’ Even when he got the bone marrow transplant, that day I was like, ‘This is all it is? This is going to be better than we thought it was going to be.’

Because of this, one nurse surrogate needed her cousin, who was also a nurse, to help her separate from the emotional part of the experience and to think through it rationally. She stated that even though she would obviously always have the emotional aspect of the experience, she needed someone to help her rationally think through where the patient really was, and what things could be done to make sure his wishes were upheld while giving him the best care they possibly could. Having someone who understood the medical side of things, but who was also part of the family, helped the nurse surrogate to take that nurse hat off and just be a part of the family. Rather than the family looking solely to the nurse surrogate to inform them, she could share this role and not feel like she

was the only one responsible for wearing the nurse hat, which decreased the stress experienced during the decision making process.

Receiving Support through Trusting Relationships

Support through trusting relationships was necessary throughout the process leading up to the decision to withdraw LST from a BMT patient because even when surrogates understood the patient as a person and were beginning to understand the clinical information, they needed to have trusting relationships in order to continue the process of making the decision to withdraw LST. Without trusting relationships, surrogates were not ready to accept information regarding the change in the patient's prognosis or trust that the healthcare team had the same goals as the patient and surrogate. Thus, there was an intimate connection between trust, relationships, and support. In order to trust members of the healthcare team, there needed to be a relationship between the healthcare team and the patient so that the surrogate could believe they had a bond with a mutual goal. These relationships were formed through consistency and allowed surrogates to share their burden with the healthcare team. Once this was established, they were then able to move forward in the process of deciding to withdraw LST.

Caring for the person, not just a patient. The relationship that was necessary in order for surrogates to establish trust and feel support with a healthcare team member was not just between the surrogate and a member or members of the healthcare team. The patient was also a critical member of this relationship. Relationships with the healthcare team, therefore, most often occurred when surrogates felt the healthcare team made an

effort to get to know the patient – who the patient was before being sedated and becoming unresponsive. One participant explained this relationship like this:

The nurse was really nice, he was a young man, he talks to [patient], he rubs him, he asks us like, 'How is your family? How did you meet?' You know, kind of a human person, like he's there to take care of this person. He would have conversation with you, contact.

In contrast, surrogates who had interactions with healthcare team members who did not make an effort to get to know the patient, aside from a medical diagnosis, did not form relationships, and trust was never established. For example, one surrogate explained that when she first saw her husband after his emergent transfer to the ICU, he was laying on the bed naked.

And I'm like, 'Is he dead? What's going on?' And they said, 'Oh, we just put him into -- ' It's like, 'Why is he naked then? Give him a blanket. It's cold. What's going on, guys?' Then I freaked out and they said, 'Oh, we're sorry, we were just finishing.' Hospitals take care of life first. I had to take care of the rest.

This participant, whose time in the ICU was shaped by this first negative experience, still expressed doubts about the decisions the medical team made regarding her husband's care. This caused her to have a more difficult time coming to terms with her husband's death.

When healthcare team members made the effort to get to know the patient on a personal level, surrogates felt they were able to establish a bond with those team members. The bond centered on a mutual goal – what was best for the patient understood

in context of who the patient was as a person. One surrogate talked about a resident she was able to form a relationship with because of how he brought “the human side” to her mother’s care.

There was one that I actually appreciated immensely, as well. He was a resident, I think...He definitely brought the human side and was very cute. I saw him get the information that Mom did not appear to be bleeding from the lungs, and he was like, 'Yes! [with a fist pump]' That was very cute. He wore his heart on his sleeve much more than anyone else on that team did, so I definitely liked him a lot just because I felt like he actually was pulling for her as a person, not just looking at a set of symptoms.

This bond is what allowed the surrogate to trust the healthcare team member and seek her support. One surrogate describes being forever grateful to the nurses who were present and really did reach out and develop a bond with the family. She explained that she did not think she could have made it through the experience without them.

They got a chance to get to know her – the nursing staff got to know her personally – so she wasn't just a diagnosis at that point; she was a person, and her personality was taken into consideration as far as decisions for her care.

Someone I know and trust. Surrogates felt relationships were formed more easily when the healthcare team had known the patient and taken care of him prior to him being intubated and unable to communicate. For example, one surrogate explains:

They saw him and knew him prior to the ICU. This was important because then I could trust that they were actually taking the personal experience they had with

him into what words were coming out of their mouths right then. I could trust that that was a little more of a consideration.

Even though relationships were easier to form if members of the healthcare team had a previous relationship with the patient, the goal was the same. Surrogates wanted healthcare team members to consider the patient, not just the medical situation.

Joking together became another way of establishing relationships and for surrogates to know that there was a trusting relationship present. One surrogate tells a story about making jokes with the patient's physician. The family met with the physician to talk about how things were going with the patient, and he told the physician that the patient was going to pull through. The physician responded by saying that if the patient pulled through, she wanted to go out to lunch with the family. The surrogate responded by saying "Yeah, cool, you're buying." He remembers that they all laughed at this. Being able to joke created a sense of normalcy for surrogates when everything else in their life had been turned upside down.

Pre-existing relationships, even if they were minor, also increased surrogates' trust in the healthcare team. Surrogates expressed relief when they knew someone on the medical team. For instance, one surrogate recalled her excitement when a neurologist came into the patient's room because her place of employment referred patients to him.

I recognized him from the pictures, and it was just like someone I know that was there...I guess it was just a familiar face...I'd never met him before in my whole life, but I'd seen pictures of him because we refer a lot of kids to him, so I know that he knows our patients, so it's like, 'Oh, someone that I know and trust.' Not

that the other people weren't good; I just didn't know them...It happened again when there was a nurse who went to our church there – it was just so nice to see a familiar face.

Another surrogate talked about a physician in the hospital who was a good friend. She relied on this physician because she felt like they were family – their daughters went to school together. She explained that he would come to the patient's room all of the time to help explain what was going on. She described him as a friend and a doctor.

Time to build relationships. Perhaps the most imperative element in forming relationships with the healthcare team was consistency. This was vastly more likely to occur with nurses than any other member of the healthcare team because oftentimes nurses were in the room with the patient and family for over 12 hours a day, three days in a row. Thus, the main group of people with whom surrogates formed relationships, began to trust, and called on for support were the patient's nurses. Surrogates felt that the patient's nurses were in the best position to share their burden because of the amount of time nurses, in contrast to any other healthcare team member, spent with the family. Surrogates felt this continuity of 12-14 hour days, three days in a row, built and fostered relationships.

Because of these relationships, discussions and conversations occurred during these long days that could not occur with other members of the healthcare team. Surrogates expressed that during these days, they were able to express their real worries and questions in a non-formal manner, as opposed to in a formal family meeting with the entire medical team. The most important aspect of this relationship and these

conversations is that they could continue throughout the day, stopping when they needed to, and restarting when the family wanted to restart the conversation. One surrogate explained that she could not have those conversations during five minute visits from the medical team when they came in to present their plan and ask families to make a decision. She said those conversations take time and trust, something she believed only could happen with the continuity and time of nursing care.

Additionally, the 12 hours that nurses spent with the patient and family were important to the surrogate because the nurse got to know the patient during this time as well.

The blessing in the ICU was she had a nurse – she had 24-hour care – which was really nice – so there was some continuity. There was clear communication between the nurses because one was relieving the next. That was something we relied so heavily on; clear communication from the clinical staff with us, as far as even just the smallest things, the smallest changes. Having that 24-hour care made a big difference. I felt like then I got a chance to get to know them, and they also got a chance to get to know me, and they got a chance to get to know her [the patient], so she wasn't just a diagnosis at that point; she was a person, and her personality was taken into consideration as far as decisions for her care.

In contrast, surrogates were never able to form the same relationships or feel the subsequent support when a physician or nurse would only spend a short time with the patient, such as a physician from a different discipline who was asked to consult with the patient. When surrogates were not able to build a relationship with the healthcare team,

they not only did not feel support from them, and they did not want those healthcare team members to interrupt time with the patient. For example, one surrogate talks about her experience with a social worker with whom she was never able to build a relationship. She explained that she only had so much energy and emotion to give, and that it certainly was not going to go to someone who barely knew her, her family, and most importantly, the patient. She described this social worker as coming to the patient's room, knocking on the door, and wanting to come in and have a very intimate experience with the family. The surrogate said there was just no way anyone in the family wanted her to be there because no rapport had been built with her.

Sometimes forming a relationship with a healthcare team member happened for no particular reason other than personalities. For example, one surrogate expressed that she especially trusted one particular physician. When asked what this physician did that gained her trust the most, she replied:

That's a good question. I knew he had been head of that ICU unit for a long time and had a lot of experience, but I would imagine at the end of the day, like with most things, it has a lot to do with personality and just how you feel talking to someone. I felt like he spoke to me in a way that was a good blend of clear, decisive, and knowledgeable, but also with just enough of the human piece of it to understand when to say something one way versus another way. And like I said, he also exuded a confidence.

Sharing the burden. Surrogates needed to feel like they had a relationship with members of the healthcare team so they could trust them. This trust assured them the

patient was not just a medical diagnosis, and the surrogate could trust decisions took into account the patient as a person. One thing that was particularly helpful was when surrogates described certain members of the healthcare team as cutting them some slack by calling and updating certain family members instead of the surrogate needing to call everyone. This made them feel supported.

They told me, 'If you need help, you can call me,' like they were taking care of me. I felt taken care of also, along with [patient]. You don't always have that, but I felt like they were taking care of me, too, and that was important. Sometimes I needed that...I think sometimes it's not about the person who's sick. The family's also sick, too, along with that. They were supportive of me, too.

Other healthcare team members helped take care of the surrogates' physical needs. One surrogate recalls the BMT doctor telling her not to stay at the hospital every night as she had planned.

'No. you go back to the [BMT Housing] and you sleep every night, and you let the nurses take care of him [the patient] at night. You go get sleep, because you aren't any good to him if you're tired, because the nurses come in and check this and check that, and you don't get any sleep.' I could understand that fine.

Another surrogate remembers several doctors or nurses asking him if he had eaten anything. He couldn't remember who, or even when, but he knows people were asking him if he was doing what he needed to be doing.

Surrogates also explained that with nurses there was always a pulse with what was going on with the patient. The nurses were almost always with the patient – they

knew the smaller things, like whether the patient had had a good night's sleep or if she'd been in any pain. If surrogates were not able to be present for rounds, they trusted the nurses to communicate the updates to them. They trusted them to be able to tell them what the physicians had said, what the plan of care was, and explain anything to them that was unclear. This took some of the pressure off the surrogate to continually be at the hospital and allowed them to step away from the hospital and take an occasional break. The nurses updated them so they could know what was going on and be able to update the rest of the family. It was important for surrogates to feel like nurses could share some of this responsibility since surrogates felt updating and interpreting for the family was a major role for them.

Surrogates also needed support when they felt they were not being heard or had difficulty communicating their wishes. In particular, when surrogates began to think about withdrawing LST but did not feel the medical team supported this decision, they depended on nurses to help them communicate their decision to the medical team. For instance, one surrogate explained that there came a time when the family was starting to feel ready to withdraw LST, but the medical team was still pushing aggressive treatments. During this time, she was struggling with how to communicate to the medical team that she and the family did not want to pursue any more aggressive treatments. She remembers that she relied on nurses to help her.

If I would get stuck in the middle of rounds, like, I couldn't come up with the words right then, one of the nurses could speak for me.

‘What [surrogate] is trying to say is – and tell me if I’m wrong, but what I think she’s trying to say is X, Y, and Z.’

And I’m like, ‘Yeah, yeah.’ This was so helpful because I could share that with them [the nurses].

The majority of surrogates established trusting relationships with the bedside nurses and others on the medical team which helped them share the burden of the decision making process. One surrogate articulated that she was forever grateful to those on the healthcare team who really did reach out and develop a bond with her and her mother. She said she needed the support from this trusting relationship because “I don’t think any of us could have made it without them.”

In contrast, a negative relationship between surrogates and patients and the healthcare team, especially the patient’s bedside nurse, created an increased burden. This was only described by one participant, but this surrogate and her husband (the patient), did not feel safe when in the care of a particular nurse. When the patient was still able to communicate by writing notes, he told his wife that he did not feel comfortable being around this nurse alone. The patient and surrogate were afraid to say they did not want his nurse anymore, so they actually developed a code. Whenever this nurse was caring for the patient, the patient would write a note to the nurse asking him to call his wife and ask where their youngest son was. This was a code for the surrogate to know that her husband did not feel safe, and he wanted her to come and be with him. When she received this phone call, the surrogate needed to drop everything and run to the hospital so that her husband was no longer afraid. Clearly this increased the burden on the surrogate and

demonstrates a more negative experience for surrogates who did not receive support through a trusting relationship with the healthcare team.

