

A Theoretical Model of the Psychological Processes of Surrogate Decision-Making at Adult End-of-Life in the Intensive Care Unit: A Case Study Design Using Cognitive Task Analysis

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**A THEORETICAL MODEL OF THE PSYCHOLOGICAL PROCESSES OF
SURROGATE DECISION-MAKING AT ADULT END-OF-LIFE IN THE
INTENSIVE CARE UNIT: A CASE STUDY DESIGN USING COGNITIVE TASK
ANALYSIS**

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J. Nicholas Dionne-Odom

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**A Theoretical Model of the Psychological Processes of Surrogate Decision-Making
at Adult End-of-Life in the Intensive Care Unit: A Case Study Design Using
Cognitive Task Analysis**

J. Nicholas Dionne-Odom

Dissertation Chair: Dr. Pamela Grace, RN, PhD, FAAN

Abstract

Significance/Background: Surrogate decision-makers (SDMs) take part in 1.5 million end-of-life (EOL) decisions per year. Most find the role burdensome, often do not make decisions concordant with patients' wishes, and many suffer negative psychological aftereffects.

Specific Aims: 1) Identify and describe the psychological processes of recent SDMs for adults at EOL in the intensive care unit (ICU) and 2) develop a theoretical model of SDMs' psychological processes.

Methods/Analysis: Descriptive, multiple case study research design using a cognitive task analysis (CTA) interviewing approach. Participants completed an in-depth semi-structured CTA interview and a demographic form. Verbatim transcribed interviews were encoded and analyzed until theoretical saturation was met.

Results: Nineteen SDMs (female=11) with a mean age of 59 years (± 11) who made decisions for patients (mean age, 67 ± 13 years) who died in the ICU completed interviews. Data analysis yielded 27 psychological processes representing the hypothesized theoretical links amongst 20 individual psychological concepts. The PREDICAMENTS model (**P**psychology, **R**easoning, and **E**thics **D**emonstrated **I**n **C**hoices

about the Aceptability of Medical Treatments and Patient Conditions Encountered in Life Threatening Situations) of surrogate decision-making was assembled from these psychological processes and concepts. The model depicts a complex web of psychological processes wherein SDMs ultimately express acceptance or rejection of medical treatments and/or the patient's physical condition based on their perception of the acceptability (or lack thereof) of medical treatments and/or the patient's physical condition.

Conclusions: The PREDICAMENTS model offers an initial picture of the underlying psychological processes operating in SDMs decision-making.

Implications for Practice and Research: The PREDICAMENTS model can be used to assess and understand SDMs' thought processes, emotions, and ethical concerns. Further research is needed to test and corroborate constructs and linkages in this model with the aim of developing decision support interventions. Ethicists need to discuss the implications of this descriptive theoretical model for the normative ethical standards expected of SDMs.

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Chapter 1

Introduction to the Problem and Research Aims

Surrogate decision-makers (SDMs) potentially make or influence nearly 1.5 million end-of-life (EOL) treatment decisions per year (Buckey & Abell, 2010) and impact over three-quarters of the decisions to withhold or withdraw life-sustaining treatments in the ICU (Curtis, 2005) where one in five patients die (Angus et al., 2004). SDMs are expected to make decisions for decisionally incapacitated patients according to ethical standards of concordance, which require that decisions approximate as closely as possible those choices patients would have made if they had been able (Beauchamp & Childress, 2009; Buchanan & Brock, 1990). For the past three decades, this concordance criterion has served as the theoretical basis upon which the research and intervention development agenda related to SDMs has been based (Berger, DeRenzo, & Schwartz, 2008; Jonsen, 1998; Shapiro, 2007).

However, a large body of evidence strongly suggests that making decisions based on this criterion of near concordant decision-making between SDMs and patients is not realistic. Not only have SDMs been repeatedly shown to be poor predictors of patients' treatment preferences (Ditto et al., 2001; Moorman & Inoue, 2013; Shalowitz, Garrett-Mayer, & Wendler, 2006; Sharma et al., 2011), but research has also shown that serving in the SDM role can be extraordinarily burdensome and is often associated with negative psychological aftereffects that may persist for months to years after the death of a patient (Wendler & Rid, 2011). These psychological aftereffects can include depression, anxiety, and guilt about whether or not the "right" decision was made (Melhado, 2011;

Wendler & Rid, 2011). These problems are significant because they suggest that the ethical standards of surrogate decision-making, based on an ideal of achieving perfect concordance with patients' wishes, are not psychologically practical. Therefore, clinical practice and the vast research on SDMs which presupposes the concordance criterion as a primary theoretical assumption might be an unrealistic psychological and ethical expectation (Berger, et al., 2008; Radwany et al., 2009).

Researchers have made great strides in characterizing the outward behavior of SDMs (Meeker & Jezewski, 2009). However, little is known about the psychological processes that are associated with these behaviors. Understanding these underlying psychological processes potentially offers a picture of SDMs decision-making processes that best predicts and explains the psychological burden during and after the experience (Fagerlin, Ditto, Danks, & Renate, 2001). This is a significant knowledge gap in what currently exists in the empirical research literature. Theoretical understanding of the moral and decision psychology of surrogate decision-making is inadequate for the decision-making task surrogates assume. This gap in knowledge warrants prioritization in nursing research given the ethical and professional obligation to support patients and families in health care decision-making that approximates patients' values, goals, and preferences, especially at end of life (National Institute of Nursing Research, 2011).

Recent methodological innovations in cognitive decision sciences have resulted in the development of qualitative case-study design techniques that are particularly well suited to characterize the psychological processes of decision-makers. One such case-study technique is called cognitive task analysis (CTA). Based on an underlying

psychological conceptual framework called macrocognition, CTA is an interviewing approach designed to elicit the cognitive processes decision-makers use to perform in their roles (Crandall, Klein, & Hoffman, 2006). Though underutilized in nursing for theory generation, case study designs coupled with CTA are ideal for theory development because they are able to trace processes that link causes and outcomes, detail the causal mechanisms of a process, and generate new hypotheses (George & Bennett, 2005; Yin, 2009). Hence, this dissertation research used a case study research design using a CTA interviewing approach with a cohort of recent SDMs of adults at EOL in an ICU setting in order to generate a theoretical model of how individuals psychologically perform in the surrogate decision-making role. A theoretical model of SDMs' psychological processes of decision-making for adults at EOL could facilitate the development of realistic ethical expectations and theory-based decision support interventions.

In the remainder of Chapter 1, I first briefly summarize the historical and socio-cultural background that gave rise to the SDM role, which will be more fully explicated in Chapter 2. Next, the research literature illustrating the difficulties associated with surrogate decision-making is summarized to underscore the problem of using the current triad of ethical principles as a guide for SDMs and the concordance criterion as an ethical and psychological expectation. The rationale for using a case study design and a cognitive task analysis interviewing approach is then given along with a synopsis of the conceptual basis of this method. Finally, the research aims and the relationship of the study's significance to nursing's social contract are stated.

Brief Historical and Socio-cultural Background

Surrogate decision-makers (SDMs), typically family members, are persons entrusted with the authority to make decisions for decisionally incapacitated patients (Buchanan & Brock, 1990). In the late 1970s and early 1980s, a shift from medical paternalism to patient self-determination and autonomy occurred, prompting the SDM role to become more prevalent (Buchanan & Brock, 1990; Jonsen, 1998). This movement was highlighted in the legal sphere during the seminal judicial decisions concerning two young women who lacked decisional capacity: Karen Ann Quinlan in 1976 and Nancy Cruzan in 1990 (Luce, 2010). In these highly publicized cases, the courts ruled that a decisionally incapacitated patient's previously stated wishes about medical care, as related by a family member, could be used as "clear and convincing evidence" to refuse life-sustaining medical interventions. In the U.S., these court cases in part sparked the passing of the Patient Self Determination Act of 1990 which mandated that any health care institution receiving federal funds must provide patients with their rights upon admission—including their right to accept or refuse treatment (Omnibus Budget Reconciliation Act of 1990, 1990). Concurrent with these cultural and judicial trends was a technological one: the emergence of life-sustaining technologies such as mechanical ventilation, hemodialysis and cardiopulmonary resuscitation. Although potentially lifesaving, these technologies began to sustain and protract the time-period of a person's physical existence regardless of impaired cognition, often prolonging the dying process (Jonsen, 1998; Kaufman, 2005). Thus the role of SDMs quickly emerged and has become essential and commonplace in the last three decades.

The widely endorsed expectation is that surrogates follow three hierarchical ethical standards when they consider health care decisions on behalf of others (Berger, et al., 2008). Listed in order of priority, this 3-standard hierarchy includes: (1) *the patient's known wishes (e.g. expressed verbally or in writing)*, (2) *substituted judgment*, and (3) *the "best interest" standard* (Beauchamp & Childress, 2009). This 3-standard decisional hierarchy, based on patient autonomy and the underlying notion that individuals are in the best position to know what is best for them, has been used over the past several decades to help health care practitioners and surrogates make health care decisions for adults who lack decision-making capacity (Beauchamp & Childress, 2009; Berger, et al., 2008).

Patient's known wishes refers to the standard of first choice whereby patients' explicitly stated desires to accept or decline specific medical treatments made in advance of an acute clinical situation are used to guide care. In the absence of a patient's known wishes, the *substituted judgment* standard is appealed to directing surrogates to interpret a patient's expressed or written wishes (such as those expressed in an advance directive), taking into account the person's values if known, and apply them in a given situation. Lastly, the *best interest standard* takes precedence in situations where the patient's preferences are unstated and otherwise unknown. The surrogate decides the greatest benefit to the patient according to what a "reasonable" person would do by weighing the costs, risks, and benefits of available treatment options (Beauchamp & Childress, 2009).

As mentioned at the beginning of the chapter, the underlying criterion of this 3-standard hierarchy is that SDMs approximate as closely as possible the decisions patients would have made if they had been decisionally capable (Beauchamp & Childress, 2009;

Buchanan & Brock, 1990). The next section highlights several problems argued to be associated with the ineffectiveness of the 3-standard hierarchy as a decision making guide for SDMs.

Problems Associated with Surrogate Decision-Making

Several significant problems are associated with the SDM role in the context of adult EOL in the ICU. The first set of issues relate to the negative effects frequently experienced by SDMs both during the surrogate decision-making experience in the ICU and for extended periods of time after the death of the patient. In a large systematic review of 40 studies representing over 2,800 SDMs, Wendler and Rid (2011) reported that a third of individuals in the quantitative studies and nearly all the participants in qualitative studies suffered burdensome aftereffects months to years after their decision-making experiences. Wendler and Rid note that the psychological sequelae of having been a SDM ranged from reports of “extraordinarily high” stress and anxiety to symptom presentations consistent with clinically significant depression and post-traumatic stress disorder.

As noted by Wendler and Rid, the origin of these negative aftereffects can be traced back to traumatic experiences SDMs had as decision-makers in the ICU. In ICU settings characterized by fast paced, rapidly changing circumstances, alien technological environments, and conflicting personal and interpersonal cultural and moral values (Baggs et al., 2007), SDMs are challenged with situations and ethical dilemmas of such complexity that performing in the SDM role has been found to be extraordinarily difficult (Chambers-Evans & Carnevale, 2005; Meeker & Jezewski, 2005; Melhado, 2011). In a

systematic review of 19 studies whose aim was to identify characteristics of SDMs in the context of withdrawing life-sustaining treatment, Melhado (2011) reported that almost half of the studies emphasized the psychosocially complex and emotionally tumultuous experiences of SDMs. Factors contributing to a negative SDM experience included feeling unprepared for the decision-making role (Chambers-Evans & Carnevale, 2005; Hayes, 2003); inadequate communication with physicians resulting in SDMs having inaccurate understandings of the medical situation and prognosis (Azoulay et al., 2000; Boyd et al., 2010; Meeker, 2004; White, Braddock, Berekenyei, & Curtis, 2007); and a lack of decisional support (Kirchhoff et al., 2002). For SDMs, these factors can magnify an already strained experience associated with the patient's grave illness (Chambers-Evans & Carnevale, 2005; Meeker & Jezewski, 2005).