Recognizing Reality

Throughout the process of understanding who the patient was as a person, working through the clinical information, and finding support through trusting relationships with the healthcare team, surrogates began to recognize reality as red flags emerged. Red flags were things that advanced the decision making process because of their ability to help surrogates recognize the reality of the situation. They subsequently moved surrogates closer to making the final decision to withdraw LST. Red flags could emerge at any point in the process, sometimes spaced but sometimes one after the other.

Problems stacking up. When surrogates took stock of all of the issues going on with the patient, they often realized there were too many problems from which the patient could recover. One surrogate explained the situation as plugging holes in the dam.

I had a feeling that, at that stage of the game, it's the dam with holes popping up and you're sticking fingers into them as fast as you can, and every day it's a different set of problems, like I said, maybe being grounded on one thing -- like, [continuous dialysis] is going great and her fluids are coming down -- however, her skin is now extremely weak and we're having sores start to open; so you're constantly running to keep up with the new ways in which this person is struggling.

They commented that if it had just been one or two of the problems, the patient might have been able to recover, but with so many problems, they began to lose hope and move toward the decision to withdraw LST:

There comes a point in time where there was hope, and then the body just can't do it anymore. If it would have been just one thing – you know, but they thought she had an infection, and her kidneys weren't working right; they had her on continuous dialysis. They didn't think her liver was working right, and then they were concerned about the brain shutting down. I mean, if it was one of those, maybe – but when you start stacking it up...and to me that was you know, enough is enough. And she couldn't do that. There was no way she could have...They had so many things hooked up to her, and I'm like – there's just so much the human body can take. I mean, when you've pumped in chemos and things like that – these things are poisonous; that's what they are. And you know what the body can take.

This decreased hope often occurred after the patient had been in the ICU for a period of time. For example, one surrogate remembers being hopeful the first week of the patient's stay in the ICU. However, she explained that they had to do dialysis a few times during the second week, and when the medical team began to wean the patient off the propofol (a general anesthetic), she knew "things just were not going well". She remembers having this feeling especially when the nurses would turn the patient because he had no pain reaction. "There just wasn't anything at all."

Similarly, another surrogate listed all of the things that were wrong with the patient shortly before she decided to withdraw LST: infections, encephalitis, two different types of pneumonia, no white blood cell count. She explained that she “could see the writing on the wall” because she knew that without a white blood cell count the infections could not get any better, “even with all the medications in the world.” Yet another surrogate recalls the physician telling him they would have to do something “invasive” to the patient. He remembers not even knowing what they could do that would be invasive.

All I could see was like they were in a horror movie and her blood goes shooting out all over the place because there’s nothing there. She had no platelets. How do you get invasive on someone who won’t clot? So, I said, ‘If it would have been one thing – you know, if it would have been the liver but the kidneys worked and there was no infection...I mean, there was just no way – not when you can’t clot, when you have a blood disease. They were pumping platelets into her and they were pumping blood into her as fast as they could, and they just could not get her counts up, you know.

When so many things were going on with the patient, surrogates began to lose hope because they could see nothing was moving in the right direction. They wondered how long they could continue with more and more interventions without any sign or data that was telling them that the patient was in any sort of recovery process. Thus, this was a red flag that, when realized, the surrogate often moved closer to the decision to withdraw LST.

More harm than good. Another red flag that often emerged during the decision making process was the surrogates' realization that the multiple interventions could actually be harming the patient as they prolonged the patient's life. One surrogate decided to take steps toward withdrawing LST when she came to believe that ventilation support was torturing the patient.

I don't want him to get oxygen anymore [ventilator support]. If his organs are done, then what's the point? Lying there with tubes – he can't do anything himself. He's not like that. As his wife, as his friend, I couldn't torture him anymore...I'm like, you can't torture him any more. That's it. It's done. He told me upfront, 'Don't let anyone torture me, Honey. If I'm about to die and it is my time, let me out.' To him, torture was life support.

Other surrogates explained that even though the medical team told them the patient was not suffering because she was well-medicated, they still felt as though the patient was suffering in a different way. Suffering in this case meant the patient was not living the life she wanted to live: she was hooked up to machines, she could not interact with people, she could not be active. Thus, surrogates believed the patient was indeed suffering because of this, and they wanted to withdraw LST shortly after they came to believe this. One surrogate explained that the patient's parents wanted to wait a couple of more days, but he did not feel comfortable with that. He explained he did not want to see her lay there and suffer for two more days; he said that to him, she was already gone.

A new perspective on an extreme treatment. Some surrogates explained that they did not want to give up on the patient. This meant needing to change their

perspective regarding the BMT. For example, one surrogate explained that they went into the BMT fully aware of the potential complications, but not feeling like they had a choice of whether or not to undergo the BMT. They believed it was either having the BMT or dying of AML, and they did not see this as a choice. Thus, in order to be ready to withdraw LST, he needed to recognize that the BMT was not successful and he needed to accept death as the outcome of the transplant.

Another surrogate explained that once the patient started down the BMT path, the path seemed to perpetuate itself because of the culture of BMT. She explained that during her father's BMT workup, they were never told that he only had a 5% chance of survival. The BMT team presented the transplant as the next step – the only thing the medical team could offer as an intervention to try and stop the progression of the disease. She made the analogy that from that point forward, they were on a train they could not easily get off.

It was like, the train is already leaving and here's where we're going, and I'm going to make an analogy here, but here are our conductors and here are the folks who are driving the train, and here's the information...and it was just a train that was just continuing to go down. The BMT team would present to him 'Here's our next step,' almost like this is our next treatment, and I would constantly say to them, 'Please phrase it the way that it is. This is a clinical trial. This is not a proven treatment. Please be honest with my dad so he knows what he really is saying yes to.' Because previously if my dad had a respiratory infection, he got an antibiotic and he got better, and so that's what treatment meant to him. Why would the language around treatment not mean the same thing now? The BMT

team never presented withdrawing life support as an option. We had to do that as a family. Because the BMT team never says never.

As a result, this surrogate needed to help change the perspective of the physicians in charge of her father's care – she needed them to understand that her family did not want to continue on that “train,” and they wanted to withdraw LST.

Seeing the changes. It was important for surrogates to physically witness the patient prior to making the decision to withdraw LST – to see the changes that had occurred and to understand the suffering the interventions were causing. One surrogate spent nearly a month with her mother in the ICU. When she began to believe the patient was actually suffering, she decided that they had pursued aggressive treatment long enough. Her family, however, disagreed. They wanted her to wait to withdraw until after another family event took place. This caused a great amount of distress for this surrogate, because as she explained:

At that point, I didn't care about anybody else. I wanted what was right for mom...I had seen my mom that way for 25 days, and I saw the reality of what was going on. Nobody else but my aunt saw what I saw, and I didn't want to keep making my mom go through that. I saw her every day, and my aunt saw her two or three days before, so she got the reality of what I was seeing every day.

Nobody else got to see that.

Thus, this particular surrogate called her aunt, who was the only other family member who had seen the patient periodically throughout the month of her ICU stay and just three days prior to the surrogate's decision. She explained to the aunt that she believed the

patient had been through enough, she did not have any hope left that the patient would recover, and she did not want her to suffer even one more day. Even though the rest of the family wanted the surrogate to wait, the aunt agreed that it was time. She encouraged the surrogate to go with her gut and to stop the patient's suffering.

One surrogate made the comment that she was not going to make any decisions until she was able to see the patient. When she was able to see the patient, she reported that it helped her to make the decision to withdraw LST – it solidified her thoughts because she could see the hopelessness of the situation and see the suffering the patient was experiencing, even though the patient did not seem to be in physical pain. Another surrogate called a nurse relative to come to the hospital to offer the surrogate support.

So she's like, 'All right. I need to go in and lay eyes on him.' Just like I did [when he first needed to be transferred to the ICU]. You just have to have that visualization of him. And she walked into the room, and I could see her demeanor just completely change. That's where it just goes 'yeah!' in the pit in your stomach – OK, so she was seeing what I saw.

Another surrogate explained that seeing the patient's progression over a period of three weeks without any signs of improvement made it easier for her to make the final decision to withdraw LST. If she had not been there to see the lack of positive change, she does not know how she would have come to the decision to withdraw LST.

Being able to see the patient on a regular basis created another red flag for surrogates that moved them toward the decision to withdraw LST. They were able to note

changes in the patient condition immediately, even if they could not articulate what the change was.

I think it seemed to me his color looked different. He just seemed a little different, really wasn't responding at all. Even if he opened his eyes, he looked – not that he looked at you before, but, I don't know, it was just different.

Therefore, whether patients saw no change or a negative change, there were times that physically seeing the patient proved to be a red flag that moved the surrogate toward the decision to withdraw LST.

Additionally, when surrogates saw these changes (or lack of changes) in the patient and saw that they were hooked up to countless IV bags with multiple types of tubes coming out of them, they felt the patient just was not the person anymore. When the surrogate felt confident they understood the patient as a person, they realized this ICU patient was not the person anymore.

To me, she was already gone, you know what I mean? It was just the saddest thing you could ever see somebody go through – just helpless and hopeless and just lying there and not able to say or do anything.

Another surrogate explained:

It's still hard to say, 'Okay, that's enough,' but, you know, if the person is lying there and they're not that person, and there's 15 machines hooked up to them, and if you disconnected any one of them they would go.

Thus, physically seeing the patients helped surrogates see the patient in a new way. They saw that the patient in the hospital bed was no longer the person they knew and loved, and this moved them closer to the decision to withdraw LST.

Listening to my gut. Sometimes surrogates just had gut feelings that it was time to withdraw LST. They were unable to verbalize how they knew, but many participants stated that in their gut, they knew it was time.

You know...I think you get to a point where you just feel this isn't going to go well, and not only that it's not going to go well...I just think there's a sense. I don't know how to describe it. Probably all of us were thinking this isn't going to end well and we're going to probably have to do something...I don't know how to describe it. I don't know what word to say.

Similarly, some surrogates thought the patient's body was telling them they were finished, that it was time to withdraw. One surrogate explained that he just felt like the patient's body said, 'I'm out. I can't do it any more.' Another surrogate had the gut feeling that her husband was telling her to let him go. In this particular case, the feeling she had was especially critical in leading the surrogate to withdraw LST because the patient's family was not supportive of her withdrawing the LST. An additional complication in this situation was that in her Somali culture, the husband's family was the one to make decisions. Thus, even though she believed her husband was suffering by being hooked up to a ventilator – something he did not want – she was more hesitant to withdraw LST because of the disapproval of her husband's family. Thus, she looked to him for a sign.

He [husband] was in me. I don't know. He was in me. He was telling me, '[Wife], let me go.' I felt that. And I talked to him. I visited him all the time. I went back and I told the nurse to please leave, and it was only me and him and I said, 'Show me a sign, Honey. Just show me a sign.' And then he gave me the strength of, 'Stand up for yourself.'

Thus, this surrogate felt confident that she needed to make the decision, regardless of what the patient's family wanted because her gut feeling was verified by her sense that he was telling her to let him go. This surrogate felt so strongly inside of herself that her husband made the decision to stop the LST that she did not even feel like she was the one who made the decision.

Just as surrogates came to rely on gut feelings that the patient was saying he was finished, in contrast, one surrogate remembers that one of her husband's physicians wanted to stop the ventilator a week before the surrogate made the decision to remove it. The surrogate just was not ready, and another physician said they could wait some more time to "let the patient decide." Although the surrogate did decide to stop the ventilator a week later, it gave her great peace of mind that they waited the extra week. She stated that she believed in her gut that the patient would have breathed on his own if they had stopped the ventilator when the first physician recommended it, and she did not want that. A week later, however, when they stopped the ventilator, the patient did not take a single breath on his own.

That first week, there was possibly a chance that he could recover and this body could have sustained for awhile without the ventilator. But we had peace of mind

knowing that he was given the chance to get better before his body gave up. This took away some of the decision I had to make away from me. If he had breathed on his own, I would have thought, 'His body's still mending. It's still healing. It's got a chance.' When he didn't even take a breath however, it was like he had decided it was over, and I can't say, but I would have guessed that the week before, he probably would have breathed on his own a little bit... That would have bothered me because I wouldn't have felt as certain that he decided. So I have no regrets, none whatsoever, about waiting that extra week.

Thus, surrogates relied on their instincts to help them decide both to withdraw LST and to wait to withdraw LST.

Accepting the change in prognosis. When surrogates began to reconcile their understanding of who the patient was as a person with their understanding of medical information, had supportive, trusting relationships with the healthcare team, and began to recognize reality, surrogates found that they needed a different kind of information than when the patient was first placed on LST. They still wanted to understand the medical information – the general treatment plan and what was going on in the patient's body – but they also wanted to understand what the physician believed the patient's outcomes were. They did not merely want to know if the patient would survive; they wanted to know at what quality of life the patient would have if she survived. When they were able to obtain this information, they began to see and accept a change in the patient's prognosis. They could then begin to understand that either the patient would not live, would never recover to live off of machines, or would not recover to a level that was

acceptable to the patient. This was the penultimate red flag that caused them to think about withdrawing LST.

It was just really the realities. The numbers, the statistics, were not changing. They were not improving; they were decreasing, and her condition was not improving... Also, I guess, looking at what we knew my mom's wishes were, and knowing the risks involved in this, and knowing that she was at high risk based on her age (but she was a fighter, and we took that into consideration), we just had to accept the fact that her fight probably was coming to an end...I was with her all day long. I didn't see progression. I didn't see any positive prognosis going on...Then within the last weeks or so, when nothing was improving and the doctors weren't seeing changes, and knowing the sensitivity of her situation and not getting any kind of positive feedback, it was like decisions needed to be made a little quicker, as opposed to pondering on them for some time, so that was kind of why we made those final decisions.

Another surrogate explained that she remembered talking with her husband when they were completing his advance directive. He wanted them to do everything they could do, as long as there was a chance he could recover. This surrogate explained that she began to understand that there was not a chance that he could recover to a level that was acceptable to him, and shortly thereafter, she chose to withdraw LST. Still another surrogate explained that after the physicians told her that her mother would not be able to survive without some kind of machine, she knew she had to make the decision to stop treatments. She remembered that her mom had always told her she did not want to be

hooked up to machines to be kept alive – if she was going to survive, she wanted to survive naturally. Thus, after hearing the physician’s prognosis, the surrogate knew the decision had to be made, and she said, “Okay, no more.”

It was necessary for the surrogate to have a sound understanding of who the patient was as a person before they could accept the change in prognosis that moved them forward in the decision to withdraw LST.

Even if he does now respond to antibiotic therapy and has some turnaround for his organ failure, he could potentially be on dialysis for the rest of his life. He could potentially be neurologically impaired. Would he want any of that? No.

Absolutely, we knew that hands down he would not want that. We knew that answer. We had that answer. We had that gift from him. We already knew that.

In addition to having a clear understanding of who the patient was as a person, surrogates were better able and more willing to receive information regarding a change in prognosis if the surrogate had a trusting relationship with the member of the healthcare team relaying the information.

But the ICU attending at that point, we had built a relationship with her because she had been attending at certain points while my sister was there and while I was there, and she was the one afterward who had come in and broke it down and explained a little bit more in detail and a little more personally. She was the one who used the word irrecoverable. Again, she was able to reach out, I think, more on a personal level.

Sometimes surrogates were ready to receive this information but the medical team did not come straight out to tell them a quality of life prognosis. One surrogate described her strategy with her aunt to elicit this information from the medical team:

In my conversations with my aunt, a lot of times I would tell her, ‘Look, if you ask them, “What would you do if this was your family member?” they could give you a more honest opinion than if you just ask them, “What would you do?” because of liability.’ I told her, ‘They can’t tell you, but if you phrase it that way, you can get a better understanding of the reality of what’s going on, since we’re not the medical experts.’... So on the next phone consult, my aunt asked the doctor again – the first time he had said, ‘If it were my family member, I still would like to give her some more time. I think there’s still possibility.’... But when my aunt asked again later, and he said, ‘Most likely, she probably at this point won’t be one who could survive without some kind of machine. She’s not really showing the signs of recovery we had hoped for.’

Another surrogate stated that she believed nurses were in the best position to inform families of their options if the patient’s physicians were not being upfront or clear about the patient’s deteriorating prognosis. In her professional experience as a nurse and her personal experience as an surrogate, she believed that nurses who are caring for patients and families who are not doing well on LST should be bold and have conversations with the family about what they want for the patient, what the patient would want, and letting them know that they have options. "Do you guys know that you don't have to do what's being proposed right now? [More interventions, prolonged LST.] Do you know that you

have a choice?" This is related to the surrogates' common belief that since nurses are the people who are present with the family the most, they have a relationship with the family and can, therefore, talk to them about these sensitive questions.

Toggle switch: helping them get better versus prolonging life. In order to truly accept the change in the patient's prognosis and move forward in the process to withdraw LST, surrogates experienced what one participant called a "toggle switch." The toggle switch was the emotional work the surrogates needed to do in order to accept the change in prognosis. Specifically, it was the consideration of whether or not the patient could come back from and recover from the illness to be normal again. Surrogates considered whether the decision they were about to make and the intervention the medical team was presenting was a temporary solution that just needed to be done to get to the next point or whether it would be permanent. For example, would the patient need to live with this decision even if she recovered from the original problem? Would the dialysis that the medical team was presenting just be short term until her kidneys recovered? Or would she get through this ICU stay and still need dialysis three times a week?

Yeah, I would usually ask the question; like when they wanted to do [continuous dialysis], I asked, 'Does this mean a lifetime of dialysis?' They said, 'No, not necessarily. The objective is short-term, to pull all this excess fluid off, and hopefully once we get the fluid down her kidneys will be able to really restart.' They hadn't completely stopped, either, so that was an indicator that they maybe weren't down for the count; they were just extremely taxed, and that stress was killing – or not killing, but reducing their functionality. I would just ask and try to

get a handle on what the objective was and whether we were going to get somewhere with it.

During this decision-making time, surrogates talked to the patient about their decision making process. Whether or not the patient could hear their voice, they wanted to reassure the patient that the intervention was going to be short-term; it would not stick around.

So it was tough, every day, to make those decisions, but like I said, I decided that if it was a short-term thing that we needed to do to try to save her life and get through this crisis, then I would proceed with it. And most of the decisions as they were presented to me were those types of decisions. No guarantees, of course, but it was explained to me that, once she was put on [continuous dialysis], it didn't mean she was going to be on it forever, it depended on how long she was on it. Is this something that will answer a question that will help us direct her treatment and keep us on the path toward real recovery, or is this something that's going to induce undue stress or pain...I didn't want to put her in a situation where, if she recovered from the aspiration and recovered from the lung infection, she was still going to be on dialysis and compromised in other ways, unable to live the life that she would probably want to live.

Another surrogate said that she made decisions that were aimed at helping her mother recover, not directed toward artificially extending her mother's life. The decisions were to do whatever necessary so her mother could get better. There was a difference in her mind – it was acceptable to do a life-sustaining treatment that would help her recover, but

once she began to believe the treatment was just prolonging life, she no longer endorsed that treatment. Another surrogate, who knew his wife did not want to be kept alive on machines stated:

It's easy to sit there and say, 'Yeah, don't do that,' but when you're the one that actually has to say, 'We're done here.' ... That's not a word you just blurt out, you have to think about it and weigh it.

During the initial stages of the decision making process, most surrogates did not make decisions based on the toggle switch. Indeed, their decisions were not presented as and did not feel like actual decisions. Rather, they understood the decisions presented as what needed to be done next – the natural thing to do. One surrogate described that there were many times she felt like it really was not a decision as much as the physicians presenting her with something they needed to do to take care of her mother. She felt she had to trust this because she was not a physician, and she was not about to go on the internet and try to find ten different options. Another surrogate explained the hardest decision she made was choosing to put in a central line.

Maybe the hardest one [decision] was when they wanted to put a central line in, but again, if they're saying, 'We need this to administer a medication that she needs to survive,' what kind of decision is that?

After the initial crisis of the patient's transfer to the ICU when surrogates were able to make decisions based on the toggle switch - making decisions based on whether they were temporary solutions and not just extending a life the patient would not want to live - they were able to recognize the futility of the situation and realize there was nothing

left to do. When they were presented with decisions that seemed to only prolong the patient's life, they reached a point where they began to shift toward making the decision to withdraw LST.

At that point, she was already gone. It was just the physical body responding...Again, I think we both knew that there really wasn't a decision to be made, that the decision had already been made, that from that point forward, we knew -- again, "irrecoverable."

At this point, surrogates also used clinical understanding to realize the interventions the medical team was proposing were not going to provide the patient with the quality of life the patient desired. For example, one surrogate recalls that the medical team helped him understand that his wife needed her immune system and drugs to get through the serious infection she was battling. When the physician explained that the patient did not have the immune system and the drugs could not do it alone, the surrogate decided to withdraw LST. He recognized that the ventilator was maxed out - she was on 100% oxygen and the PEEP [positive end-expiratory pressure] was maxed out. He told the physician there was nothing more to do and that he wanted to withdraw the ventilator. Another surrogate considered the choice to withdraw LST inevitable.

Well again, with the doctors coming in and saying we continue to medicate him with whatever they were using, thinking that it would kill the virus, continue to do that, but then he would have to go on dialysis because his kidneys were shutting down. And there was just no way, there was just no way. So you do nothing and it

takes longer for the passing, or you do what's inevitable and you turn the machines off.

Although it was different for everyone, it took time passing for some surrogates to be able to make decisions based on the toggle switch. It took them time to transition from the immediate, crisis phase of the patient's transition to the ICU, to looking at the situation with the patient as a person at the center, surrounded by an understanding of the medical situation and support from trusting relationships.

Making the Decision

When surrogates understood the patient as a person, had a grasp on the clinical situation, felt supported through trusting relationships with members of the healthcare team, and recognized reality, they moved toward the decision to withdraw LST. They first experienced the toggle switch – weighing what they had come to understand about the patient and the reality that were beginning to recognize. Then they had family meetings and discussions with the family. After the surrogates discussed the situation with their family and understood there was nothing left they could do that would sustain the patient's life as he/she had wished, the family chose to withdraw LST.

The importance of talking with the family. When the surrogate came to the decision to withdraw LST, next, they needed to discuss things with the family. The medical team usually facilitated these discussions. For example, the medical team sometimes suggested getting everyone in the family present at the hospital to see the patient, discuss the options, and hear what the surrogate was thinking. These meetings were both formal and informal – usually they started as a formal patient meeting, in a

reserved room, with the surrogate, immediate members of the patient's family, sometimes a spiritual advisor, and the medical team (physician, social worker, physician assistant, etc). For the most part, the surrogate decided who would be present from the patient's family, which was usually just immediate family members.

Her family started calling all the close relatives to come over, so I think there were about 20 people at the hospital from her side, but we only wanted her parents and me in the meeting. We just wanted us three in the meeting; we didn't want too many voices voicing their opinions.

Surrogates also did not want to have formal family meetings prematurely. For example, one surrogate called in only her children – not the children's spouses – for the first family meeting because she did not want her grandchildren to get scared. However, for the final family meeting, she asked the children and spouses to come as well. She explained that the second time, she knew the meeting was going to be final, so she wanted everyone there.

After the formal discussion, the family often stayed in the room or went back to the patient room to discuss various things. One surrogate explained that after the hospital meeting, the social workers, nurses, and physicians left. She and her children remained in the room so that they could share what each of them were feeling. Another surrogate explained that she and her aunt waited until the physicians left the room. She explained that even though they were on the same page with what they thought needed to be done, they did not make any decisions in the meeting that day. They talked afterward – appreciative that the medical team gave them time for that. It was during that time, after

the formal family meeting, that the surrogate and her aunt came to the decision to take the patient off support. This was also a time that family members could ask questions. For instance, one surrogate called his sons back to the hospital when it was time to make the final decision. He believed that both of his sons knew something was happening. He explained the options to them – that the medical team could try doing more invasive treatments, or they could choose to withdraw LST.

My youngest goes, ‘Well, if they can try something else [invasive], why wouldn’t they try it?’ They were there and I listened to them. And I said, ‘Okay, and if they do go invasive, then what?’ I think after I explained to them – I think his question was a desperation question. That’s a question that was made, that was spoken with the heart, not the mind. It was not a long discussion; it was not an hour thing hemming back and forth. It was pretty much, and they both had copies of her wishes as well. I called the boys in, we had some discussions and they just asked, ‘What do you want to do?’ I think my words were, ‘Yeah, we have to do it.’”

After family members had these formal and informal family meetings and came to a joint family decision, it was stressful for families if the medical team then had different conversations with separate people. One surrogate remembers that the physicians would pull her mother aside to have a separate conversation with her.

And I just thought, ‘No. We are united together in this decision.’ They wanted to make sure that she was getting all the information, but they also wanted to make sure that – I think because I was verbal about this situation and I was willing to have the discussions with them, they thought my mom’s opinion wasn’t

necessarily being heard, but it was. She's just not quite as verbal as I am. We made a joint family decision together... We had many discussions – my sister, my brother, my mother – and we just again came back around to, 'Dad verbally told us he did not want these things.'

Thus, families wanted time to have a formal meeting with the medical team, to hear the options, to ask questions. But then they also wanted time together – to talk about the patient, what s/he would have wanted, and to come to a joint family decision. After this time, they wanted to proceed with the decision to withdraw LST. Once the decision was made, they did not want to wait, and they did not want to have people question their decision.