When SDMs experience the extreme stress of their role, they may be prone to stalling or vacillating in the decision making process (Anderson, 2003) or making decisions that are contrary to patients' expressed wishes, either of which can lead to the prolongation of dying and undue harm (Hayes, 2003). This highlights yet another aspect of the problem related to surrogate decision-making: surrogates are prone to being non-adherent to or direct use of medical interventions that are inconsistent with a patient's previously known or stated preferences. Empirical evidence has shown that making decisions based on the criterion of having near perfect concordant decision-making between surrogates and decisionally incapacitated patients is not psychologically realistic (Dionne-Odom & Bakitas, 2012). Researchers have found that SDMs poorly predict patient preferences (Ditto, et al., 2001; Fagerlin, et al., 2001; Fried, Bradley, & Towle,

2003; Meeker & Jezewski, 2005; Pruchno, 2006; Shalowitz, et al., 2006), use different criteria than patients for predicting treatment preferences (Pruchno, 2006), have different perceptions of illness states than patients (Andresen, Vahle, & Lollar, 2001; Fried, et al., 2003; W. T. Phillips, Alexander, Pepin, & Riley, 2003; Yip, Wilber, Myrtle, & Grazman, 2001), and allow their own preferences for treatment to unwittingly bias their decisions for the patient's care (Ditto, et al., 2001; Fagerlin, et al., 2001; Marks & Arkes, 2008).

In summary, the key problems related to the role of surrogate decision-making include 1) the negative psychological aftereffects suffered by individuals months to years after having served as SDMs; 2) the undue stress and decisional conflict experienced by SDMs in their role; and 3) the potential for non-adherence to patient's previously expressed treatment preferences and wishes. Over the last two decades, research and intervention development aiming to address these problems has been based almost exclusively on the 3-standard hierarchy and its concordance criterion. Yet commentators on this agenda are increasingly noting that conceptualizing the role and objectives of SDMs exclusively through the lens of this 3-standard hierarchy is inadequate (Berger, et al., 2008; Jonsen, 1998; Shapiro, 2007). This agenda and its inadequacy was first signaled over two decades ago in the SUPPORT intervention (Teno et al., 1997), which failed to improve SDMs' adherence to patients' advance directives despite strategies employed to improve communication of these directives. Yet studies and interventions have persisted in subscribing to the aim of the 3-standard hierarchy of surrogate decision-making (Berger, et al., 2008; Radwany, et al., 2009). If researchers continue to base their research and intervention development agendas on this unfeasible 3-standard model, it is

likely that SDMs will continue to suffer negative aftereffects of their decision-making experiences and many decisionally incapacitated patients may undergo an EOL experience that is contrary to what they would have chosen for themselves (Hayes, 2003; Melhado, 2011; Wendler & Rid, 2011).

Purpose of this Research

Development of decision support interventions must be based on sound theoretical foundations that specify the underlying concepts and mechanisms that are purported to be active in situations or phenomenon (Charles, Gafni, Whelan, & O'Brien, 2005; Curtis, 2005; Elwyn, Stiel, Durand, & Boivin, 2011). In an integrative review of the literature regarding interventions designed to improve patients' EOL experiences, Curtis (2005) concluded that the mechanisms by which interventions affected the processes of care were not well understood. Because the 3-standard hierarchy of surrogate decision-making has performed sub-optimally as a framework upon which to base clinical practice and intervention efforts, nurse researchers are obligated to conceptualize alternative theoretical frameworks upon which interventions addressing the problems of surrogate decision-making could be based.

Given the need for a theoretical model of how individuals perform psychologically in the SDM role at adult EOL in the ICU, this study employed a descriptive multiple case study research design using a cognitive task analysis (CTA) interviewing approach. The resulting theoretical model from this research was the logical first step in a program of research focused on surrogate decision-making at adult EOL in the ICU before novel interventions and systematic changes can be developed and tested

in future research. Although prior research has described the experience of SDMs and identified variables in their decision-making, a literature review failed to elucidate a sufficient theoretical model of surrogate decision-making depicting the underlying psychological processes of the role (Dionne-Odom & Bakitas, 2013). A case study design was ideally suited to explore the nature of this problem given its success at generating testable hypotheses and middle-range theoretical models; its in-depth focus on a real-life event set within a specific context; and its honed methods of within and between-case comparison analysis (Miles, Huberman, & Saldana, 2014; Sandelowski, 2011; Yin, 2009). Case study researchers have also endorsed the use of an a priori framework in order to: account for what is already known in a topical area instead of naively or prematurely claiming that “not much is known” (Siggelkow, 2007), organize data collection (Yin, 2009), and facilitate data analysis (Miles, et al., 2014; Yin, 2009). The a priori conceptual framework used in this study was based upon the conceptual model of macrocognition, which served as the basis for development of CTA (Crandall, Klein, & Hoffman, 2006). Originating in cognitive psychology, *macrocognition* highlights the concepts that most comprehensively describe how people think and perform in real-life situations. It has served as the basis for development of the novel research approach of CTA, which has been successful in research describing how people think and make decisions in real-life situations. Undergirded by the conceptual model of macrocognition, CTA examines both the *functions* of thinking such as decision making, sensemaking, and problem detection, as well as the *processes* of thinking such as mental modeling, mental simulation, story building, managing uncertainty and risk, and

identifying decision points (Crandall, Klein, & Hoffman, 2006). Modeling the psychological processes of the SDM experience at adult EOL in the ICU using this research design generated new findings about the psychology of SDMs that may help palliative care and EOL care researchers develop theory-based decision support interventions.

Significance and Statement of Research Aims

“Nursing is the protection, promotion, and optimization of health and abilities, prevention of illness and injury, alleviation of suffering through the diagnosis and treatment of human response, and advocacy in the care of individuals, families, communities, and populations.” (American Nurses Association, 2010)

To meet the above social and ethical social contract nursing has with society, nursing organizations, scholars, and scientists are increasingly emphasizing the importance of understanding how individuals and groups make health and wellness decisions. The American Nurses Association in their newly revised *Nursing’s Social Policy Statement* (2010) calls for nurse scientists to concentrate their knowledge building efforts on patients’ and families’ decision making processes and their ability to make choices. In their statement of a central unifying focus for the nursing discipline, Willis, Grace, and Roy (2008) note that one of the primary directives of nursing practice is to help patients and families make optimal choices. And in their most recent 5-year strategic plan, the National Institute of Nursing Research (NINR) (2011) specifically denotes understanding and facilitating the decision making processes of patients and

families as a top priority in nursing's research agenda (p. 19). The science of health care decision-making is gaining prominence in the purview of nursing scholarship. In the ICU, perhaps even more than in other settings, nurses witness patient and family suffering due to the inadequate support for decision-making. The context of surrogate decision-making for adults at EOL in an ICU is an interdisciplinary issue, but one where nurses and nurse scientists have a valuable perspective, and the skills to further knowledge development.

Modeling the psychological processes of the SDM experience using a multiple case study approach can help nurses and other EOL care researchers to develop theory-based decision support interventions. The findings from this dissertation research also help to clarify whether a paradigm shift in decision making for the incapacitated patient should be developed as some scholars have suggested (Berger, et al., 2008; Braun, Naik, & McCullough, 2009).

The specific aims of this research were to:

- 1) Using a cognitive task analysis interviewing approach, identify and describe the psychological processes of a purposive sample of 15-25 individuals who recently acted as a primary surrogate decision-maker for an incapacitated adult at end-of-life in the intensive care unit; and
- 2) Develop a theoretical model of the psychological processes of SDMs who are acting on behalf of an incapacitated adult at end-of-life.

The **long term aim** of this study is to provide the theoretical foundations for developing decision support interventions that help optimize the SDM role. This

program of research will strive to ultimately uphold the treatment preferences of patients and reduce the burden on SDMs both during and after their experiences. This research addresses the National Institute of Nursing Research's (2011) strategic focus on EOL, specifically to support initiatives that "identify factors that influence...decision-making and treatment at the end of life" (p. 23) and the National Institutes of Health's State-of-the-Science Panel's (2004) recommendation to "develop and utilize instruments with an awareness of minimizing burdens on patients near end of life and their families" (p. 9).

Chapter 2

Evolution of the Study and a Review of the Literature

Introduction

The purposes of this chapter are twofold. First, the evolution of this researcher's motivation, personal journey, and reasoning processes is detailed, which led to the realization of this study's importance that was outlined in Chapter 1. Second, this chapter describes the researcher's critical review of the salient philosophical, empirical, and theoretical literature regarding surrogate decision-making at adult end-of-life in the intensive care unit. Consistent with qualitative methodology, these purposes are addressed in order to be forthcoming about this researcher's reflexive processes in formulating the background and planning of this study. According to Malterud (2001), reflexivity is a key component of rigor in qualitative research and is defined as "a researcher's background and position [that] affect[s] what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions" (pp. 483-484). Reflexivity underscores the value of intellectual transparency and communicates to the community of scholars the researcher's underlying knowledge, values, and beliefs towards a particular phenomenon of scientific interest.

This chapter is organized into six main sections and ordered in the sequence of my progression as a scholar in the area of surrogate decision-making at adult EOL. The first section relates how this researcher's experiences as an ICU nurse clinician triggered interest in the topic of surrogate decision-making at adult EOL.

The second section orients the reader to the topical area of this dissertation proposal by outlining the historical emergence of the role of surrogate decision-making related to healthcare decisions especially at EOL. It provides an overview of contemporary understandings of the purposes and limits of surrogate decision-making in clinical situations. The first part of this section explores the socio-cultural context of surrogate decision-making in the United States. I trace its rise as a societal and healthcare phenomenon emerging in response to the larger trends of patient and family centered care, the patient rights movement, advances in life-sustaining technologies, and the heavily emphasized Western value of patient autonomy. The second part of this section describes contemporary surrogacy by defining relevant terms and legal processes.

The third section describes and critically assesses the 3-standard ethical hierarchy of surrogate decision-making introduced in Chapter 1. This 3-standard hierarchy has been used over the past several decades to aid health care practitioners and surrogates make the best health care decisions for adults who lack decision-making capacity. Based on the principle of autonomy, this 3-standard hierarchy prioritizes the criterion of perfect or near concordance between the decisions of a surrogate and the hypothetical decisions made by a patient should they had been able to make them. The case is made that this 3-standard hierarchy has implicitly served as the theoretical framework for most of the research and intervention development in this area over the past three decades, but that it ultimately is insufficient as a basis upon which to formulate ethical and psychological expectations.

Given the inadequacy of the 3-standard hierarchy as a model for “good” surrogate decision-making, the fourth section explores possible alternative theoretical models that can account for the complexities of what happens in real-life. An integrative review is provided of published theoretical models of surrogate decision-making relevant to the context of adult end-of-life in the ICU. Eight theoretical models of surrogate decision-making were identified and critically assessed for their capacity to capture the mechanics of decision-making, thus permitting the development of evaluative measures and ultimately the development of interventions. The conclusion is drawn that while theorizing about the process of surrogate decision-making is ongoing and some progress has been made, a sufficiently articulated and sophisticated model suitable for design of decision support interventions has yet to be developed.