Even though the decision was made at this point, surrogates struggled with the finality of their decision. The finality caused many surrogates to experience increased stress. One participant struggled with this even though he knew the decision he was making was what his wife would have wanted.

I never wanted to have a life in my hands like that. And to have somebody's life in your hands and not knowing if you're making the right decision or not, even if that's what they want, it's just such a final answer that you can't take back.

Another surrogate explained:

But it's just difficult to have the finality of the decision. Just to have it go – 'Psh! Done.' – was obviously horrible.

Thus, the finality of the decision could create doubt for the surrogate, even when the surrogate was confident he had made the best decision.

The whole time – then and now...I wanted to make sure I was making the right decision, you know, and even now – people tell me it was, and I know it was, but it still hurts.

Even though they continued to struggle with the finality of the decision, surrogates moved forward with the decision to withdraw LST. At this point, it was important to spend time with the patient – to be able to say goodbye and share the moment with loved ones. When expectations were met and the surrogate believed she had acted as the patient's advocate and not according to her own wishes – doing everything the patient would have chosen – the surrogate was able to live peacefully with the decision that was made.

After the decision was made. Once the decision was made to withdraw LST, the healthcare team always let the surrogate decide how much time they wanted to wait until they stopped the support. Family members generally wanted this to happen as soon as possible – once they decided it was time, they did not want the patient to suffer any more. Thus, they waited (if necessary) for any family or friends to come who were not already there to say goodbye to the patient. They explained to the medical team that they did not want the patient to struggle during the withdrawal, and they wanted to know what was going to happen. After these needs were met, the surrogate was ready to withdraw.

Knowing what to expect. Surrogates wanted to know what to expect once the LST was removed. They found it extremely helpful and comforting when the healthcare team informed them of what was going to happen, what they should expect, and made an effort to be sensitive and supportive.

When we took her off the ventilator and all the tubing, I will tell you, the staff was incredible. I don't remember the nurse's name, but the nurse was so incredibly supportive. She brought in the end-of-life team. They were really good. Everybody was really, really nice. Everybody was telling me what was going on and what was happening... The nurse was so, so incredibly sensitive to the issue, just telling me everything she was doing, and I was really respectful for that. She was very, very sensitive to keeping me updated and informed about what was going on.

One of the main things surrogates wanted to know was if there was any chance the patient could continue to breathe once the ventilator was removed. One of their main fears was that the patient would gasp for air and appear to be struggling. Thus, many of them asked the nurse to make sure the patient was properly medicated prior to removing the ventilator so they would not hear or see the patient gasp.

I kept saying, 'I know that she's sedated, but I don't want her to starve for air, so make her as comfortable as possible.' So he did. That was important to me at that point. I don't know if she would have even known that she was in need of air, but I wanted to make sure that – and maybe that was for my own benefit, as well – that we not see that physical response of starving for air.

Another surrogate thought it seemed like the patient was having a little trouble breathing, and she asked the nurse to give him something. She, too, guessed that it was maybe more for her than the patient, and to make sure no one else in the room was upset. Another surrogate remembers that her brother-in-law breathed for a day and a half after his

ventilator was removed, and she was terrified of this happening to her husband. She needed to know what to expect, so she asked the doctor if her husband was going to breathe on his own after the ventilator was removed. She felt better choosing to remove the ventilator after the doctor told her he most likely would not breathe on his own.

Surrogates experienced more stress, doubt, and a more difficult experience when they had unmet expectations. For example, when the physician told one surrogate that the patient would most likely not breathe, but the patient did breathe for awhile after the ventilator was removed, she experienced doubt and stress.

He said, 'I don't think she will take another breath after we disconnect from the vent. The damage is that extensive that I don't think she will.' It had set my expectation for one thing to happen, and then something very different from that happened; and that threw me, for a moment, and made the process longer than I had expected it to be – which, given too much time, you'll doubt just about anything...It was awful, listening to someone struggle for breath. It's a horrible thing. She probably breathed, I don't know, a few minutes - much longer than anticipated, which of course gives you that moment of terror: Wait a minute. Have I chosen wisely? Just the fact that she held on so much longer than we expected was obviously really difficult.

Even though this surrogate was confident that withdrawing LST was the best decision for the patient, having unmet expectations did cause her to question that confidence. Another surrogate explained that her only complaint for the entire time her mother was in the ICU happened when the on-call physician came into the room to declare her mother dead. She

remembers that the doctor came into the room to assess the patient, saying that she did not hear a heartbeat or feel a pulse. The surrogate explained that she did not say anything else, and so she asked the doctor if she was pronouncing her mother dead. The doctor replied yes, but the surrogate wished the doctor would have said that without her asking, would have said the words that her mother had died. She needed this to finalize the process for her, and knew from her own experience with grief counseling that you need to use the word dead or death or deceased to finalize the process and provide closure. Because her expectation of closure was not met, she had a more difficult time with the process.

Sharing the moment and saying goodbye. Prior to withdrawing LST, it was important for surrogates (and other family members) to have time to say goodbye to the patient individually. One surrogate looked to the nurses to help facilitate this. She felt it was a difficult role to play herself, but she knew that each person in the family probably wanted individual time with the patient. She found it helpful when the nurses would facilitate that time, asking if anyone needed time alone with the patient. She felt it was most meaningful when she had that time alone with the patient. Another surrogate described this role of the nurses as “creating space.” The nurses helped “police the door” so that the family – either individually or as a group – did not have to deal with anyone coming into the room unless the family wanted that person there. Surrogates were thankful for the time and space that nurses provided. They also appreciated when nurses involved them as a partner in the process, such as by asking the family members if they

wanted to help with any of the patient's cares or asking what could make the experience better for them.

They'd [the nurses] ask, 'Do you want to do this, or do you want me to do this?' it was very much more of a partner sharing – like washing his face or washing his hands...they gave us the time and space to be alone with him and partner with some of the cares...There's all varying levels of experience with nurses. There were nurses there those last couple hours, shifts, where they'd been a nurse for two years. Gosh, this is an emotional way, very hard for a new nurse to go through, because you just haven't gathered the coping part of it or whatever. But they still knew to say: 'Do you want me to put some music on? Do you want some time? What can I do to make this awful experience better?' That was so great.

After family members had the opportunity to say their individual goodbyes, most families chose to share the moment of the patient's death. One surrogate described that she and her sister sat with their mom, each holding one of her hands. They had a picture of the patient's grandchildren sitting on the patient's chest, and the surrogate's aunt and uncle were nearby in the room, praying quietly. Another surrogate whose husband could not be there Face Timed with the surrogate. The surrogate held the iPad up so that she and her husband could be there as her mom passed away. They both talked to the patient while the surrogate held her hand. One surrogate, who was actually in the room by herself, just laid her head on the patient's chest – explaining she wanted to share the moment with just the patient. She said that she could hear his heart beat, and it was very

beautiful. Another patient had many people come to share his moment of death. The surrogate remembers:

They all came down. He had friends come down. His sister and brother and his two nieces flew in. Our [Pastor] came and my brother, so we were all there at one time or another. At one time we had all these people in to see [Husband], knowing that would probably be the last time. I don't know if he was cognizant or if he could understand what was being said or why all those people were there. You couldn't ask for a more gentle kind of passing, I don't think. My sister-in-law and my brother had brought a poem that he wanted to read that he thought [Husband] would like, and he read the poem to [Husband]. And one of the gentlemen who was in [Husband]'s singing group was a good friend of his, and he came to the hospital and sang to him. So I think the people who mattered most in his life got a chance to see him one last time.

This was very important to the surrogate, and it made the experience more peaceful and meaningful to have others there to share it with them. Surrogates, as awful as the situation was, cherished the moments they had to say goodbye. One surrogate, whose sons and sister-in-law were with him shared that he had never seen his wife more beautiful during that moment.

She was lying there, she'd just passed, bald head – and I said something to the effect of, 'I don't think she's ever looked more beautiful.'

Living with the Decision

There were two narratives that followed the finality of the decision to withdraw LST: acting as an advocate and having doubts about the patient undergoing the BMT in the first place and the role they may have played in the decision to do so. These two narratives were not always distinct and separate, but for ease of discussion they will be discussed separately. Regardless of the narrative that surrogates experienced, in order to have peace with their decision and continue with their life, it was critical to honor and remember the patient.

Trusted to do what's right. Surrogates dealt with the decision making process, the death of the patient, and their own grief better when they could say, with some degree of confidence, that they had made the right decision. A main way they were able to believe they made the right decision was when they believed they acted as an advocate for the patient and not making the process about themselves. Several participants said that this patient-focused attitude helped them think more clearly, rather than becoming overtaken by the grief and stress of the situation.

I was aware of a lot of those decisions that needed to be made at the time I was going through it, because I stepped out of my shoes and into the role of myself as a psychologist working on the crisis team...because we're not supposed to do therapy, and we're not supposed to operate on family members or people we're close to because of the emotional connection. So as I was going through a lot of this, I really tried to make myself separate from the emotional piece so I could make the right rational decision on behalf of Mom; because as I said, and I

repeated over and over, I kept telling myself that I can grieve when it's over, but during this time, it's the time when Mom needs what's right for her.

Another surrogate explained:

In the situation, you know, I thought it was the right choice, because I thought it was what she wanted, and it was absolutely important to me make decisions based on what she wanted.

Although many surrogates described the experience of choosing to withdraw LST as the most difficult thing they ever had to do, they also described it as a privilege to be able to do what they felt was right for the patient.

I don't know, whatever makes that person happy, whatever they want. This is what [Wife] would have wanted, and if you can respect that, then you're doing your part of it. They put their lives in your hands for a reason – not for a reason, but they chose you, and if they give you the confidence, and they trust you to do that, then I think you need to fulfill that and do what you need to do.

It was important for surrogates to advocate for the patient after the patient's death, as well. Several surrogates described that their role of advocating for the patient's wishes continued after the patient's death, especially regarding things such as funeral arrangements. For example, one patient wanted to be cremated, but this was against his mother's religious views. However, the surrogate helped her mother come to terms with the patient's wishes, and they ended up cremating the patient. Another surrogate explained his experience of respecting the patient's wishes for after her death, even though it was difficult for him.

We still have the remains. She had put three things down which she wanted done with the remains, so... We have a lake we fished a lot, and she would like some there, but we haven't done that yet. I guess I'm not ready for that yet, but eventually. [Voice breaks.]

Second-guessing the BMT decision. Although the participants in this study came to peace with their decision by remembering they acted as the patient's advocate, several surrogates experienced a more difficult time after the patient's death when they doubted that making the decision to go through with the BMT was the best decision. Since patients must be in remission in order to have a BMT, surrogates found themselves second guessing if they should have proceeded with the transplant since the patient was doing well and in remission at the time of transplant.

It wasn't until probably about six months after her death where I had a wave of just sheer terror, like, did I make the right decision? Did we make the right decision? It was obviously a family decision. Should we have continued with eight rounds of chemo, total, and taken our chances from that point forward, where she would have maybe had some quality of life?...It really struck me several months after her death. It wasn't until much later that I really started to process all of that. But, you know, that was an emotional response. I think rationally we know we did what we thought was the right thing to do, but you just have that emotional piece of it. I've even talked with another friend of mine whose mother has been fighting bladder cancer, and had surgery to remove the bladder; and during surgery, something wasn't reconnected properly, and she ended up in

septic shock and has had a two-year battle of being in and out of the hospital for months at a time and basically zero quality of life. Now she's weeks away from dying, and he wishes that they had just -- he thinks that maybe if they had just not done the surgery and given her a year of quality life, maybe that would have been the better option. I think about that, too, that maybe it would have been better; she handled chemo so well maybe that was our better option, in retrospect.

Surrogates describe dealing with this doubt by realizing that they could “second guess themselves to death” on things like this. They reminded themselves of the high odds that the cancer would come back, that it would come back even more aggressively, and that the medical team wouldn't be able to get the patient into remission for a transplant. Thus, surrogates comforted themselves with the fact that only hindsight is 20/20, and remembered that they took as much information as they could, made a decision, and had to live with it.

Honoring and remembering the patient. Regardless of the narrative of either advocacy or doubt, honoring and remembering the patient was critical to living with the decision. It was important for surrogates to grieve in a way that was meaningful to them as an individual. One surrogate explained that she was grieving differently than others in her family. For example, her sister set up a sort of shrine in her apartment to her brother and made necklaces of the patient's thumbprint for the rest of the family. The surrogate explained feeling guilty that she didn't feel the need to have those things. It was more important for her to remember him in her heart and do little things, such as buy a book by his favorite author and read it, or buy a bottle of Coca Cola that said “Have a coke with

[Brother's Name]"on it. Others relied on good friends and their church to help them get through the grief process. Still others talked about the healing process of preparing for the patient's funeral.

The two sons-in-law and the son and his carpentry partner built his casket for him.