Given that neither the 3-standard ethical hierarchy nor alternative theoretical models of surrogate decision-making identified in the literature are practically suitable for helping surrogates perform optimally in their role, the fifth section introduces a conceptual model originating in cognitive psychology and ergonomic sciences that is foundational to the purpose of this research aimed at generating a theoretical model of surrogate decision-making at adult EOL. This model is called macrocognition and was briefly introduced in Chapter 1. Macrocognition is a grand conceptual model that was developed in cognitive psychology and ergonomic sciences. The concepts of macrocognition attempt to capture how people think and perform in real-life situations. Based on macrocognition, an innovative qualitative interviewing approach called cognitive task analysis (CTA) was developed. CTA has facilitated the modeling of how

people perform and make decisions in real-life situations, making it an apt and promising scientific tool for the research aims of this research study.

In order to highlight how this study's research aims emerged, the sixth and final section provides a summary and synthesis of the previous five sections. This chapter concludes with a restatement of the study's research questions and aims.

Section 1: Experiential Evolution of the Study

I have worked as an ICU nurse since 2002 when I graduated from nursing school. Since that time, I have had countless experiences as an ICU nurse clinician in situations where SDMs were faced with having to make treatment decisions for patients at the EOL. On many of these occasions, SDMs seemed incredibly burdened by the decision-making role and often struggled with doing the "right" thing.

One experience in particular has stood out in my memory as particularly representative and influential regarding the evolution of my personal perspective on surrogate decision-making. The patient I took care of I will call Mrs. M. Mrs. M was a 70 year old widow with an extensive cardiac history and type I diabetes. She was admitted for an exacerbation of her congestive heart failure and her hospital course was further complicated by an acute stroke. Medically, there were no alternatives available that the health care team could offer that would reverse or even halt the inevitable downward trajectory of her physical health. Her hospitalizations had increased in frequency over the past several years and now it looked as though she would require intensive care indefinitely. Mrs. M's condition had reached the point where she could no longer communicate. Previous to her stroke, she had been documented as requesting that

no heroic measures be taken should her prognosis be poor. Mrs. M was the mother of 4 very loving adult children. They told wonderful stories of how great a mother she was and it was apparent that she was a beloved, grand matriarch of the family. They never left her bedside and at least one of them would always be present at her side.

Despite the fact that the health care team unanimously agreed that curative medical care at that point was an unrealistic goal and that what was most appropriate at that point was comfort care, the family strongly insisted that “everything be done to save her.” Mrs. M’s children became very demanding and dictatorial towards the health care team regarding what medical treatments she was to receive and not receive. For example, they frequently refused pain medication for her when nurses would change the dressing on the pressure ulcer that was developing on her sacrum so that, according to them, she could be more awake. Despite multiple conferences with the health care team, the family never relinquished their desire for “everything to be done.” Mrs. M died about 3 months after the stroke. By that time, she had undergone multiple resuscitations after arrests and had received very aggressive medical treatments. Not only was the experience traumatic for Mrs. M, it was traumatizing for her children and the health care team.

The health care team had tried many strategies of communication but none of them appeared to achieve a more peaceful EOL experience for Mrs. M and her children. When I look back, I often wonder what was going through the minds of Mrs. M’s children as they were making decisions for their mother. What were they thinking from moment to moment? How were they rationalizing their decisions? What information did they need to hear and what did they think the health care team was telling them? What

moral and ethical values were impacting their decisions and were they aware of these values? Were they aware of the anxiety and stress they were causing the nurses and physicians?

Upon entering my doctoral studies in nursing, I endeavored to better comprehend how researchers conceptualized the role of surrogate decision-making at adult EOL. Although there is a large body of literature documenting the finding from both qualitative and quantitative studies related to surrogate decision-making, nevertheless it struck me that the psychological aspects of the surrogate decision-making process were not well studied. In practice, I was witnessing the behaviors and choices of SDMs without understanding what thoughts, beliefs, and attitudes underlay them. Moreover, a number of research reports had either explicitly or implicitly suggested that there were serious limitations to conceiving the role of a surrogate as one where an individual can make decisions that are nearly concordant with what a patient would have wanted if they had been able to choose for themselves. Yet the greater intervention and research agenda aiming to improve the performance of SDMs and the care for the decisionally incapacitated at adult EOL has continued to assume just this very notion that surrogates can accurately reproduce patient's wishes. These reflections upon the research literature in combination with my clinical experience and my commitment to nursing's ethical mandate to honor the autonomy and preferences of patients motivated the formulation of this research study.

Section 2: Historical and Contemporary Background on Healthcare Surrogacy

Historical Context of Surrogate Decision-Making

During the 1960s and 1970s when the civil rights and welfare movements in the U.S. were at their peak, another cultural shift was gaining momentum as a growing faction of people began demanding more protections and rights in the medical care they received (Jonsen, 1998). Grassroots activists began to demand certain protections in their medical care (Jonsen, 1998). Several of these demands included not being treated without consent, having confidentiality maintained of both their medical records and their communications with physicians, and receiving compensation for occurrences of medical malpractice (Jonsen, 1998). In 1972, the American Hospital Association, which represented almost 5,300 hospitals, responded to the pressures of this movement and drafted a Patient Bill of Rights (Jonsen, 1998). Although this document had no legal weight, it decreed that patients had a right to respectful medical care; a right to know who the physician in charge of their care was; a right to sufficient information regarding their diagnosis, treatment, and prognosis in order to make informed decisions about their treatment; the right not to be subject to medical experiment; the right to have their medical records kept confidential; and finally the right to received an itemization of their hospital bill (Curran, 1974). Writers looking back on this movement have noted that the patient rights movement triggered a pendulum swing from medical parentalism to patient self-determination and autonomy (Jonsen, 1998; Starr, 1984), which subsequently set the stage for the emergence of the surrogate decision-making role.

This role and the patient rights movement gained a more prominent national spotlight when two highly publicized court cases came to the forefront concerning two young women who lacked decisional capacity: Karen Ann Quinlan in 1976 and Nancy Cruzan in 1990 (Luce, 2010). In these highly publicized cases, the courts ruled that a decisionally incapacitated patient's previously stated wishes about medical care, as related by a family member, could be used as "clear and convincing evidence" to refuse life-sustaining medical interventions. In the U.S., these court cases in part sparked the passing of the Patient Self Determination Act of 1990 which mandated that any health care institution receiving federal funds must provide patients with their rights upon admission—including their right to accept or refuse treatment (Omnibus Budget Reconciliation Act of 1990, 1990).

Concurrent with these cultural and judicial trends was the birth of high tech hospital units called intensive care units in the 1950s and 1960s that catered to the sickest patients (Starr, 1984). Patients in ICUs were treated with a host of new and life sustaining technologies. One of these was mechanical ventilators. Mechanical ventilators were successors to the iron lung and became common in the 1950s after the technology was adapted from the oxygenation systems of World War II airplanes (Jonsen, 1998). The 1950s also saw the appearance of the artificial kidney which today we call hemodialysis (Jonsen, 1998). Other medical innovations noted by Jonsen (1998) during this time period included the first cancer chemotherapies in the 1940s and 1950s, the first pacemaker in 1950, and cardiopulmonary resuscitation in 1960. Although potentially life-saving, these technologies began to sustain and protract the time-period of

a person's physical existence regardless of impaired cognition (Kaufman, 2005). Hence the role of the SDM started to become essential and commonplace (Jonsen, 1998).

Surrogate Decision-Making in the Present Day

Given this overview of the social and historical context in which surrogate decision-making arose, the ensuing discussion describes how surrogate decision-making is generally understood today. To recall the definition introduced in Chapter 1, a *surrogate decision-maker* is an individual, usually a spouse or relative, who undertakes the responsibility of advocating for a patient's welfare should he or she become unable to make healthcare decisions due to temporary or permanent cognitive impairment due to illness or medication (Beauchamp & Childress, 2009). Surrogates are privy to the same healthcare information and allowed the same scope of decision making authority as a decisionally capable patient. However, the laws and official nominal designation of the surrogate decision making role are variable depending on individual state laws and specific institutional policies (for example, "health care proxy", "durable power of attorney", or "health care agent") (Jonsen, 1998).

SDMs are typically but not always officially designated and instructed in what decisions to make by an individual in a written advance directive (American Bar Association, 2005; Jonsen, 1998). An *advance directive* is a legally recognized document that stipulates individuals' preferences regarding their medical care should they become unable to make or communicate decisions (Kass-Bartelmes & Hughes, 2003). Advance directives can come in the form of a living will, a durable power of attorney for healthcare (DPOAHC), or some combination of the two. Varying greatly in their level of

detail, *living wills* specify general and particular preferences for medical care including but not limited to comfort versus aggressive treatment, cardiopulmonary resuscitation, intubation, intravenous medication and hydration, hospitalization in the event of a serious illness, antibiotic therapy, and the use of tube feeding (Beauchamp & Childress, 2009). A *DPOAHC* specifically designates an individual to act as a surrogate decision maker in the event of a future incapacity (Kass-Bartelmes & Hughes, 2003). Although states vary on their language and legal authority, advance directives are generally portable across states (American Bar Association, 2005). Should a person not have an advance directive and experience a loss of decision-making capacity, SDMs can be appointed to the role by a health care institution or by a court (Sabitino, 2007). When this is the case, the typical order in which individuals are granted the right to be a patient's surrogate is: spouse, adult children, siblings, then other family members, and friends (American Bar Association, 2005). However, this order varies by state.

A surrogate assumes their role when it is determined that a patient is no longer capable of making decisions for his or herself (American Bar Association, 2005). Although seemingly straightforward, deciding with complete confidence and unanimous agreement whether a patient can make decisions on his or her own behalf can, in some instances, be difficult and problematic (Gavisk & Greene, 2007). Although full treatment of this topic is beyond the scope of this discussion, it is worth briefly describing how medical institutions such as hospitals and long term care facilities and judicial courts handle determinations of an individual's ability to make decisions and assign surrogate decisions makers. Whereas judicial courts issue verdicts of an individual's *competence*

which is an official legal status, health professionals in medical institutions including nurses, physicians and psychiatrists assess a patient's *decision-making capacity* (Beauchamp & Childress, 2009). These two terms, competence and decision-making capacity, are not interchangeable in the strict sense as they are defined differently by courts and hospitals. Courts determine competence based on whether an individual is fit for safe independent living and there are state specific domains of competence such as competence to be married, be a parent, and serve as a witness (Beauchamp & Childress, 2009). Decision-making capacity, on the other hand, is narrower in scope and limited to the decisions and situations faced while being a patient with a medical condition.

Criteria used to assess decision-making capacity of patients include (1) the ability to understand the nature and consequences of different options including the benefits, risks and alternatives of any given diagnostic test or medical intervention; (2) to make a reasoned choice among those options; (3) and to communicate that choice (Beauchamp & Childress, 2009; Buchanan & Brock, 1990). There is no widely recognized formal test or instrument measuring these criteria of decisional capacity (Beauchamp & Childress, 2009). Though some tests such as the mini-mental status exam are sometimes used as an adjunct to such determinations, all such tests are interpreted on a case by case basis. This is because being decisionally incapacitated is highly context dependent and subject to fluctuations over time as a patient's medical condition changes. For example, a patient who is anesthetized for an operation is unable to communicate but soon regains that ability once in recovery and the anesthesia wear off.

Further complicating the matter is that one can also be *partially* decisionally incapacitated (Beauchamp & Childress, 2009). A patient may evidence a degree of decision making capacity that suffices for some circumstances but not others. As situations become increasingly complex or the stakes of the decision become higher, higher standards of the above criteria must be met. Hence, being decisionally incapacitated in one setting or situation does *not* necessarily equate to one's being unable to make decisions in *all* settings and situations. After a patient has been assessed to be wholly or partially in a decisionally incapacitated state, SDMs are recruited to make medical decisions on that patient's behalf (Kass-Bartelmes & Hughes, 2003).

Section 3: The 3-Standard Ethical Hierarchy of Surrogate Decision-Making and Empirical Evidence of its Problems as a Decision-Making Framework

Ever since individuals started assuming the surrogate role, the ethical gravity of the types of decisions that SDMs made were recognized to be extraordinarily high for they frequently involved choices about life-sustaining therapies in the context of patients near death (Buchanan & Brock, 1990; Jonsen, 1998). Given that the ethical principles of autonomy and self-determination had usurped paternalistic beneficence in the 1960s and 1970s, an autonomy-based ethical framework emerged to help guide SDMs in making ethical decisions. The ethical principle of autonomy asserts that patients have the right to make decisions about their own medical treatment. In the case of a surrogate decision for a decisionally incapacitated patient, the autonomy principle dictates that the choice of a particular medical treatment ought to approximate as closely as possible the option a patient would have chosen if they had been able to (Buchanan & Brock, 1990). Based on

this criterion of choice concordance, three ethical standards emerged for guiding the decisions of SDMs in these circumstances including in order of priority: 1) *following the patient's known wishes*, 2) *substituted judgment*, and 3) *best interest standard* (Beauchamp & Childress, 2009).

Following the patient's known wishes refers to the standard whereby SDMs execute the explicitly stated desires for specific medical treatments made in particular acute clinical situations where the patient has most recently lost decision making capacity (Beauchamp & Childress, 2009). This standard applies to those situations where a patient has decision-making capacity for a limited period of time during an acute illness or injury but then loses that capacity. During the brief period when the patient had decision-making capacity, he or she was aware of and had considered the specific treatment options and had explicitly stated what specific measures were or were not to be taken should they soon lose the ability to make decisions.

The *substituted judgment standard* directs SDMs to follow the verbal or written wishes of the individual, such as those in a living will, and to act in the person's stated interests, taking into account the person's values if known (Beauchamp & Childress, 2009). In these circumstances, individuals premeditatively reflect upon and indicate in some way whether in an advance directive or in conversation with a family members, friends, or primary health care providers what kind of care they would want in the event they could not make decisions. These individuals then experience illness or trauma and become decisionally incapacitated patients in a specific medical circumstance. SDMs then have the task of making decisions on behalf of these patients that most nearly aligns

with their previously written or verbal wishes even if the exact medical scenario is not one that was specifically anticipated by the patient.

The *best interest standard* takes precedence in situations where a patient's preferences for medical treatment are unstated and unknown (Beauchamp & Childress, 2009). The surrogate is to make decisions based upon what a "reasonable" person would want. Because reasonable people can differ about what to do in any situation, SDMs are to decide the greatest benefit for the patient given the particular circumstances by considering the clinical evidence, life expectancy, comfort, and the costs, risks and likely benefits of treatment options (Beauchamp & Childress, 2009).

This 3-standard hierarchical model of ethical principles has been used over the past several decades to help health care practitioners and SDMs make the best health care decisions for decisionally incapacitated patients (Jonsen, 1998). However despite the good intent and at times helpful guidance of the 3-standard hierarchy, empirical studies over the past two decades show repeatedly that SDMs do not (and perhaps cannot) employ these standards and meet the autonomy-based criterion of surrogate-patient choice concordance in real-world contexts.

The problem of SDMs ability to make choices in agreement with the wishes of their charges received broad attention from the medical ethics community as a result of a large multicenter seminal study conceptualized in the 1980s and conducted in the early 1990s called the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). This aim of study was to improve the concordance between patients' previously expressed preferences and their actual care (Phillips, Hamel,

Covinsky, & Lynn, 2000). Patients in this study had one of nine life-threatening diagnoses. The design consisted of two phases involving five teaching hospitals: phase I was a 2-year prospective observational study involving 4,301 patients. The findings of Phase I were used to inform Phase II. Phase II was a 2-year randomized controlled trial involving 4,804 patients divided into a control group and an intervention group. Physicians in the intervention group received daily updates on patients' prognosis as well as regular updates on patients' treatment preferences. In addition, a specially trained nurse communicated with patients, their families, and their physicians regarding treatment goals, care preferences, pain control, and advance care planning. By the year 2000, 67 manuscripts had been published on the results of the SUPPORT study (Phillips, et al., 2000) that all reiterated one overall conclusion: efforts to improve communication and discussion of patients' EOL treatment preferences did not result in a higher likelihood of those preferences being implemented in patient care (Lynn et al., 2000).

Along with physicians, SDMs in the SUPPORT study were shown to be poor at knowing and executing patient's treatment preferences (Covinsky et al., 2000). Of patients who did not want CPR performed on them should they arrest, 50% of SDMs incorrectly believed that they did. SDMs were also poor at reporting whether the patients' preference for goals of care should concentrate on comfort or maximizing life expectancy. SDMs also over estimated patients' willingness to endorse longer life over optimum health and were inaccurate in the degree to which patients either were or were not willing to live in a nursing home.

Research since the SUPPORT study has continued to corroborate these kinds of findings. Multiple studies (Ditto, et al., 2001; Fagerlin, et al., 2001; Fried, et al., 2003; Pruchno, 2006) and reviews (Shalowitz, et al., 2006) have shown that when presented with hypothetical scenarios involving illness states and life preserving measures, SDMs are inaccurate in predicting the preferences and treatment wishes of patients. Though some researchers found improvement in surrogate accuracy when completed advanced directives are available (Silveira, Kim, & Langa, 2010), many studies (Bakitas et al., 2008; Cohen-Mansfield & Lipson, 2008; Ditto, et al., 2001; Fagerlin, et al., 2001; Pruchno, 2006) including the SUPPORT study (Covinsky, et al., 2000) found that SDMs do not adhere to patients' preferences even when they are provided with advance directives or stated wishes.

Recent commentators (Berger, et al., 2008; Braun, et al., 2009; Shapiro, 2007) attempting to make sense of this corpus of research findings argue that there are under appreciated variables and processes that do not comport with this 3-standard hierarchy. For example, although we expect surrogates to try and reproduce the wishes of patients, surrogates have been found to make decisions based on their own values and preferences,(Fagerlin, et al., 2001; Hayes, 2003; Marks & Arkes, 2008; Pruchno, 2006; Vig, Taylor, Starks, Hopley, & Fryer-Edwards, 2006) consider factors beyond those of the patient's medical condition(Chambers-Evans & Carnevale, 2005; Limerick, 2007; Vig, et al., 2006), and prioritize other ethical principles over the patient's wishes (autonomy) such as beneficence (Elliott, Gessert, & Peden-McAlpine, 2009; Pruchno, 2006).

Despite this overwhelming evidence that SDMs perform poorly when seen exclusively through the lens of the 3-standard hierarchy, the research and intervention development agenda has largely been based implicitly on this framework (Berger, et al., 2008; Radwany, et al., 2009). While researchers continue to base their research and intervention development agendas on what appears to be an unfeasible 3-standard model, SDMs continue to suffer extreme negative aftereffects of their decision-making experiences and many decisionally incapacitated patients are undergoing an EOL experience that is less than optimal (Melhado, 2011; Wendler & Rid, 2011).

Section 4: A Review of Theoretical Models of Surrogate Decision-Making Relevant to the Context of Adult End-of-Life

In light of the discussion in the previous section, it is argued that the 3-standard hierarchy of surrogate decision-making has performed poorly as a sole basis upon which to base clinical practice and intervention efforts. Hence nurses and nurse scientists have a professional moral obligation to develop alternative theoretical frameworks upon which decision support interventions can be based. These interventions need to be developed based on sound theoretical foundations that specify the underlying concepts and mechanisms that are purported to be active in situations or phenomenon (Charles, et al., 2005; Curtis, 2005; Elwyn, et al., 2011). Therefore, I conducted a review of published theoretical models of surrogate decision-making applicable to adult EOL in order to assess the state of the science (Dionne-Odom & Bakitas, 2013). The scope and limits of what is known highlights gaps in the knowledge base that need to be bridged.

Language Used for Characterization of Theoretical Models

General agreement exists that theoretical models in nursing research are developed in part to enhance the intelligibility of events and phenomena, to predict phenomena to a degree greater than chance, and to base interventions upon (Burns & Grove, 2009; Conn, Rantz, Wipke-Tevis, & Maas, 2001; Fawcett, 2005). Yet, ‘theory’ and its associated language has been noted to have a wide assortment of usages in the empirical and conceptual literature (Fawcett, 2005; Wu & Volker, 2009), thus causing confusion about what the purposes of theory are in research.

A *theory* or *theoretical model* is regarded here as a network of clearly defined *concepts* linked together by specific relationships and set within a particular socio-cultural context (Fawcett, 1999). Theoretical models are depicted diagrammatically in a conceptual map, which are also sometimes called nomological nets or path diagrams (Shadish, Cook, & Campbell, 2002) or event state networks (Miles, et al., 2014). Relationships that link concepts to one another are made explicit by *relational propositions*, which can describe the direction, shape, strength, symmetry, sequencing, probability of occurrence, necessity, and sufficiency of a relationship between concepts in a nomological net (Burns & Grove, 2009). Relational propositions should be sufficiently reflected in a theory’s conceptual map. *Concepts* or constructs are words that represent key phenomena or essential characteristics of a phenomenon (Fawcett, 2005). In contrast to a theoretical model, a *conceptual model* is a set of two or more relatively abstract concepts that have very loosely specified relationships. Fawcett (1999) notes how conceptual models are often the precursors to theoretical models. In this same vein,

theories can be identified along a spectrum ranging from abstract to concrete. Theoretical models are more concrete than conceptual models. *Grand theories* are more abstract than *middle range theories* but less abstract than conceptual models (Fawcett, 2005).

Literature Search Strategies

Given the limited published reviews focused on theoretical models themselves, a literature review approach was conducted imitating Elwyn et al.'s (2011) review of theoretical models of decision-making used in the development of decision aids. A search was conducted of the databases PubMed, MEDLINE, CINAHL, and EMBASE using various combinations of the search terms “surrogate”, “proxy”, “end-of-life”, “life support withdrawal/withholding”, and “decision-making” with articles identified published between 1997 and 2011. Article reference lists were reviewed for additional reports. Selection criteria included: (a) empirical research studies or integrative reports synthesizing empirical and theoretical research; (b) articles modeling how SDMs make decisions for decisionally incapacitated patients in the context of EOL; and (c) authors depict diagrammatically their model of surrogate decision-making specifying key variables and relationships. Articles focusing upon decision-making for decisionally incapacitated children were excluded.

Data Extraction and Data Analysis

Upon retrieval of relevant literature, theoretical models of surrogate decision-making were compiled into a data matrix, which included authorship, methodology of theory construction, sample if applicable, theory focus, and delineation of major and minor concepts of the model (see Table 2.1). Major concepts were those which had

minor concepts as sub components. Identified theoretical models of surrogate decision-making were appraised in terms of their feasibility in the design of a theory-based intervention. Theories were evaluated regarding their selection and ample description of concepts, their description of relational statements linking concepts, the degree to which conceptual maps were reflective of the literal articulation of concepts and conceptual relations, and the degree to which authors of these theoretical models specified use of the model for possible measurement and intervention development.