I thought it was good healing for them, too. The girls put together picture boards, and we're going through pictures reminiscing, and those guys were out working in the shop where [Husband] would have been, and yeah, it was good healing.

One surrogate explained the grief process like the children's book *Going on a Bear Hunt*. The story explains that in order to catch the bear, they have to go through the marsh – they can't go under or over it, they have to go through it. She explained that she learned she had to lean right into her grief. She said people can try going around it or avoiding it, but that grief gets you in the end, so it's best to just hit it straight on, dealing with it and being upset about it and laughing about it – this is better in the end.

Many surrogates explained that grief would hit them when they were not expecting it. For instance, multiple surrogates explained that when they were driving and came anywhere near the hospital [where the patient died], they'd experience a huge wave of grief. Another surrogate told the story that the patient's girlfriend wanted his recliner, and she thought she was ready to give it to her. But when her brother came to pick it up to give to the girlfriend, the surrogate started crying and said that he couldn't give it away – she just wasn't ready yet.

Several surrogates also dealt with their grief by frequently visiting the patient's grave. One surrogate went every week. She explained that she needed time and the

reminder of the grave site to remind herself that her husband was actually gone. Other surrogates felt it was important to do things they'd previously planned to do when the patient was still living. For example, one surrogate took her four young children on vacation to a place they'd planned to go as a family when the patient recovered. She explained that as hard as it was, it was necessary to do that in his memory.

Conclusion

In conclusion, surrogates kept their understanding of who the patient was as a person at the center of their decision making process, were able to work through the clinical information of the patient's situation, and had support through trusting relationships with the healthcare team. Eventually, they recognized reality through a number of red flags which moved them toward the process of making the decision to withdraw LST by using the toggle switch and discussing things with family. When they were able to have individual time to say goodbye to the patient and then share the moment with loved ones, when their expectations were met, and when the patient did not suffer, they were able to live peacefully with the decision they made, and a year later reflect the following:

In the end, I think we did very right by him. Very right by him.

Chapter 5: Discussion of Findings

This chapter will discuss the findings and contributions of this study. The findings will be considered in light of the literature review. Similarities and differences will be examined, and implications for practice, education, and research will be considered. Finally, an examination of the strengths and weaknesses of the current study will be presented.

Overall Findings

Ten family surrogate decision makers described their experience of the process used to withdraw life-sustaining treatments from their significant others who were a blood and marrow transplant patient. While this process took varying lengths of time, the essence of the experience was similar for all surrogates. Knowing the patient as a person was the core of the process. This meant that even though surrogates needed time to work through information (the ICU course of care, the physiological changes that were happening to the patient, and the medical team's prognosis), none of this information could be interpreted without first knowing who the patient was as a person. Thus, surrogates could only work through the information listed above after first considering the patient's advance directive in the context of the patient's life. While advance directives were helpful in this process, they were considered a starting point and were not more important than remembering the discussions of the patient's goals for life. Surrogates explained that it was most important to remember and tell stories about the patient – considering what was most important to them. When surrogates were comfortable that they knew the patient as a person, knowing what the patient would have

considered an acceptable quality of life, they were then willing and able to work through the information they were receiving.

Surrogates had various ways of getting the information they needed – namely, being present at the patient’s bedside for the medical team’s daily rounds. When they weren’t able to be physically present, they relied on nurses to update them – either by telephone or when they returned to the bedside. They also relied on various members of the medical team to debrief them at the end of the day – it was most helpful when a member of the medical team stopped in to the patient’s room before going home for the night to update the surrogate on any changes throughout the day.

An important aspect of the work surrogates needed to do while receiving information was navigating the sea of doctors and people involved in the patient’s care. Part of doing this meant playing the telephone game – hearing information from someone who heard it from someone else and working to make sense of it. This also meant that surrogates needed to bridge the communication gap which could occur between various family members and/or the multiple disciplines involved in the patient’s care. Surrogates had an easier time during this process if they had one person they could hone into – someone they trusted to help make sense of the different messages they were receiving. Surrogates who had experience in health care, specifically nursing, had a slightly different experience as they worked through the information because they had to dance between wearing two different hats – the nurse hat (advocating for the patient) and the family hat (supporting the patient).

Surrogates needed to receive support through trusting relationships in order to move forward in the process of making the decision to withdraw LST in a positive manner. Surrogates were able to trust members of the healthcare team when the healthcare team member included the patient in the relationship, making an effort to know who the patient was as a person before being sedated and unresponsive. This allowed surrogates to believe that the healthcare team member was taking the patient into consideration when making recommendations for their care or suggesting interventions. They felt like the healthcare team member shared a bond with a mutual goal – doing what was best for the patient as a person. This type of relationship was able to form most easily when there was consistency. Thus, the closest relationships were formed most often with nurses because nurses were assigned to take care of the patient for 8-12 hour shifts several days in a row. Additionally, nurses often were only assigned to take care of the one patient for their shift, which allowed them to spend a significant amount of time with the patient and family. It was necessary to form these relationships to move forward in the process in a positive manner because it allowed surrogates to share some of the burden they felt. When they had trusting relationships, they were able to take breaks and leave the patient's bedside for periods of time, and they were able to rely on the healthcare team member to help communicate with the rest of the family.

Surrogates began to recognize reality through emerging red flags at any time during the patient's ICU care. However, it was only when the surrogate was confident he/she knew the patient's goals and wishes, had an understanding of the clinical information surrounding the patient's situation, and felt support through trusting

relationships that the recognition of reality moved the surrogate closer to making the final decision to withdraw LST. A critical red flag was when surrogates acknowledged that there were too many problems occurring with the patient, such as multiple organ failure. It was then that they began to believe they were causing more harm than good for the patient. When they saw interventions as harmful to the patient, they moved closer to the decision to stop those interventions, even if that meant the patient could not survive. However, in order to do this, they sometimes needed a new perspective on an extreme treatment, recognizing that the last treatment option for the patient's underlying cancer diagnosis (BMT) was not going to work.

It was also important for surrogates to be able to witness the changes in the patient's condition. When they saw changes that made them believe the patient wasn't the person anymore, they often decided to withdraw LST. This was in contrast to family members who were not present to witness the changes and thus were not supportive of withdrawing LST. Surrogates also relied on their gut feelings to know whether or not it was time to withdraw LST, as well as to know what the patient wanted. The penultimate red flag was when surrogates accepted the change in the patient's prognosis, such as the fact the patient would never be able to live without being connected to a ventilator. This recognition moved them along in the process of making the decision to withdraw LST based on a toggle switch decision making method. The toggle switch meant that surrogates considered whether or not the patient could come back from and recover from the illness to an acceptable quality of life. If surrogates believed the interventions were only prolonging an inevitable death, they decided to withdraw LST.

After the recognition of reality and the toggle switch decision making process moved the surrogate to the decision to withdraw LST, it was important for the surrogate to talk with the family. Regardless of whether the family was supportive of withdrawing LST, the surrogate needed to update them about the patient's situation, prognosis, and goals for life. These discussions occurred during formal and informal family meetings. After discussing with the family, the surrogate made the decision to withdraw LST, and needed time to share the moment with other family members and individual time to say goodbye to the patient. Before the surrogate could make this decision, however, it was necessary for them to understand what would happen after LST was stopped, and they needed to be assured that the patient wouldn't be in pain or struggle.

Surrogates lived with the decision of withdrawing LST by experiencing two narratives – feeling like they made the right decision by advocating for the patient and experiencing doubts about the BMT itself. Surrogates were able to experience peace after the patient's death because they kept the patient's goals at the center of the process, and thus believed they made decisions solely based on what the patient would have chosen for her/himself. However, this did not mean they did not have moments of doubt, when they questioned whether or not the patient should have undergone the BMT, especially since the patient was in remission and feeling well at the time of transplant. None of the surrogates expressed regret at the decision to undergo transplant because they reminded themselves of the likelihood of relapse and the inability to treat the patient's cancer without a BMT. Finally, surrogates were able to experience peace in their grief when they were able to honor and remember the patient in a way that was meaningful to them.

Links to Related Literature

A difference in focus. The prominent difference between the surrogates in the current study and the surrogates in the literature review is their primary focus on the patient. Surrogates in the literature review were not as familiar with the healthcare environment or the illness of the patient because the patient generally experienced an unexpected illness or accident. In contrast, all of the surrogates in the current study were already familiar with the patient's underlying disease process and treatment plan because the patient had a history of the illness – their illness was not diagnosed immediately prior to needing LST. Therefore, surrogates in this study did not need to spend as much time working through the information of the healthcare environment and the treatment plan and could thus focus primarily on the patient's wishes and goals for life after treatment.

Another difference between surrogates in the current study and those in the literature is that those in the current study had a more thorough understanding of the patient's end of life wishes than surrogates in the literature. Again, this is because the surrogates in the literature were generally making end of life decisions with little warning. The patients in the literature were typically not hospitalized for a potentially life-threatening treatment prior to needing LST, as the patients in the current study were. It was helpful to surrogates in the current study that BMT patients are strongly encouraged to complete an advance directive prior to undergoing the transplant because BMT is known to have serious complications that can lead to the need for LST and potential end of life decision making. As a result, surrogates were more aware of patients'

end of life wishes, goals for treatment, and beliefs of what was an acceptable quality of life.

Additionally, part of the process patients underwent in preparing for their BMT and completing an advance directive was choosing a surrogate. Thus, surrogates in this study knew this was a role they were trusted to perform if needed. This may have been what made them more willing than surrogates in the literature to make the decision to “do the right thing” regardless of family consensus. The patient asked the surrogate to fulfill this role, which essentially authorized the surrogate to make the decision. Thus, surrogates in this study did not need to do the work that surrogates in the literature needed to do in order to understand and figure out this information about the patient. As a result, surrogates in the current study had a higher level of confidence that they were making decisions in line with what the patient would have decided for her/himself. This resulted in a decreased burden during the process, confidence to move forward with withdrawal of LST even when family or the medical team was not supportive, and increased peace after the decision was made.

Although surrogates in this study found it helpful to have an advance directive, the advance directive was only helpful within the context of the patient’s life. It was less important to have an official document stating the patient’s end of life wishes than it was for the surrogate to have had conversations with the patient. Having conversations with patients about their goals for life after the transplant, what was important for them to be able to do – such as being able to recognize people, talk to them, and live without the assistance of machines – was a larger influence for surrogates who were making the

decision to withdraw LST. These conversations were more likely to occur between patients and surrogates in the current study because of the emphasis on completing an advance directive prior to transplant. In contrast, in the literature, advance directives provided the most security to the family in coming to terms with their decision. Because they generally did not anticipate the need for this information, families in the literature often did not have conversations to the extent of those in the current study. BMT patients were more likely to have had these conversations with multiple members of the family, thus making it easier for families to come to consensus about the patient's end of life wishes than for families in the literature.

Differences and similarities in working through information. Rather than a primary focus on knowing the patient as a person, surrogates in the literature first needed to work through understanding the illness before they had the ability to make decisions regarding withholding or withdrawing LST. Understanding the illness severity was a preoccupation with the disease and how to understand the physiological problem that had occurred, the means by which it was being treated, the mechanisms of deterioration, the consequences of the deterioration, and the reasons the deterioration could not be stopped. Again, surrogates in the current study needed to work to understand information. This was not, however, the primary focus; the information they needed to understand focused around the patient. They needed to understand what the patient's treatments were so they could be more certain the treatments were actually helping the patient to recover and be comfortable. They also needed to understand the information because they felt the need to communicate this to the patient, in ways they did not think the healthcare team was

able to. Finally, they needed to know information about the patient's course so they could make comparisons about whether the patient was getting better or worse, which helped them determine if they should continue LST or withdraw it.

An additional dilemma unique to surrogates in the current study was the need to reconcile patient requests for "no extreme measures" when they believed the BMT itself was an extreme measure. This is highlighted by the surrogate who explained she was in a difficult place because she was reading her mother's advance directive that stated she didn't want any "extreme measures", but went into the BMT willingly and making her own decisions, knowing a transplant was extreme. This is when it was critical for surrogates to reconcile what was in the patient's advance directive with conversations they had about goals for quality of life.

A significant difference between surrogates in the literature and those in the current study is that while working through information, surrogates in the literature wanted information from many different sources. They needed this to corroborate and confirm the information they were receiving. In contrast, surrogates in the study wanted one source of information. It was an increased burden and stress when they received different information or a different delivery of information from various members of the healthcare team. Furthermore, the majority of surrogates in this study did not find it helpful to go to the internet to find out more information. They did not find it helpful to read general information when the patient's situation was so unique. This can likely be related to the lack of information specific to BMT. While surrogates in the literature

could more easily find information that pertained to the patient's specific problem, there is a lack of information that deals with the complications of BMT.