Author(s) and Year	Method of theory development and sample (if applicable)	Summary Focus	Key Major and Minor Concepts of Model	
Buckey and Abell, 2010	Developed from the Health Belief Model along with integration of empirical literature	Demographic characteristics, sociopsychological attributes and beliefs, and physician-patient communication impact degree to which SDM perceives treatment as advantageous or disadvantageous.	<ul style="list-style-type: none"> • Physician and patient communication • Age • Education • Gender • Race-Ethnicity 	<ul style="list-style-type: none"> • Religiosity-Spirituality • Social Support • Self-Efficacy • SDM perception of Treatments as Benefits/Advantageous vs. Barriers/Disadvantageous
Caron, Griffith, and Arcand, 2005	Grounded theory, N=24 SDMs of dementia patients	Decision-making role is impacted by 1) the context of the interactions with the medical team, 2) the character of the treatment, 3) the family context, and personal factors related to the 4) dementia patient and 5) the caregiver (SDM)	<ul style="list-style-type: none"> • Decision-making <ul style="list-style-type: none"> ○ Collaborative ○ Unilateral ○ Delegated • Person with Dementia Dimensions <ul style="list-style-type: none"> ○ General health ○ Expressed wishes ○ Stage of disease ○ Quality of Life • Caregiver (SDM) Dimensions <ul style="list-style-type: none"> ○ Schema(s) of references ○ Values ○ Nature of relationship with patient ○ Interpretation of experience 	<ul style="list-style-type: none"> • Context of Interactions with Medical Team <ul style="list-style-type: none"> ○ Quality of relationship ○ Frequency of contact ○ Level of trust ○ Values and beliefs • Family Context <ul style="list-style-type: none"> ○ Absence of family ties ○ Facilitating - supportive ○ Conflictual – problematic • Treatment <ul style="list-style-type: none"> ○ Invasiveness ○ Side effects ○ Contribution or not to quality of life
Colclough and Young, 2007	Grounded theory, N=22 Japanese American family members	Age similarities and differences and the involvement of health care providers affect 4 dimensions of family understanding	<ul style="list-style-type: none"> • Age cohorts of SDMs (less than 70 years old and greater than 70 years old) • Health care providers 	<ul style="list-style-type: none"> • 4 Dimensions of Family Understanding <ul style="list-style-type: none"> ○ Awareness of Seriousness of Condition ○ Decision-making process ○ Readiness for impending death ○ Experience of dying process

Limerick, 2007	Grounded theory, N=17 SDMs	Decisions to withhold/withdraw LST are a result of actions undertaken by SDMs within a personal domain and an ICU environment domain	<ul style="list-style-type: none"> • Event triggering surrogate decision-making status • SDM Personal Domain <ul style="list-style-type: none"> ○ Rallying of family support, information sharing ○ SDM Evaluation of patient condition ○ Realization of past and future patient quality of life 	<ul style="list-style-type: none"> • ICU Environment Domain <ul style="list-style-type: none"> ○ SDM seeks information from the healthcare team ○ SDM develops relationship with the healthcare team ○ Discusses the patient's potential outcome from healthcare team's perspective • Coming to the Final Decision <ul style="list-style-type: none"> ○ SDM arrives at belief about futility ○ Inward reflection ○ Makes and communicates decision
Meeker and Jezewski, 2009	Metasynthesis of 14 qualitative studies using grounded theory	Family decision-making to withhold/withdraw LST involves three core processes including reframing reality, integrating, and relating	<ul style="list-style-type: none"> • Reframing reality <ul style="list-style-type: none"> ○ Cues ○ Information • Relating <ul style="list-style-type: none"> ○ Family ○ Providers 	<ul style="list-style-type: none"> • Integrating <ul style="list-style-type: none"> ○ Reconciling ○ Going On
Radwany et al., 2009	Grounded theory, N=23 family members	How family meetings and emotional burden impact the decision making process over time	<ul style="list-style-type: none"> • Illness Experience <ul style="list-style-type: none"> ○ Understanding of the medical condition ○ Occurrence of critical incident • Family Meeting <ul style="list-style-type: none"> ○ Preparation ○ Support for decision-making • Dying Process <ul style="list-style-type: none"> ○ Information about the dying process ○ Degree of consistency between decisions and care 	<ul style="list-style-type: none"> • Emotional Burden <ul style="list-style-type: none"> ○ Linger issues or questions ○ Resentment toward providers ○ Decision guilt • Time

White, 2011	Developed from the Donabedian structure-process-outcome theory and further specified by the conceptual and empirical literature	How barriers stemming from the family, the clinical team, and the structure/process of care impact the optimal functioning of each in affecting good and bad outcomes of decision-making	<ul style="list-style-type: none"> • Family Barriers <ul style="list-style-type: none"> ○ Emotional distress ○ Uncertainty about patient's preferences ○ Personal desires about goals for patients ○ Intrafamily conflict ○ Spiritual/moral concerns about stopping life support ○ Distrust of clinicians • Clinical Team Barriers <ul style="list-style-type: none"> ○ Inadequate communication skills ○ Lack of interest ○ Cultural orientation toward "life extension/rescue" ○ Personal moral beliefs about appropriate end-of-life care ○ Inadequate attention to emotional and moral considerations • Structural/Process of Care Barriers <ul style="list-style-type: none"> ○ Clinical turnover ○ Time constraints ○ Lack of convenient space for family meetings ○ Lack of timely/regular communication ○ Failure to include key members of family/team 	<ul style="list-style-type: none"> • Ideal Surrogates <ul style="list-style-type: none"> ○ Manages strong emotions ○ Accurately understands and conveys patient's values ○ Comprehends key medical information ○ Authorizes decisions that promote patient's interests • Ideal Clinical Team <ul style="list-style-type: none"> ○ Accept diverse goals of care ○ Effectively communicate prognostic information ○ Present treatment options without undo bias ○ Deliberate with surrogates ○ Provide emotional and moral support • Ideal Structure/Process of Care <ul style="list-style-type: none"> ○ Early and timely communication ○ Clinician continuity ○ Convenient space for meetings • Multidisciplinary involvement Mutual trust and respect • Decision-making • Good outcomes <ul style="list-style-type: none"> ○ Patient-centered decisions about life support ○ Health grieving ○ Appropriate resource use • Bad outcomes <ul style="list-style-type: none"> ○ Nonpatient-centered decisions about life support ○ Adverse psychiatric sequelae for surrogates ○ Inappropriate resource use
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Wiegand, Deatrck, and Knafl, 2008	Hermeneutic phenomenology, N=56 family members representing 19 families	How family management styles both affect and are affected by how family members define the situation, the management behaviors of families, and the various consequences of the decision-making experience	<ul style="list-style-type: none"> • Definition of the Situation <ul style="list-style-type: none"> ○ View of the person ○ Illness/injury view ○ Management mindset/family readiness ○ Family mutuality • Management behaviors <ul style="list-style-type: none"> ○ Family philosophy ○ Family interaction ○ Family presence ○ Preparing for death 	<ul style="list-style-type: none"> • Consequences <ul style="list-style-type: none"> ○ Physiological effects ○ Emotive responses ○ LST withheld ○ LST withdrawn • Family Members • Family management style <ul style="list-style-type: none"> ○ Progressing ○ Accommodating ○ Maintaining ○ Struggling ○ Floundering
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Results and Analysis

A total of 8 manuscripts proposing 8 different theoretical frameworks meeting the selection criteria were retrieved. Five theoretical models were developed using grounded theory approaches (Caron, et al., 2005; Colclough & Young, 2007; Limerick, 2007; Meeker & Jezewski, 2009; Radwany, et al., 2009). Of these, one cited using a grounded theory approach to analyze a metasynthesis of 14 qualitative studies (Meeker & Jezewski, 2009). The other manuscripts using grounded theory approaches reported conducting face to face interviews and used constant comparative analysis to analyze transcribed interviews. Two of the theoretical models were developed from other grander theories and had concepts further specified using support from the empirical and conceptual literature (Buckey & Abell, 2010; White, 2011). The model proposed by Wiegand, Deatrck, and Knafl (2008) was generated using a hermeneutic phenomenological approach.

Each theoretical model evidenced a distinctive scope and focus with which they attempted to capture the experience of surrogate decision-making. Two were framed at the level of the individual surrogate decision-maker (Caron, et al., 2005; Limerick, 2007). Four of the models were conceived around the dynamics of interpersonal relations, locating the SDM within a network of family relations and family-health care team relations (Colclough & Young, 2007; Meeker & Jezewski, 2009; Radwany, et al., 2009; Wiegand, et al., 2008). Two models took a systems perspective and included the surrogate, family, clinicians, and environment (Buckey & Abell, 2010; White, 2011).

In the following, a brief summary description of each of the 8 theoretical models of surrogate decision-making is given in alphabetical order of the lead author's last name.

Buckey and Abell (2010): Surrogate Decision-Making Framework based upon the Health Belief Model

The theoretical model of surrogate decision-making proposed by Buckey and Abell (2010) is based upon the Health Belief Model (HBM) and is further specified by a review of the empirical literature. The HBM model was chosen by the authors due to one of its core tenets that individuals partake in actions that are believed to achieve an expected goal. Buckey and Abell's theoretical model was a prediction model that the authors developed primarily for use in a descriptive, cross-sectional survey in order to address the research question of whether surrogates' personal attributes, perceptions of communication, social support, and self-efficacy influenced their life-sustaining treatment decisions. A variety of concepts were operationalized into measured variables that were used to predict the degree to which a surrogate perceived a treatment to be advantageous or disadvantageous to the decisionally incapacitated patient. These variables fell into categories of demographic characteristics, socio-psychological attributes and beliefs, and structural influences.

Caron, Griffith, and Arcand (2005): Dimensions Associated with Decision Making at the End of Life of a Relative with Dementia

A grounded theory approach using a sample of 24 caregivers of dementia patients was used to generate two theoretical models: 1) the key factors caregivers of dementia patients took into account in their EOL decision-making and 2) the different phases of

EOL decision-making. Regarding the former, key factors were grouped under 5 main dimensions that included factors associated with the person with dementia, factors associated with the caregiver, treatment considerations, family context, and interactions with health care providers. This first model depicts how the combination of these factors under these dimensions impacts whether the surrogate's decision-making was "collaborative", "unilateral", or "delegated". The second model depicted four phases of the decision-making process including a transitory phase, curative phase, phase of uncertainty and palliative phase, which are defined by the family caregiver's perceived degree of quality of life of the patient. The model highlights how the type of care a patient receives is mostly dependent upon how high or low his or her quality of life is deemed to be by the SDM.

Colclough and Young (2007): The Four Dimensions of Family Understanding in End-of-Life Decision Making Among Japanese American Families

Colclough and Young (2007) also used a grounded theory approach using a sample of 22 Japanese American family members in order to generate a theoretical model that focused on the impact that 1) age similarities and differences of individuals either less or greater than 70 years of age and 2) the involvement of health care providers had upon four dimensions of family understanding, which could range from high to low. These dimensions included awareness of the seriousness of the condition, the decision-making process, the readiness for impending death, and the experience of the dying process. Within each dimension, the authors comprehensively described the components

of each dimension which included further subcomponents although these were not included in their conceptual map.

Limerick (2007): The Process Used by Surrogate Decision Makers to Withhold and Withdraw Life-Sustaining Measures in an Intensive Care Unit Environment

Interviews with 17 surrogates who decided to withhold or withdraw life-sustaining measures in the intensive care unit were analyzed using a grounded theory approach and used to generate a model that depicts the process individuals go through to make a decision to withhold or withdraw life-sustaining treatment. The process oriented model begins with an event that initiates surrogate decision-making status. From here the individual interacts within and between two main domains, the personal and the ICU environment. Within each of these domains are actions (see Table 2.1) undertaken by the surrogate that impact the final stage of the process, the decision domain, which includes three components: believing that LST is futile, inward reflection, and making and communicating a decision.

Meeker and Jezewski (2009): Metasynthesis of Family Participation in Decision-Making to Withhold or Withdraw Life-Sustaining Treatment

Meeker and Jezewski conducted a metasynthesis of 14 qualitative studies using a grounded theory approach in order to generate a theoretical model consisting of three major, mutually interacting process categories including “reframing reality”, “relating”, and “integrating”. Each of these categories had two subthemes: “reframing reality” included “cues” and “information”; “integrating” included “reconciling” and “going on”;

and “relating” included “family” and “providers”. Meeker and Jezewski’s (2009) abstract and parsimonious conceptual map was complimented by an extensive description of each concept.

Radwany et al. (2009): Theoretical Model of End-of-Life Decision Making and Emotional Burden

Using the methods of grounded theory, Radwany et al. (2009) interviewed 23 family members who had acted as SDMs for a relative at end of life and who had also participated in a structured family meeting with palliative care clinicians in order to talk about those decisions. The theoretical model is oriented temporally having 3 distinct stages including “the illness experience”, “decision making in the family meeting”, and “the dying process”. Each of these stages includes two main themes which could be described as key tasks. The model emphasizes the role of emotional burden endured by surrogates and its impact on the transition from one phase to the next and upon the decision making outcome.

White (2011): Multidimensional Framework of the Barriers to High Quality Surrogate Decision Making in the ICU

This theoretical model of surrogate decision-making is based upon the Donabedian structure-process-outcome theory and furthered specified by a review of the conceptual and empirical literature. The model depicts how dimensions of ideal surrogates, ideal clinical teams, and ideal structure/processes of care are mutually supported by mutual trust and respect. These ideal dimensions however are negatively impacted by dimensions of family, clinical team, and structure/process barriers. Both the

ideal and barrier sets of dimensions have multiple concepts further characterizing them (see Table). In addition, the model specifies good and bad outcomes resulting from the decision-making of surrogates.

**Wiegand, Deatrck, and Knafl (2008): Family Management Styles of
Withdrawing Life-Sustaining Therapy**

A hermeneutic phenomenological research design using a sample of 56 family members representing 19 families was used to develop a model of different family management styles related to how surrogates decided to withhold or withdraw life-sustaining therapy. A typology of five family management styles is described including progressing, accommodating, maintaining, struggling, and floundering. The major components that characterize the particular family management style include how the family defines the situation, the management behaviors, and the perceived consequences of the actual or expected outcomes.

Discussion

This review identified and briefly described 8 theoretical models of surrogate decision-making that are applicable to adult EOL. The following discussion is oriented by the perspective that theoretical models are formulated in part to serve as frameworks from which possible interventions to improve the experience and performance of SDMs can be developed. Intervention developers use theoretical models as road maps for conceptualizing the design of an intervention and as guides in the identification of both modifiable mechanisms and appropriate outcome and process indicators (Conn, et al., 2001; Shadish, et al., 2002).

To this researcher's knowledge, none of the aforementioned theories have been used explicitly to develop and test interventions, although Radwany et al. incorporated an intervention within their theory, and only one (Buckey & Abell, 2010) has formally attempted to test and develop clinical measures of the relevant concepts and conceptual relations. Given how recent each theoretical model is, this should not be interpreted to indicate that these theories are therefore not useful with regard to intervention development. Most of the theoretical models described with the exception of White (2011) were not explicitly intended by authors for the purpose of developing interventions. Hence, this discussion is not intended to identify flaws in the scientific rigor of these studies but rather to elicit reflection about what kind of traits theoretical models of decision-making need to have in order to be amenable to intervention development. In that spirit, the following sections highlight five key insights of this review in order to explain why a disconnect exists between theories of surrogate decision-making and development of theory-based interventions to improve outcomes related to EOL surrogate decision-making.

Conceptual Maps of Surrogate Decision-Making Lack the Sophistication and Complexity Described in Authors' Findings and Discussions

The mechanics of how the decision-making process operates for SDMs described by authors was only minimally illustrated in the conceptual maps of their theoretical models. Most authors provided detailed descriptions of concepts and conceptual relationships that were not included in their conceptual maps. White's model depicted an exhaustive list of concepts relevant to the surrogate experience which on first look seems

to represent an exception in this regard; however, there is minimal representation in the model of and little discussion specifying the particular relationships between these concepts. The dynamics of decision-making was often completely absent in conceptual maps. For example, the mechanics of a deliberation process where information, values and choice options were weighed and processed were mostly absent in over half of the identified models.

Description of Concepts has been emphasized over the Generation of Relational Linkages and Propositions

Most theories were centrally focused on detailing the concepts in their model rather than the complexity and character of relationships existing between and among concepts in their conceptual maps. In general, there was little to no methodical listing of relational propositions that described the direction, shape, strength, symmetry, sequencing, probability of occurrence, necessity, and sufficiency of relationships among concepts. Without such precise specification of relational linkages, it was difficult to discern whether a *process* was being represented in most of the authors' conceptual maps. A possible exception in this regard was Limerick's (2007) process oriented theoretical model. It was also notable that Bucky and Abell (2010) statistically tested the hypothesized relationships between their predictor concepts and the degree to which SDMs perceived a treatment as advantageous or burdensome. However, Colclough and Young (2007) devote an entire section to systematically discuss the relationships among concepts in their model, and yet their discussion was not inclusive of all the concepts in their conceptual map. Given that most of the identified theoretical models were

descriptive in nature, Burns and Grove (2009) note that such early stage models typically evidence sparse discussion of relational propositions between concepts. However, interventions need to be based upon fully characterized conceptual relationships because it is essentially these relationships that get tested through interventional research (Burns & Grove, 2009; Shadish, et al., 2002).

There has been Inadequate Integration of Ethical Concepts and Relationships into Conceptual Maps

As noted in the introduction, it is increasingly apparent that a research agenda based upon the 3-standard model of surrogate decision-making is an inadequate ethical foundation upon which to base expectations about how surrogate decision-making should be performed. Moreover, it was noted above that SDMs often suffer negative aftereffects related to guilt, shame, and rumination upon whether they had done the “right” thing for this patient. It is imperative that theoretical models of surrogate decision-making attempt to incorporate how concepts related to ethics and values operate in this process. However, though often included in written discussion, over half of the authors’ conceptual maps completely lacked concepts related to values and ethical concerns. Although White’s model had concepts related to ethics and values such as “Spiritual/moral concerns about stopping life support” and “Accurately understands and conveys patient’s values”, it remained unclear from the model how these ethical and moral concepts operated cognitively and psychosocially and in relationship to other concepts in their map. Similarly in their conceptual map, Caron, Griffith, and Arcand

depicted a concept called “values and beliefs” but again there was no indication of how this concept interacted with other phenomena.

There has been Relatively Little Emphasis on how Theoretical Frameworks Might Aid Intervention Development

Consistent with Elwyn et al.’s (2011) findings from their review of decision-making theories, the primary aims of authors developing surrogate decision-making theories has been on depicting how decision-making occurs rather than describing how key concepts and their relationships could be developed into measures and interventions. It is helpful when developing these theoretical frameworks to specify in discussions how interventions and confirmatory type research might be developed based on these theoretical foundations. In this regard, only White (2011) focused extensively on how interventions could be developed from his theoretical model. Buckey and Abell’s (2010) theoretical model was tested using survey instruments and thus was able to test several measures important to surrogate decision-making. Otherwise, discussions of how interventions and measures could be based upon theoretical models ranged from a brief paragraph to a few sentences.

Constructing Middle Range Theories of Surrogate Decision-Making from Grander Conceptual Frameworks of Decision-Making has been Under-attempted

Buckey and Abell’s (2010) and White’s (2011) theoretical models were the only two models that were conceptualized in part based upon grander conceptual models. The process of formulating a middle range theory from a grand theory or conceptual

framework has been noted in the literature to have the advantages of comprehensively accounting for the major concepts and relationships of a topical area instead of naively or prematurely claiming that “not much is known” (Corbin & Strauss, 2008; Siggelkow, 2007). As noted by Elwyn et al. (2011), it may be the case that theory developers are simply unaware of the plethora of decision-making conceptual frameworks in existence.

Concluding Remarks from the Literature Review

There is a critical need and moral obligation on behalf of nursing’s social contract to develop sound theoretical frameworks of surrogate decision-making. Such frameworks are needed because interventions targeting the optimization of the decision-making role and processes of SDMs need to be theory-based (Curtis, 2005). Given the significant impact of the surrogate role on caregiver burden and patient outcomes, the above review and analysis of 8 theoretical models of surrogate decision-making was undertaken in order to offer possible reasons why theoretical models of surrogate decision-making have yet to spawn theory-based interventions that do not implicitly rely exclusively on the concordance criterion of the 3-standard model. Based upon the results of this substantive review, it can be surmised that researchers have made initial strides in theorizing the process of surrogate decision-making. However, a sufficiently comprehensive and sophisticated theoretical model of surrogate decision-making suitable for theory-based intervention development has yet to be formulated.

Section 5: The Conceptual Model of Macrocognition

In the previous section, the point was made that grand conceptual frameworks of decision-making have been underutilized in the development of middle range theories of

surrogate decision-making. Given this and that neither the 3-standard ethical hierarchy nor alternative theoretical models of surrogate decision-making are optimal for development of decision support interventions, this fifth section describes a grand conceptual model of decision-making called macrocognition. Originating in cognitive psychology and ergonomic sciences, the conceptual model of macrocognition has spawned the development of a novel interviewing approach called cognitive task analysis (CTA). The techniques of CTA have performed well in non-healthcare fields at eliciting how people think and make decisions in real life contexts (Crandall, et al., 2006). Hence, the grand conceptual model of macrocognition and the interviewing methodology of CTA offered an ideal approach to meeting the aims of this research. In the following, I will briefly introduce the reader to macrocognition and CTA.

Emerging in the 1990s, macrocognition is a grand conceptual model that purports to highlight the key major concepts involved in how individuals think and act in real-world environments (Crandall, et al., 2006; Klein, 1998; Klein et al., 2003).

Macrocognition contrasts with *microcognition*. Microcognition studies cognitive functions, such as puzzle solving ability and probability estimation, in controlled, laboratory-like conditions (Crandall, et al., 2006; Klein, et al., 2003). The model of macrocognition on the other hand asserts that the cognitive landscape is quite different in real world settings as opposed to laboratory settings. The macrocognition maintains that people have different thought processing strategies in *naturalistic*, or real-life, contexts (Crandall, et al., 2006). Macrocognition has been used to characterize situations featuring high time pressure, uncertainty, unclear goals, high stakes, and social and

environmental constraints (Klein, 1998). In short, the model is aimed at capturing the sort of processes that SDMs exhibit in making decisions for adults at EOL in the ICU.

Two points are important to note regarding this model. First, this model is technically a grand conceptual framework and thus the concepts are not presented with a pre-specified set of hypothetical relationships. The model is meant to be applied via its methodological analogue, CTA, to specific contexts in order that relationships between these concepts can be elucidated (Crandall, et al., 2006). Second as noted by Crandall, Klein, and Hoffman (2006), the model of macrocognition is still a work in progress and



Figure 2.1 Model of Macrocognition (adapted from Klein, et al, 2003)

hence the model is subject to refinement. Researchers using the model and CTA are encouraged to supplement the model with other key concepts as is appropriate to particular areas of investigation. These points will be raised again and become important in sections of Chapter 3 where the methods are discussed.