Both surrogates in the current study and the literature had similar needs regarding communication. Both groups of surrogates experienced increased stress when they did not feel like they had a consistent source of information. For both groups, this created difficulty in obtaining a clear clinical picture, greatly increasing the stress and confusion level of the surrogates, conflicts within families, and the time required to understand the critical nature of the illness because they did not know which clinician to trust.

Surrogates in the current study were better able to deal with this, because they were already familiar with the nature of hospitalizations and healthcare. Thus, they were able to use tactics to navigate the sea of doctors, learn who they could hone in on as a primary source of information, and rely on nurses to help them sort through the information.

In contrast to surrogates in the literature, surrogates in the current study felt that there was always someone from the healthcare team available to them. This was helpful as they felt their questions were always answered, there was always someone to explain what was happening with the patient, and they could even leave the bedside for periods of time because they trusted the healthcare team to update them via telephone or when they returned to the hospital. Surrogates in the current study, therefore, did not feel the need to chase doctors or schedule formal family meetings in order to get the information they needed. This could again be attributed to the surrogates' main focus being on the patient and not on working through information. Moreover, surrogates in this study were already familiar with the healthcare environment.

A significant finding for both groups of surrogates was the need for trusting relationships between surrogates and the healthcare team. This was necessary for both groups in order for surrogates to feel comfortable making the decision to withdraw LST. In both groups of surrogates, trusting relationships grew out of the consistency of providers. This gave surrogates the confidence the healthcare team truly knew them and the patient, which created trust that everyone had the same goal and everyone was considering the patient's best interests. For both groups of surrogates, these trusting relationships were formed most often with the patient's nurses, who were present with the patient for eight to 12 hours a day, multiple days in a row. This consistency and amount of time gave families the ability and comfort to discuss things with the nurses that they weren't able to discuss with others who spent less time with the patient.

Recognition of futility led to withdrawal of LST. Once both groups of surrogates felt they had received adequate information through satisfactory communication and had a trusting relationship with clinicians, they were able to recognize the red flag of futility. Both groups of surrogates needed to recognize futility before the decision to withdraw LST could occur. This happened at varying times for surrogates, however once futility was recognized, it was important to avoid prolonging the death, which was equated with harming the patient, and the decision to withdraw and the subsequent withdrawal happened a short time later. The toggle switch method of making decisions was unique to the surrogates in the current study; there was not a similar method of making decisions articulated in the literature. This method of making decisions may be unique to surrogates in the BMT population because they were more

prepared for some of the basic medical information and the culture of the healthcare environment than those in other studies.

All surrogates wanted the patient to have good pain control and thus when the surrogate believed the patient to be in continuous pain and/or suffering, they were much more likely to withdraw LST. In the literature, withdrawal generally happened within 24 hours of the surrogate stating they recognized the situation was futile. This time was even shorter for surrogates in the current study.

Surrogates in the literature described several barriers to recognizing futility. These included a sense of hope that the patient would “rally” and start to improve, denial, issues with the meaning of futility, and the spirituality of the surrogate, which included praying for a miracle. Surrogates in the current study, in contrast, did not describe barriers to recognizing futility. This may be because BMT patients and surrogates knew that a transplant was the patient’s last treatment option. Thus, surrogates and patients may have been more ready to accept futility, even though they had great hope that the transplant would be successful.

Different considerations of the family. Surrogates in the literature had a different consideration of the rest of the family than surrogates in the current study. Namely, surrogates in the literature worked to seek agreement about decisions among close family members. Surrogates were ready to withdraw LST before the family was ready, and withdrawal was delayed until other family members were supportive of the decision. Consensus was necessary to protect the family and also gave surrogates a degree of protection from future problems that might occur in the family regarding the

decision to withdraw LST. Thus, surrogates in the literature were unwilling to make withdrawal decisions prior to acquiring the family's support.

In contrast, although surrogates in the current study said it was important to communicate their decisions to the family, surrogates in this study did not wait for family consensus. Although there were only two situations in the current study where the family wanted the surrogate to delay withdrawal of LST, neither surrogate were comfortable with waiting. Therefore, in the current study it was even more important, once futility was recognized, for surrogates to stop "harming the patient" and withdraw LST, even if the family was not supportive of the decision. Again, this is likely because they felt more empowered than surrogates in the literature to make these decisions without family consensus because prior to the transplant, the patient had authorized the surrogate to make that decision.

After the decision. Surrogates in both the literature and the current study described the decision to withdraw LST as the hardest decision they had ever made. However, the burden for both groups of surrogates was decreased, and surrogates felt a sense of pride (in the literature) or that it was a blessing (in the current study) to be able to fulfill this role, choosing to do what they believed honored the patient's wishes. Both groups of surrogates experienced more peace with their decision to withdraw LST after the death when they had a firm belief that they made decisions that the patient would have made for him/herself – that they acted as the patient's advocate, not their own wishes.

Surrogates in the current study had an added complexity to their ability to live with their decision to withdraw LST because they experienced the doubt of whether or not the patient should have undergone the BMT. They struggled because they thought about what the patient's outcome would have been if they had not chosen the BMT, questioning whether the patient would have had a longer time with a higher quality of life. This was not a doubt that surrogates in the literature expressed because the patients' reliance on LST was not a result of a treatment they underwent willingly.

Contribution to the Literature

Because of both differences and similarities between the experience of the surrogates in the current study and those in the literature, this study contributes to the literature in multiple ways. First, it was evident in the current study that the patient, not the information surrounding the patient's diagnosis and plan of care, is the central focus of surrogates of BMT patients.

Second, there is value in advance directives, but not in the document itself. The value lies in the conversations that occur in making the document. Advance directives are seen as a means to having the conversations that surrogates relied upon to remember and understand the patient's goals. These conversations were more important to the surrogates than the document because they allowed surrogates to put the document in the context of the patient's life. For example, even though one patient in the current study stated in his advance directive that he did not want his wife to "pull the plug," she remembered that while they were completing the document, he also said that he wanted to be able to recognize his family and be able to communicate with them.

Third, the current study also emphasizes the importance of one consistent source of information – from someone that is trusted by the surrogate and who takes the patient into consideration. Receiving information from multiple people increased stress for surrogates because, even when the message was consistent, the way in which the message was relayed may not be consistent. This caused surrogates to have the increased burden of needing to interpret the messages they were hearing. One of the most important ways to ensure the surrogate had a consistent source of information from someone they trusted was by having consistent caregivers. This most naturally and easily occurred with nurses, but it also occurred when the physicians, social workers, and respiratory therapists were consistent.

Fourth, the current study included two surrogates who were nurses. None of the existing literature discussed a different experience for surrogates based on their profession, which makes this study's findings very unique. The nurse surrogates in this study experienced an increased burden compared to other surrogates because of the added responsibility they perceived from their family. This responsibility included interpreting information and advocating for the patient in the way only a family member could.

Fifth, the recognition of futility, or the change in the patient's prognosis, was the penultimate red flag for surrogates in the current study. Once this red flag was recognized and accepted, surrogates needed to communicate their decision to withdraw LST to their family, and needed to move ahead with the decision regardless of the family's support. Thus, these surrogates believed even more strongly than those in the literature that once they came to understand the futility of the situation, they needed to stop treatments and

stop harming the patient. At this time, it was important that surrogates had a time to individually say goodbye to the patient, which is something that the literature did not mention. Nurses were instrumental in providing this time for the surrogate – they were best able to police the door and make sure that only people the surrogate wanted there for the moment of death were allowed in the room.

Finally, surrogates needed to be confident they acted in the patient's best interests, not their own, in order to have peace with their decision. This was achieved by again making sure the patient was at the center of the entire decision making process. They needed to remind themselves of the patient's prognosis prior to treatment – that even though they were in remission, the cancer had a high chance of recurring and would have been even more difficult to treat. Remembering this gave the surrogates peace that undergoing the BMT was not something they should regret, which allowed them to continue with their life after the death of the patient.

Implications for Practice and Nursing

There are several implications for practice and nursing as a result of this study. First, although BMT patients should continue to be encouraged to complete an advance directive prior to undergoing the transplant, the focus should not be on the document. Rather, the focus should be on the conversations that go into completing the document. In order to have the most meaningful conversations, patients and surrogates need to be well-informed. They need to know about the complications of BMT, the various types of LST they could become reliant upon, and should have an understanding of what life can look like after being reliant on LST. For example, surrogates in this study said that some of the

most helpful information they had during the patient's ICU care was what the patient's life would be like if they survived. How much rehab would they need? Would they need a feeding tube? Could they breathe without the support of a ventilator? How likely would it be they would need frequent hospitalizations? The surrogates needed to grapple with these questions. It would, therefore, be helpful if patients and surrogates had these conversations with members of the healthcare team prior to transplant. Honoring Choices and Respecting Choices are two programs in the Midwest that currently focus on end of life conversations between individuals, their decision makers, and members of the healthcare team. These are programs that would be helpful for BMT patients and their surrogates, especially if there were end of life facilitators trained/familiar with the BMT population.

Information was important for surrogates, but it was difficult for them to receive information from multiple sources, especially different disciplines. Surrogates found it helpful when the different disciplines would confer outside of the patient's room before coming in to present the information. This meant that surrogates did not need to go through the work of interpreting what information was the most accurate because they were only receiving one message. When surrogates did not have a good experience with communication between different medical teams, they explained that it would be helpful to have a type of case manager, not just for one aspect of the patient's care, but one person who knew and understood all aspects and could provide continuity. Since there was not a person assigned for this role, surrogates felt they needed to fulfill this role,

which added more stress to their experience. One participant explained how helpful it would have been to have this type of case manager:

I felt like she [the patient] almost needed a case manager. She had a social worker who was in some ways a case manager as far as making arrangements for her being in the rehab facility and things like that, but I don't know that there was a clinical case manager that oversaw all of that. It ended up being that we as family members tried to be that, without having the medical background. Obviously it's a crash course. You learn as quickly as you can everything that you might need, but just one person who communicates with everybody else and has that full picture [would have helped]. I used to work for a fire department, and with a fire department there are three shifts, so if there's something that needs to be overseen on a day-to-day basis, there isn't any one person who's there every day. There's the telephone game, and there's always information that's lost as one person tries to communicate with another, [and then] to communicate with yet another the following day, and I felt like in some ways that occurred at times with Mom's care.

If one case manager was responsible for relaying information and having a whole picture of the patient, this would decrease the burden of surrogate decision makers. Surrogates would not need to exert as much effort navigating the sea of doctors or playing the telephone game because they could rely on one person to provide them with a consistent message. Since this was not the current practice, nurses were able to help fulfill this role. They did this by being present for rounds, having access to the medical team outside of

the patient's room, and being present with the patient and family for long shifts multiple days in the row. They were subsequently able to interpret information for the surrogate, update other members of the family for the surrogate, and have conversations when the surrogate thought it was a good time.

Nurses are also in the best position to form trusting relationships with surrogates because of the time they spend in the patient's room. Surrogates look to them to help them with the information they are receiving, and nurses need to be prepared to fulfill this role. They must also make an effort to get to know the patient, whether or not the patient is able to respond. Nurses are able to do this by asking the surrogate questions about the patient – what things the patient liked, their relationships, and their personality. When nurses make the effort to get to know the patient as a person, they gain the trust of the surrogates and are able to share their burden by acting in ways the surrogates believe center on the patient as a person. Other members of the healthcare team need to make the same effort, regardless of the time they spend with the patient. It may be even more important for healthcare team members to make the effort so surrogates do not see them as “peripheral” members of the healthcare team.

Healthcare team members need to be supportive of surrogates as they recognize the reality of the situation during the decision making process. They can do this by explaining the number of problems that are occurring with the patient at one time, what things are potentially hurting the patient, and the prognosis of the patient to the surrogate. Surrogates want the healthcare team to be honest and to provide consistent information. This assists them in making decisions based on the toggle switch – determining whether

or not interventions are just prolonging the patient's inevitable death or whether they are a fix to a temporary problem. Healthcare team members need to be present to have these conversations with surrogates. Again, surrogates saw nurses as the most appropriate people for this role since they were the most present and also able to physically witness the changes in the patient from day to day.

Once surrogates make the decision to withdraw LST, it is critical for members of the healthcare team to explain the process of removing LST. Surrogates want to know what will happen, what the patient's response will likely be, what they should expect, and how long it will take before the patient's death. A primary concern of surrogates is that the patient not struggle once the LST is removed. Thus, it is critical to have measures to keep the patient comfortable, and nurses need to be prepared to implement these measures.

Once the decision to withdraw LST is made, nurses can play a role in helping the surrogate and other family members have individual time with the patient to say goodbye. Surrogates explained that it was helpful when nurses offered time and space for them to say goodbye individually so they did not need to coordinate this themselves. Nurses should also "police the door" during this time, making sure the family is not interrupted by people they do not wish to be there. Surrogates also appreciated when nurses included them in the cares for the patient and gave them choices, such as whether or not and what type of music they wanted to be playing.

Since several surrogates in this study talked about the doubts they experienced months after transplant regarding the decision to undergo the BMT, this is something that

should be addressed. Surrogates should be given the contact information of people equipped to assist them through these doubts during their grieving process. This could be a social worker, counselor, or chaplain. Regardless of who it is, communication should be maintained with the surrogate after the patient's death. Surrogates currently receive cards on the anniversaries of the patient's death, but this may not be sufficient for a surrogate struggling with doubt six months after the patient's death. More effort should be made to make sure the surrogate is dealing with his/her grief in a positive manner, without lasting doubts or regret. One participant explained that she wished families could have a type of exit interview at some point after the patient's death so they would have a chance to tell someone what their experience was like in the ICU.

Participant recommendations. In addition to the majority of surrogates recommending a clinical case manager, surrogates also had a number of recommendations for what would have made their experience better. The main thing that surrogates wanted, but did not always receive, were realistic expectations. This ranged from what to expect in the ICU to what to expect once the patient needed to be sedated.

Expectations in the ICU. When BMT patients become reliant on LST, they are transferred to the ICU. This is after spending time on the BMT unit. Thus, surrogates were unfamiliar with the expectations in the ICU and did not feel like expectations were ever clearly explained to them. One participant explained it would have been helpful to have written expectations for the ICU, similar to what they received in the BMT unit – such as when nurses will have their change of shift, when vital signs will be taken, what the visiting hours are, or whether or not they are allowed to spend the night in the ICU

with the patient. Surrogates explained that having clear expectations would have decreased the stress of trying to figure out this information on their own.

Expectations for the Patient. Surrogates experienced much more stress when they were told to expect something in the patient's care but something different happened. For example, one surrogate was told her husband would be sedated only temporarily. However, he never woke up again. She was experiencing extreme pain nearly a year later because she and her family did not have a chance to say goodbye since they were not told the patient might never wake up again. She wished the medical team had just told her to expect anything – that they did not know what would happen.

It would be good for them to say, 'Hey, he's in ICU. Expect anything.' But when they put him full sleep [sedation], I wish they'd tell families that if you go into full sleep, you never know, so say goodbye to your people, your family. If they can just say, point-blank, 'We don't know. We don't know.' Like, 'We're going to put [Husband] full sleep and if he wakes up, he wakes up. If he doesn't wake up, I want you to be prepared for that.'

Thus, it is more important that surrogates be told no one knows for sure what will happen to the patient rather than be given false assurances or no information at all.

Implications for Future Research

The literature, which only includes eight articles, provides evidence that saturation has been reached for surrogates' experiences of withdrawing LST. Although eight is a small number for a critical literature review, the narrow inclusion criteria, the consistency of findings between the studies, and the rich findings presented in Chapter 2

indicate that the healthcare community has nearly 20 years of research describing the decision making process of surrogate decision makers withdrawing or withholding life-sustaining treatments for critically ill family members.

The current study provided the next step in the process of understanding this phenomenon more thoroughly by seeking to compare a different population – the population of BMT surrogate decision makers. The similarities and differences of the experiences were described above, and since the knowledge of the general decision making process is rich, it is necessary for researchers to take the understanding provided in the qualitative studies and use it to inform practice for healthcare professionals. This can be done by using the qualitative findings to inform quantitative studies testing various interventions to assist surrogates during this stressful time. There are a number of studies that focus on what is, and is not, helpful for surrogates during this process, and it is necessary to combine those findings with the current knowledge to design and implement appropriate interventions. It is known that surrogates need time to understand the patient as the person, work through information they receive about the patient, recognize futility, and be able to live peacefully with the decisions they make. It is also known that they need adequate communication and trust in clinicians. Thus, healthcare providers need to learn how to best assist in this process, making a highly stressful and difficult process easier for surrogates to experience. Finally, it is known that this experience is a process, not an event. Thus, future research should be aimed at finding where and how healthcare providers can make the most significant and positive impact

on surrogate decision makers going through the process of making the decision to withdraw LST.

Critique of the Study

Strengths of the study. The primary strength of this study was the consistency between the research question, design, and method of analysis. The aim of this study was to understand the experience of family surrogate decision makers who made the decision to withdraw LST from a BMT patient. Since the researcher believed the BMT population was different from populations previously studied in the literature, phenomenology was an appropriate qualitative methodology to explore the phenomenon in this population. The ten participants in this study provided data that was interpreted using van Manen's (1990) anecdotal narrative to give meaning to the experience of withdrawing LST in the BMT population. Unstructured interviews allowed participants to reflect upon and describe their experiences as a surrogate without being influenced by preconceived interview questions. Additionally, participants were given the grand tour question prior to the interview in order to have time to consider and reflect upon the most meaningful aspects of their experience.

A unique strength of this study was the professional experience of the researcher. During interviews, there was an almost immediate rapport as participants knew the researcher was personally invested in their experience due to her professional experience working with the population. Participants were thus more likely to give an honest and complete description of their experiences since there was a certain level of trust that

would not have been present if they had been talking to someone they considered an outsider.

Study Limitations. This study had a number of limitations. The focused qualitative design of interpretive phenomenology is reflective. It does not offer a real-time account of the participants' experience. Thus, participants told their reflective interpretations and memories of their experience. This does not threaten the study's validity, however, since the purpose of this study is to understand the meaning of these experiences, which is provided by the reflective nature of the participants' stories.

The small sample size is a potential limitation. However, recruitment and interviews continued until data saturation was reached. Typically, small sample sizes limit generalizability, but again, this is not a goal of phenomenological research. The findings of the study will be able to be transferred to relevant contexts. Similarly, recruiting from only one site creates a potential lack of diversity and transferability in the sample. This limitation is partially negated because the site chosen for recruitment serves a diverse population of patients from around the world.

Having one researcher interpreting the data could potentially bias the results. However, in order to deal with this limitation, the primary investigator implemented the use of member checks for participant feedback during interviews. Additionally, an audit trail was created that documented analysis decisions so that others could follow how key decisions were made. Finally, the primary investigator enlisted the assistance of expert qualitative researchers for review.

Since the primary researcher is an experienced BMT nurse, it is possible that preconceived ideas of the participants' experiences biased interpretation of the data. The use of unstructured interviews helped to lessen the threat of this limitation. Generally, unstructured interviews "do not reflect preconceived ideas about content or flow" (May, 1989, p. 173), and as the study progressed, the interviews became more structured, based on preliminary findings and emerging themes of previous interviews. Another technique used to prevent analytical bias was the use of a reflexive journal. This type of journaling provided a means of recording personal biases or idiosyncrasies and strategies implemented to maintain neutrality (Lincoln & Guba, 1985).

Purposeful sampling posed the limitation of who agreed to participate. Self-selection and self-report have the potential for bias. For example, it was possible that only surrogate decision makers who had a good experience chose to talk to about it. These results would potentially look different from a group of surrogates who had very negative experiences. However, several of the participants in this study did explain a negative experience in some dimensions of the decision making process.

Conclusion

This phenomenological study resulted in an interpretation of the experience of family surrogate decisions makers who made the decision to withdraw life-sustaining treatments from a family member who received a blood and marrow transplant. Six essential themes – knowing the patient as a person; working through the information; receiving support through trusting relationships; recognizing reality; making the decision; and living with the decision – emerged from the analysis of data obtained from individual

interviews. The results of this study increase the understanding of this experience and help to fill the gap in the literature of what this experience is like for an understudied population. These findings can provide information to help nurses and other health care providers decrease the burden surrogates experience during this time, helping to promote a peaceful end of life experience for patients and their families.

References

- American Medical Association. (1847). *Code of Ethics*. Online document at www.ama-assn.org/resources/doc/ethics/1847code.pdf. Accessed December 5, 2012.
- Angus, D. C., Barnato, A. E., Linde-Zwirble, W. T., Weissfeld, L. A., Watson, R. S., Rickert, T., & Rubenfeld, G. D. (2004). Use of intensive care at the end of life in the United States: An epidemiologic study. *Critical Care Medicine*, 32(3), 638-643.
- Azoulay, E., Pochard, F., Kentish-Barnes, N., Chevret, S., Aboab, J., Adrie, C., ... Schlemmer, B. (2005). Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *American Journal of Respiratory Critical Care Medicine*, 171, 989-994.
- Beauchamp, T. L., & Childress, J. F. (2009). *Principles of biomedical ethics* (6th ed.). New York, NY: Oxford University Press.
- Carmel, S., & Mutran, E. (1999). Stability of elderly persons' expressed preferences regarding the use of life-sustaining treatments. *Social Science and Medicine*, 49, 303-311.
- Danis, M., Garrett, J., Harris, R., & Patrick, D. (1994). Stability of choices about life-sustaining treatments. *Annals of Internal Medicine*, 120(7), 567-573.
- Edwards, D. (2002). A philosophical discussion of end-of-life decision-making methods for incompetent patients. *International Journal of Palliative Nursing*, 8(3), 146-151.

- Fink, A. (2010). *Conducting research literature reviews: From the internet to paper*. Los Angeles: SAGE Publications.
- Giorgi, A. (2005). The phenomenological movement and research in the human sciences. *Nursing Science Quarterly*, 18, 75-82.
- Hayes, C.M. (2003). Surrogate decision-making to end life-sustaining treatments for incapacitated adults. *Journal of Hospice and Policy Nursing*, 5(2), 91-102.
- Houts, R., Smucker, W., Jacobson, J., Ditto, P., & Danks, J. (2002). Predicting elderly outpatients' life-sustaining treatment preferences over time: The majority rules. *Medical Decision Making*, 22(39), 39-52
- Kim, S., & Kjervik, D. (2005). Deferred decision making: Patients' reliance on family and physicians for CPR decisions in critical care. *Nursing Ethics*, 12(5), 493-506.
- Kuiper, M.A. (2012). Dying: Domain of critical care medicine? *Critical Care Medicine*, 40(1), 316-317.
- La Puma, J., Orentlicher, D., & Moss, R. (1991). Advance directives on admission: Clinical implications and analysis of the Patient Self-Determination Act of 1990. *Journal of the American Medical Association*, 266(3), 402-405.
- Limerick, M. H. (2007). The process used by surrogate decision makers to withhold and withdraw life-sustaining measures in an intensive care environment. *Oncology Nursing Forum*, 34(2), 331-339.
- Lincoln, Y.S., & Guba, E. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage Publishing.

- Long, B., Clark, L., & Cook, P. (2011). Surrogate decision making for patients with severe traumatic brain injury. *Journal of Trauma Nursing, 18*(4), 204-212.
- Lopez, K., & Willis, D. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research, 3*, 726-735.
- May, K.A. (1989). Interview techniques in qualitative research: Concerns and challenges. In J. Morse (Ed.), *Qualitative nursing research: A contemporary dialogue* (171-182). Rockville, MD: Aspen Publishers.
- McCoy, M. (2008). Autonomy, consent, and medical paternalism: Legal issues in medical intervention. *The Journal of Alternative and Complementary Medicine, 14*(6), 785-792.
- Meeker, M., & Jezewski, M. A. (2009). Methasynthesis: Withdrawing life-sustaining treatments: The experience of family decision-makers. *Journal of Clinical Nursing, 18*, 163-173.
- Moses III, H., & Martin, J.B. (2011). Biomedical research and health advances. *The New England Journal of Medicine, 364*(6), 567-571.
- Nyhan, B. (2010). Why the “death panel” myth wouldn’t die: Misinformation in the health care reform debate. *The Forum, 8*(1). Online document at <http://jrnetsolserver.shorensteincnte.netdna-cdn.com/wp-content/uploads/2012/07/Why-Death-Panel-Myth-Wont-Die.pdf>. Accessed December 5, 2012.

- Prendergast, T.J., & Luce, J.M. (1997). Increasing incidence of withholding and withdrawal of life support from the critically ill. *American Journal of Respiratory Critical Care Medicine*, 155, 15-20.
- Prendergast, T.J., & Puntillo, K.A. (2002). Withdrawal of life support: Intensive caring at the end of life. *Journal of American Medical Association*, 288(21), 2732-2740
- Seckler, A., Meier, D., Mulvihill, M., & Cammer Paris, B. (1991). Substituted judgment: How accurate are proxy predictions? *Annals of Internal Medicine*, 115(2), 92-98.
- Sulmasy, D., Terry, P., Weisman, C., Miller, D., Stallings, R., Vettese, M., & Haller, K. (1998). The accuracy of substituted judgments in patients with terminal diagnoses. *Annals of Internal Medicine*, 128, 621-629.
- Swigart, V., Lidz, C., Butterworth, V., & Arnold, R. (1996). Letting go: Family willingness to forgo life support. *Heart & Lung*, 25(6), 483-494.
- Tilden, V. P., Tolle, S. W., Nelson, C. A., Thompson, M., & Eggman, S. C. (1999). Family decision making in forgoing life-extending treatments. *Journal of Family Nursing*, 5(4), 426-442.
- Torke, A., Alexander, G., & Lantos, J. (2008). Substituted judgment: The limitations of autonomy in surrogate decision making. *Journal of General Internal Medicine*, 23(9), 1514-1517.
- Uhlmann, R., Pearlman, R., & Cain, K. (1989). Understanding of elderly patients' resuscitation preferences by physicians and nurses. *Western Journal of Medicine*, 150, 705-707.

- Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Albany, NY: State University of New York Press.
- Welie, J. (2001). Living wills and substituted judgments: A critical analysis. *Medicine, Health Care and Philosophy, 4*, 169-183.
- Wendler, D., & Rid, A. (2011). Systematic review: The effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine, 154*, 336-346.
- Whittemore, R., Chase, S., & Mandle, C. (2001). Validity in qualitative research. *Qualitative Health Research, 11*, 522-537.
- Wiegand, D. (2008). In their own time: The family experience during the process of withdrawal of life-sustaining therapy. *Journal of Palliative Medicine, 11*(8), 1115-1121.
- Wilson, D. (2011). Quality care at the end of life: The lived experience of surrogate decision makers. *Journal of Hospice and Palliative Nursing, 13*(4), 249-256.
- Wojnar, D., & Swanson, K. (2007). Phenomenology: An exploration. *Journal of Holistic Nursing, 25*, 172-180.

Appendix A: University of Minnesota Institutional Review Board Approval

UNIVERSITY OF MINNESOTA

Twin Cities Campus

*Human Research Protection Program
Office of the Vice President for Research*

*D528 Mayo Memorial Building
420 Delaware Street S.E.
MMC 820
Minneapolis, MN 55455
Office: 612-626-5654
Fax: 612-626-6061
E-mail: irb@umn.edu or ibc@umn.edu
Website: <http://research.umn.edu/subjects/>*

September 15, 2011

Bethany J Gerdin
School of Nursing - AGH1331F
Room 5-140 WDH
308 Harvard St SE
Minneapolis, MN 55455

RE: "End of Life Surrogate Decision-Making with Bone Marrow Transplant Patients"
IRB Code Number: 1108P03022

Dear Dr. Gerdin

The Institutional Review Board (IRB) received your response to its stipulations. Since this information satisfies the federal criteria for approval at 45CFR46.111 and the requirements set by the IRB, final approval for the project is noted in our files. Upon receipt of this letter, you may begin your research.

IRB approval of this study includes the consent form version dated September 12, 2011 and recruitment materials received September 15, 2011.

The IRB would like to stress that subjects who go through the consent process are considered enrolled participants and are counted toward the total number of subjects, even if they have no further participation in the study. Please keep this in mind when calculating the number of subjects you request. This study is currently approved for 10 subjects. If you desire an increase in the number of approved subjects, you will need to make a formal request to the IRB.

For your records and for grant certification purposes, the approval date for the referenced project is September 2, 2011 and the Assurance of Compliance number is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003). Research projects are subject to continuing review and renewal; approval will expire one year from that date. You will receive a report form two months before the expiration date. If you would like us to send certification of approval to a funding agency, please tell us the name and address of your contact person at the agency.

As Principal Investigator of this project, you are required by federal regulations to:
*Inform the IRB of any proposed changes in your research that will affect human subjects, changes should not be initiated until written IRB approval is received.

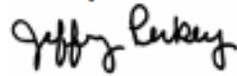
Driven to Discover™

- *Report to the IRB subject complaints and unanticipated problems involving risks to subjects or others as they occur.
- *Inform the IRB immediately of results of inspections by any external regulatory agency (i.e. FDA).
- *Respond to notices for continuing review prior to the study's expiration date.
- *Cooperate with post-approval monitoring activities.

Information on the IRB process is available in the form of a guide for researchers entitled, What Every Researcher Needs to Know, found at <http://www.research.umn.edu/irb/WERNK/index.cfm>

The IRB wishes you success with this research. If you have questions, please call the IRB office at 612-626-5654.

Sincerely,



Jeffery Perkey, MLS, CIP
Research Compliance Supervisor
JP/bw

CC: Joan Liaschenko, Cynthia Peden-McAlpine

Appendix B: University of Minnesota Institutional Review Board Change in Protocol Approval

UNIVERSITY OF MINNESOTA

Twin Cities Campus

Human Research Protection Program
Office of the Vice President for Research

1525 Mayo Memorial Building
420 Delaware Street S.E.
MMC 620
Minneapolis, MN 55455
Office: 612-626-5654
Fax: 612-626-0061
E-mail: irb@umt.umn.edu or irb@tc.umn.edu
Website: <http://research.umn.edu/subjects/>

May 20, 2014

Bethany J Gerdin
School of Nursing - AGH1331F
Room 5-140 WDH
308 Harvard St SE
Minneapolis, MN 55455

RE: "End of Life Surrogate Decision-Making with Bone Marrow Transplant Patients"
IRB Code Number: 1108P03022

Dear Ms. Gerdin

The Institutional Review Board (IRB) has received your response to its stipulations of April 4, 2014. Since this information satisfies the requirement set by the IRB, final approval for the change in protocol is noted in our files. The change includes an opt-out only return mailing procedure as outlined in your response to stipulations dated May 14, 2014.

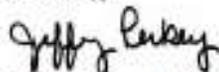
The consent form version dated January 29, 2014.

For your records and for grant certification purposes, the approval date for the referenced project is May 2, 2014 and the Assurance of Compliance number is FWA00000312 (Fairview Health Systems Research FWA00000325, Gillette Children's Specialty Healthcare FWA00004003).

As Principal Investigator for this study, you are required by federal regulations to inform the IRB of any proposed changes to your research that will affect human subjects. Changes should be reviewed and approved before they are initiated. Unanticipated problems and adverse events should be reported to the IRB as they occur. Research projects are subject to continuing review and approval.

Upon receipt of this letter you may institute the changes. If you have any questions, please call the IRB office at 612-626-5654.

Sincerely,



Jeffery Perkey, MLS, CIP
Research Compliance Supervisor
JP/bw

CC: Committee CCPRC, Joan Liaschenko, Cynthia Peden-McAlpine

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Appendix C: University of Minnesota Cancer Protocol Review Committee Approval

Masonic Cancer Center
UNIVERSITY OF MINNESOTA

Clinical Trials Office
Cancer Protocol Review Committee
MMC 61 D59/ Mayo

February 25, 2014

Bethany Gerdin, RN
Room 5-140 WDH
308 Harvard St SE
Minneapolis, MN 55455

RE: *INITIAL CPRC APPROVAL*- permission is granted to implement protocol once IRB approval is received.

CPRC #2014NTLS012

The Process Used by Family Surrogate Decision Makers to Withdraw Life-Sustaining Treatments in the Bone Marrow Transplant Population

Dear Ms. Gerdin,

The Cancer Center Protocol Review Committee/NTI was pleased to see your study come before them for review of scientific merit. On initial review, the committee approved the protocol version dated 09/15/2011. You may proceed with your submission to the IRB. The committee is requesting, however, that you clarify if this is a new protocol or an amended protocol. In addition, the committee notes that the opt-out recruitment method needs discussion with the IRB.

In the future, you are required to send the CPRC the following documents:

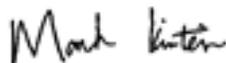
- The date the study opens to accrual, closes to accrual and is inactivated with the IRB
- A copy of all IRB continuing reviews
- Changes to key personnel
- Changes in accrual
- All amendments to the protocol.

Please note that effective Sept 16, 2013, protocol amendments which affect study design and/or study endpoints need to be reviewed and approved by the CPRC before submitting to the IRB.

The Clinical Trials Office database must be kept up-to-date in order to update local and national websites and provide accurate reports to the National Cancer Institute.

All Serious Adverse Events (SAEs) as defined in this protocol must be submitted to the Masonic Cancer Center SAE Coordinator within 10 working days of receipt of notice of the event. This includes both unanticipated problems involving risk to subjects or others (UPIRTSO) and non-UPIRTSO SAEs. Reports should be emailed to: mcc-saes@umn.edu.

Sincerely,



Mark Kirstein, Pharm.D
Chair, Cancer Protocol Review Committee/NTI

MK/jj

To be completed by CPRC Chair or Designee
Revised 6.26.13

Appendix D: Recruitment Letter

Date will vary

Dear Name will vary,

My name is XXX*, and I am the Nurse Manager of the blood and marrow transplant unit at XXX*. Your family member, *Name will vary*, was a patient on our unit. I am contacting you to ask about your willingness to talk to a researcher from the University of Minnesota who is interested in understanding experiences when decisions are made to withdraw life-sustaining treatments. If you are willing, I will give your name and contact information to the researcher, Bethany Gerdin, Registered Nurse, who is a PhD graduate student and experienced blood and marrow transplant nurse. Bethany will contact you initially by telephone to introduce the study, answer any of your questions, and see if you are willing to participate in an in-person interview. The decision is yours if you want to talk to Bethany or participate in this research. Participation is voluntary and you can withdraw from the study at any time. If you are *not* interested in receiving a call from Bethany to learn more about this research and potential participation, please return the enclosed letter in the pre-addressed and stamped envelope by *date will vary (2 weeks after letter sent)*. If I do not receive the enclosed letter by this date, I will give your contact information to Bethany and she will contact you by telephone. Thank you for considering to be a part of this research.

Yours sincerely,

*Blinded

Appendix E: Participant Letter Declining to be Contacted for Study

Dear XXX*

I am returning this letter to you because I do *not* wish to be contacted by Registered Nurse and PhD graduate student, Bethany Gerdin. Please do *not* give her my contact information, as I do not have an interest in participating in the described study. Thank you.

Sincerely,

Please write name clearly: _____

Signature: _____

Date: _____

*Blinded

Appendix F: *Consent Form*

Study Code Number: 1108P03021

Consent Form Version: 1/29/2014

1

Consent Form

The Process Used by Family Surrogate Decision Makers to Withdraw Life-Sustaining Treatments in the Bone Marrow Transplant Population

You are invited to be in a research study exploring the experiences of family members or significant others who were surrogate decision makers for an adult bone marrow transplant patient. The study seeks to understand the experience of the proxies when a decision was made to withdraw life-sustaining treatments. You were selected as a possible participant because you have experienced this. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Bethany Gerdin, an experienced bone marrow transplant nurse and PhD Graduate Student, University of Minnesota, under the supervision of her advisers Cynthia Peden-McAlpine PhD, AHCNS, BC from the University of Minnesota School of Nursing and Joan Liaschenko PhD, FAAN from the Center for Bioethics and the School of Nursing at the University of Minnesota.

Background Information

The purpose of this study is to examine the experiences of family members or significant others who were surrogate decision makers for an adult bone marrow transplant patient. The study seeks to understand the experience of the surrogate decision makers when a decision was made to withdraw life-sustaining treatments. We are interested in analyzing this data using a qualitative approach (interview) to uncover this unknown process.

Procedures:

If you agree to be in this study, we would ask you to do the following things:

Participate in an audio-recorded interview with the researcher for approximately one to two hours to discuss the decision making process that you underwent during the experience described above. These interviews will be transcribed following our time together. Sample interview questions include: "Tell me about your experience when the decision was made to withdraw life-sustaining treatments from your loved one". Other questions may include: What factors seemed to contribute to the decision to withdraw life-support? What emotions did you experience during this time? Was there anything that the medical team did that was helpful? Not helpful? What were your various thought processes during this time?

Risks and Benefits of being in the Study

The risks of this study include being asked questions that may make you uncomfortable. You may skip questions that you do not wish to answer. Also, there are privacy and confidentiality risks involved with participation. However, as described below, the records of this study will be kept private. No identifying information will be used in any potential publications. All records will be securely stored. Furthermore, all interviews will be de-identified.

There are no direct benefits to participation in this study.

Compensation:

None.

Confidentiality:

The records of this study will be kept private. In any sort of report that might be published we will not include any information that will make it possible to identify a subject or hospital. Research records consisting of transcribed tapes into a written form will be stored securely and only researchers will have access to the records. All interviews will be de-identified so that any information you give us will never be linked to you or a hospital. The electronic copies will be kept indefinitely for educational use.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions:

The researchers conducting this study are: Bethany Gerdin under the supervision of Cynthia Peden-McAlpine and Joan Liaschenko. You may ask any questions you have now. If you have questions later, you are encouraged to contact Mrs. Gerdin (651-895-6645, and01542@umn.edu), Dr. Cynthia Peden-McAlpine (612-624-0449, peden001@umn.edu), or Dr. Joan Liaschenko (612 624-2443, jliasch@umn.edu) at The University of Minnesota Center for Bioethics. If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), you are encouraged to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature: _____ Date: _____

Signature of Investigator: _____ Date: _____