The model of

macrocognition is illustrated in Figure 1. The model's concepts are divided into functions and processes. The *processes* of macrocognition support and act as a means for

the ends or *functions* of macrocognition (Crandall, et al., 2006; Klein, et al., 2003). The concept of *maintaining common ground* is meant to represent those communication strategies individuals use to maintain a common frame of an event or situation with others. *Developing mental models* refers to the use and development of mental schemata or templates that people build over time based on initial and repeated experiences with situations and interactions. Typically based to some degree on these mental models, *mental simulation* denotes how one projects what the future will look like given what is presently understood about a situation. *Managing uncertainty* are the beliefs, attitudes, and behaviors people use to cope with what they do not know but perceive needing to know in a situation. *Identifying leverage points* is what individuals do when they identify opportunities in a situation that they can act on and impact. The last process concept is *managing attention* and refers to the perceptual filters one uses to discern what information in a given context is important and meaningful.

The processes of macrocognition serve to meet the needs of the function concepts of macrocognition (Klein, 1998; Klein, et al., 2003). *Naturalistic decision-making* is a key notion of this dissertation research and is a function concept that designates how a person chooses to pursue one course of action when they perceive that others were available. *Sensemaking* is what people do to diagnose how a current state of affairs came about and what is anticipated for the future given this frame. *Planning* denotes how an individual attempts to modify elements of a situation to achieve some desired future state. *Adaptation* is what people do to modify plans in order to account for unforeseen changes or new information. *Problem detection* is a function concept that represents how one

senses when anomalies and problems are present in a situation. Finally, *coordination* is what strategies individuals use to orchestrate the actions and efforts of others in order to achieve objectives.

Together, these function and process concepts constitute the grand conceptual framework of macrocognition. Research on the psychological processes of decision-making in real life contexts has prompted the formal development of research approaches incorporating these concepts. Cognitive task analysis (CTA) is one such approach. This emerging research approach, detailed extensively in *Working Minds: A Practitioner's Guide to Cognitive Task Analysis* by Crandall, Klein, and Hoffman (2006), details how CTA can be used to study and analyze how people think and make decisions in their performance of tasks in real life settings. Techniques of CTA have been formalized and extensively used in diverse fields such as the military, aviation, firefighting, and nuclear power plant operations (Crandall, et al., 2006). CTA has also been used in the health sciences (for example Hysong et al., 2010; Fackler et al., 2009), including nursing (Crandall & Getchell-Reiter, 1993). Thus, this research adapted these techniques of CTA to understand the psychological processes of thinking and decision making in SDMs at EOL in the ICU as further detailed in Chapter 3.

Section 6: Summary, Synthesis, and Restatement of Research Aims

This chapter has demonstrated this researcher's reflexivity and elucidated what is known and not known about surrogate decision-making for adults at EOL in the ICU. SDMs are expected to make health care decisions for the decisionally incapacitated according to one of three ethical standards including stated wishes, best interest, and

reasonable person standards (Beauchamp & Childress, 2009). The underlying impetus of this autonomy-centric, 3-standard model is that medical treatments ought to approximate as closely as possible the decisions a patient would have made if they had been able to (Buchanan & Brock, 1990). For the past three decades, this 3-standard model has served implicitly as the theoretical and normative basis upon which research and interventions have been based (Berger, et al., 2008; Jonsen, 1998; Shapiro, 2007). Given the body of research showing how distressing the SDM role is, the prevalence of depression, anxiety, and decision related guilt months to years after performing as an SDM, and the inability of SDMs to perfectly concord their decisions with that of decisionally incapacitated patients, it was concluded that the concordance criterion of the 3-standard hierarchy is insufficient as a theoretical basis upon which to design decision support interventions. Furthermore, a literature review of alternative theoretical models of surrogate decision-making showed that a sufficiently comprehensive and sophisticated theoretical model of surrogate decision-making suitable for theory-based intervention development has yet to be formulated.

Modeling the psychological processes of the SDM experience at adult EOL in the ICU may help palliative care and EOL care researchers develop theory-based decision support interventions. As further discussed in Chapter 5, this research has clarified whether a paradigm shift in decision making for the incapacitated patient should be developed as some scholars have suggested (Berger, et al., 2008; Braun, et al., 2009). Interventions to enhance SDM role performance that build upon the model produced by this research may also concurrently improve other EOL processes and outcomes such as

prolonged patient suffering and dying, stewardship of financial and human resources at the EOL in the ICU, and nursing moral distress.

The specific aims of this dissertation research were to:

- 1)** Using a cognitive task analysis interviewing approach, identify and describe the psychological processes of a cohort of 15-25 individuals who recently acted as a primary surrogate decision-maker for an incapacitated adult at end-of-life in the intensive care unit; and
- 2)** Develop a theoretical model of the psychological processes of SDMs who are acting on behalf of an incapacitated adult at end-of-life.

Chapter 3

Methods

This chapter describes the research method that was used to address the aims of this study. The chapter is divided into 8 sections. The first section describes the research design and background, focusing upon the qualitative approach of case study design and its underlying philosophical basis. The second section describes the sample that was targeted for recruitment, the inclusion and exclusion criteria, and the recruitment site. The third section delineates the recruitment strategy and the step by step protocol used to contact and enroll participants for the study. The fourth section describes the data collection procedure that consisted of face to face interviews using a cognitive task analysis (CTA) interviewing protocol. The fifth section outlines the data analysis plan employed after interviews were transcribed. The sixth section addresses the measures that were taken to establish qualitative rigor. Finally, the seventh section describes the measures undertaken to protect the participants of this study and the collected data.

Section 1: Research Design and Background

Summary of the Overall Study Design

The aims of this research were met using a qualitative descriptive multiple case study of individuals' recent SDM experiences at adult EOL in the ICU. An in-depth, semi-structured interview using a CTA interviewing approach was conducted with a purposive sample of 19 individuals who had acted as a primary SDM at adult EOL in the ICU at Dartmouth-Hitchcock Medical Center (DHMC) an average of 70.3 days after the death of the patient. The originally targeted sample size was 15-25; however theoretical

saturation was met after 19 interviews. Potential participants were referred to the study by a team of DHMC ICU case resource coordinators (CRCs). Referrals were contacted by telephone and informed about the study. Willing and eligible individuals signed an informed consent and were interviewed at either their homes, the researcher's office, a location of their choosing, or over the telephone. Consistent with CTA interviewing techniques as detailed in Crandall, Klein, and Hoffman (2006), the semi-structured interviewing protocol (Appendix I) consisted of 3 "sweeps", or sets of questions, that elicited a timeline of events from the participant's perspective, a detailing of the individual's thought processes, and responses regarding "what if" queries. Interviews were digitally recorded and transcribed by a professional transcriptionist. Using methods described by Miles, Huberman, and Saldana (2014) and consistent with CTA data analysis techniques, data analysis ensued upon transcription of the first interview using HyperRESEARCH software to assist with coding and organization of raw data. Coding consisted of two cycles, beginning with descriptive coding and progressing to pattern coding. After all interviews were complete, initial findings were corroborated with 9 participants using a member check form.

Characterization of the Case Study Research Design

Prevalent across the social sciences, the case study is a research design that comprehensively investigates the workings and processes of individuals, groups, organizations, and communities within a specific social and cultural context (George & Bennett, 2005; Miles, et al., 2014; Sandelowski, 2011; Yin, 2009). Case studies are in-depth enquiries, sometimes over an extended period of time, of either a single case or a

relatively small sample of cases that rely heavily and sometimes exclusively on qualitative approaches such as face to face interviews and participant observation, although quantitative approaches such as surveys and questionnaires are also frequently incorporated. The origins of the case study are not clearly demarcated as it a research method that has eclectically integrated elements of grounded theory, phenomenology, ethnography, and narrative analysis (Sandelowski, 2011).

As outlined by Robert Yin in his frequently cited sourcebook *Case Study Research Design and Methods* (2009), case studies can be exploratory, descriptive, or explanatory. Though the boundaries among these overlap, the type of case study undertaken is largely determined by the form of the research question asked and the substance of knowledge to be gained. *Exploratory* case studies address “what”, “who”, “where”, and “how much” research questions that aim to identify what factors and what individuals might impact or predict the manifestation of a phenomenon. Questions of incidence and prevalence can be addressed by exploratory case study designs such as might be used to determine the incidence of work place bullying or the prevalence of health behavior attitudes among a certain population. One outcome of an exploratory case study is a *conceptual framework*, defined by Woods and Ross-Kerr (2011) as a grouping of operationalized concepts or variables that is speculated to be constituent or influential of a phenomenon or a state of affairs. However the relationships among these concepts are unknown or untested. The *descriptive* case study is a research design for investigators asking “how” research questions. “How” questions seek to understand relationships, operational links, and social and psychological processes that unfold within

a case and its context (Yin, 2009). Here, the researcher already has a conceptual framework or preconceptions from the literature about what factors and people might be influential in a case. The task at this point is to better understand the links and relationships among them. One product of a descriptive case study is a *theoretical model*, which is specified by Woods and Ross-Kerr (2011) as a model where a set of concepts have been explored together empirically and have had their relationships explored. “Why” research questions characterize the *explanatory* case study. Researchers in these investigations have a relatively well formed theoretical model before they begin data collection and analysis. Aims in this type of case study include verifying the relationships in the theoretical model and offering causal explanations regarding why processes within a case turn out the way they do.

Although the case study has been commonly used for decades in disciplines such as nursing, anthropology, sociology, education, community planning, and political science, it is a loosely formulated research design with no widely recognized consensus regarding its essential steps or key characteristics (Yin, 2009). However, many published case studies and authors expounding upon its design make reference to several common characteristics. These include: 1) the intensive focus upon a single phenomenon, or case, as it is manifested by a particular sociocultural context, 2) the liberty to use multiple data collection and analysis methods, whether qualitative or quantitative, 3) the use of an a priori conceptual or theoretical framework to guide data collection and analysis, and 4) the co-occurrence of data collection and data analysis. Each of these will be addressed in turn.

The first prominent characteristic of case studies is their concern with and emphasis on the context and setting in which a case occurs. The “case” of a case study is any phenomenon that is uniquely emergent within a specific sociocultural context or setting (Creswell, 2007; Miles, et al., 2014; Sandelowski, 2011; Stake, 1995). It is common for authors (e.g. Creswell, 2007, p. 73) to refer to a case as “bounded” within a system. One might be tempted to believe that a case can transcend its confines and be considered in a way abstracted from its setting or context. This, however, is contrary to the spirit of case study design. Cases and their context are inextricably intertwined. Cases are viewed as products of their environment and at the same time as affecting the makeup, design, and landscape of their setting. Yin (2009) remarks that the boundaries between a phenomenon and its context are often blurred in a case study. Sandelowski (2011) alludes to this context dependency of cases in her distinction between case-oriented analysis and variable-oriented analysis:

“In variable-oriented analyses, the focus is on the variables themselves or on comparing the relationship between variables across cases, whereas in case oriented analyses it is on comparing the configuration of elements that constitute the case as wholes. What may be seen in variable-oriented analyses as contextual factors influencing the operation of variables disaggregated from cases are seen in case-oriented analyses as elements of the cases themselves” (p. 157).

In this vein, a case designates the patterns and regularities occurring in the interplay among *elements* of a specific context. The view that cases are composed of elements

contrasts with the perspective that cases are composed of variables or themes, which again misleadingly signals that cases can be self-contained entities that maintain stability across a variety of different cultures and contexts. Given all this, it might be more precise to say that a case is a configuration of interacting elements that is “interwoven within” as opposed to “bounded by” the web of relations in a sociocultural context. In regards to this research, the case was conceptualized as *surrogate decision making* and the emergent context as *the situation of an adult patient’s dying at end of life in the environment of the intensive care unit*.

The employment of both qualitative and quantitative methods is a second frequently mentioned feature of case study research design as well as its suitability for intervention and instrument development (Creswell, 2007; Miles, et al., 2014; Sandelowski, 2011; Yin, 2009). Some authors such as Yin (2009) argue that the inclusion of both qualitative and quantitative approaches is compulsory for case study design while others (e.g. Creswell, 2007; Miles & Huberman, 1994; Sandelowski, 2011) seem to imply the option but not the strict requirement. Yin (2009) justifies the strict requirement of mixing qualitative and quantitative methods by emphasizing the advantages of methodological triangulation. In methodological triangulation, the investigator collects and analyzes together different types of qualitative and quantitative data about a case. Yin (2009) believes this converging of qualitative and quantitative evidence more fully and accurately characterizes a case, thereby enhancing construct validity.

A third common feature of case study designs is that they test and generate new conceptual and theoretical frameworks (Eisenhardt & Graebner, 2007; George & Bennett, 2005; Miles, et al., 2014; Sandelowski, 2011; Siggelkow, 2007; Yin, 2009). Similar to grounded theory research designs (e.g. Corbin & Strauss, 2008), case studies aim to produce or refine a conceptual or theoretical framework. However, unlike grounded theorists (and ethnographers and phenomenologists for that matter), case study researchers designate an a priori conceptual or theoretical framework *before* the collection of data begins, the concepts of which are altered, enhanced, and augmented based upon the findings of the case(s) (Sandelowski, 2011; Siggelkow, 2007). Reasons cited in the literature for specifying a conceptual or theoretical framework before data collection in a case study include: that it accounts for what is already known in a topical area instead of naively or prematurely claiming that “not much is known” (Siggelkow, 2007), organizes data collection (Yin, 2009), helps determine the selection of participants (Sandelowski, 2011), facilitates data analysis (Miles, et al., 2014; Yin, 2009), and fosters analytic generalization (Yin, 2009). Regarding this last notion, Yin (2009) contrasts analytic generalization with statistical generalization, arguing that case study findings are generalized to the constructs of a theoretical model as opposed to a population of individuals.

A final characteristic of case study design is the simultaneous execution of both data collection and data analysis (Miles, et al., 2014; Sandelowski, 2011; Yin, 2009). Data analysis begins immediately subsequent to the initial collection of data. The researcher starts forming preliminary characterizations of the case under investigation, or

what Sandelowski (2011) calls “casing” the case. As details and the structure of the case become clearer, the researcher is able to further collect data from those individuals and settings that will help further develop understanding of the case. Flyvbjerg (2006) refers to this as information-oriented sampling, which is analogous to the theoretical sampling technique of grounded theory design whereby participants are chosen based on the likelihood that they will be able to contribute to the development of a theoretical model (Corbin & Strauss, 2008). Concurrent data collection and analysis also allows for verification of tentative findings with individuals in the setting of interest (Miles, et al., 2014). Tentative hypotheses and findings concerning the case can be presented to participants in order to elicit their agreements, and disagreements.

Pragmatism as the underlying philosophy of case study research design.

Beyond these four common criteria, the section digresses here in order to speak to the underlying philosophical paradigm of case study research design. A paradigm is the shared worldviews or belief systems of scientific communities regarding the nature of knowledge and existence which guide how researchers approach scientific inquiry. As with the above described common characteristics, there is no explicit uniform agreement regarding what philosophical paradigm one is endorsing as a case study researcher as it has been described as both positivistic and interpretivist (Darke, Shanks, & Broadbent, 1998). However, the following discussion aims to show that pragmatism most aptly characterizes the underlying philosophical paradigm of case study research designs.

Heralded by C. S. Pierce, William James, and John Dewey, pragmatism was an American philosophical movement beginning in the late 19th and early 20th century that

challenged the then popular positivist movement and its verification and correspondence theory of truth (Rorty, 2004). Simply put, this positivist theory maintains that individuals can accurately represent and explain an objectively true reality using language and symbols (Audi, 2003). In contrast, early classical pragmatism contended that statements and concepts about the objective world are not determinable in terms of truth and falsity but that we can have more or less confidence in them to the degree that they have bearing on our practical activities and undertakings. Pierce, James and Dewey all had varying competing interpretations of pragmatism, the debates of which continue to be carried on by current day philosophers. And yet despite the contemporary diversity of positions towards philosophical pragmatism, social scientists influenced by a pragmatist orientation are generally compelled to acknowledge that the primary impetus of scientific knowledge is enabling individuals to act more purposefully and effectively in their life pursuits. This pragmatist disposition is divergent from those more positivistic researchers who believe science should primarily aim to accurately represent an observer- or mind-independent reality.

In the present day context of the social sciences, pragmatism sits alongside other philosophical paradigms prominent in the social sciences including postpositivism, interpretivism or constructivism, and participatory action or feminism. It is also common to see pragmatism called and associated with critical or transcendental realism (Creswell, 2007; Miles, et al., 2014). A helpful way to differentiate pragmatism as a distinct paradigm and to see its connections with the case study research design is to discuss

pragmatism in light of each of the major areas addressed by a scientific paradigm including ontology, epistemology, methodology, and axiology.

Ontology is the study and reflection upon existence, what reality is ultimately made of, and how entities can be said to be similar and different (Audi, 2003). Ontologically, pragmatism postulates that reality has a constitution apart from the human mind but that our ability to know reality in this way apart from our subjective point of view is limited (Creswell & Clark, 2011). Reality is objective but comprehending how to “get at” and represent this objectiveness is ultimately imperfect. For the pragmatist, the only way to evaluate the extent to which the objectivity of reality is attained is by examining the implications a claim or belief about reality has for human actions and what we decide to do with our lives (Rorty, 2004). Although it is recognized as unattainable, ascertaining an “objective” reality is an ideal that pragmatists strive for by trying to account for as many perspectives as possible and by using multiple methods, including both qualitative and quantitative approaches (Creswell & Clark, 2011). And in this way, one can clearly see how the case study’s frequent use of mixed methods reflects this attempt at comprehending many different points of view.

Epistemology addresses the topic of knowledge by questioning what knowledge is, where knowledge comes from, and what the limits of knowledge are (Audi, 2003). Epistemology in social science research design specifically addresses the issue of what the relationship is between the researcher and that which is researched (Creswell & Clark, 2011). The pragmatist acknowledges that there are times when it is and is not possible to distance oneself from the context and phenomenon of study. Judging between these

instances is made by reflecting upon how best to address the research problem of interest. The pragmatist has a “whatever works” attitude in this regard. There may be areas in need of study that require researchers to conduct face to face interviews and others that require anonymous surveys. Sometimes both might be needed. Again, this tendency to use multiple methods correlates with the exercise of case study design and thus, signals the case study’s pragmatic leanings.

Regarding methodology, the issues revolve around what processes and designs of research are valid and legitimate (Creswell & Clark, 2011). In conjunction with case study designs, pragmatist researchers endorse use of multiple methodologies to address a given research question depending on the real-world problem to be solved or question to be answered. Unlike positivist researchers who favor deductive, hypothesis testing approaches and interpretative researchers inclined towards inductive, theory building approaches, pragmatists exercise abductive reasoning. First described by C.S. Peirce (Hookway, 1998), to approach a research question abductively means one starts with a tentative conceptual or theoretical frameworks and hypotheses that make good common sense to be presupposed. These vague frameworks are “best guesses” that are admittedly regarded from the start as likely to be in need of revision and correction. In testing these frameworks inductively, the researcher will likely keep and refine some of its elements and reject others. In this way, the pragmatist amalgamates both deductive and inductive scientific reasoning.

Axiology is the area of philosophy of science that addresses ethical and scientific values. The question for social scientists is what role do values have in the research

process. Creswell and Clark (2007) note that pragmatists countenance both biased and unbiased perspectives in the research process. Pragmatists recognize that all individuals including themselves are constrained to their value-laden, subjective point of view and thus, values are intertwined in all aspects of the research process. And so pragmatists, in concert with case study researchers, encourage both the expression of one's own biases and interpretations and the negotiation of these biases and interpretations with participants. However, pragmatists and case study researchers alike also believe that by gaining as many points of view as possible, both individual and methodological, that there can be a reduction of or at least an accounting for and admittance of biases and values that potentially skew or overly distort a particular phenomenon of interest thereby meeting a certain degree of objectivity. Somewhere between the poles of relativism and absolutism is where the pragmatist rests as does the case study researcher.

Section 2: Sampling and Setting

A purposive sample of 15-25 recent surrogate decision-makers was targeted for study recruitment from the 26-bed ICU at Dartmouth-Hitchcock Medical Center (DHMC). The rationale for this sample size was based on the range of sample sizes needed to reach saturation reported in published cases studies (Teddlie & Tashakkori, 2009). It was anticipated that attaining the targeted sample size was feasible given the number of DHMC ICU deaths per year (in 2011, N=243, Bakitas, personal communication) and the high percentage (76%) of ICU deaths in which a surrogate decision-maker was involved (Curtis, 2005). A total of 19 SDMs enrolled in the study and completed a 1-2 hour, semi-structured, digitally recorded interview at either their

home (N=7), the researcher's DHMC office (N=8), a mutually agreed location of the participant's choosing (N=1), or by telephone (N=3).

Inclusion and Exclusion Criteria

Inclusion criteria included: **1)** self identification as having acted as a primary SDM within approximately the past 2-3 months for an adult patient (>21 years of age) who died in the adult ICU at DHMC; **2)** 21 years of age or older, and **3)** self identification as able to speak and read English. Regarding inclusion criterion 1, it was important that the potential participant identified as a *primary* decision maker. Although groups often do co-decide treatment decisions for decisionally incapacitated patients (Jonsen, 1998), this study sought to describe an *individual's* decision-making psychology and not the *group* decision-making dynamics. The rationale for the general 2-3 month time window was to have individuals recall their decision-making process as accurately as possible, minimizing the effects of recall bias (Addington-Hall & McPherson, 2001), while also respecting the emotional grief state of the individual who just lost a loved one. The patient must also have been 21 years of age or older as the circumstances and relational circumstances surrounding EOL decision making for adolescents and young children are distinct enough to warrant separate research investigations. Finally, qualifying participants must have made decisions for patients in the ICU as a key boundary of this study is EOL decision making in the particular environmental context of the ICU. Regarding inclusion criterion 2, participants must have been 21 years of age or older as it is reasonable to suppose that the developmental differences separating adolescence from adulthood and the specific situation itself would entail significantly

different decision making circumstances and experiences necessitating a separate study. In regards to inclusion criterion 3, individuals unable to speak and read English who had performed as an SDM in an English language dominated health care system would likely have had SDM experiences distinctive enough to merit a separate inquiry.

Exclusion criteria were 1) currently acting as a SDM for an adult patient. This study aimed to capture the process of decision making *at the end-of-life*. Thus the decision-making process necessarily included the circumstances leading up to and including the patient's death.

Section 3: Recruitment Strategy and Protocol

Subsequent to DHMC and Boston College institutional review board (IRB) approval (see Appendix II for IRB approval letters), potential participants were identified and recruited via referral through DHMC's ICU Clinical Resource Coordinators (CRCs) and social workers. The ICU CRCs and social workers coordinate care for patients and work closely with families from the time of hospital admission to discharge. The CRCs and social workers identified decisionally incapacitated patients in the DHMC ICU who were approaching EOL and their family members who were acting as SDMs on their behalf. The CRCs and social workers approached these family members to inform them generally about the study and to ask them if they would be willing for the research investigator to contact them to further inform them about the research study (see Appendix III for recruitment script). If individuals were willing to be contacted by the investigator, the CRC asked for a phone number and mailing address by which the investigator could contact them. The relaying of this contact information served as the

individual's consent to be contacted by the investigator. If an SDM both 1) gave permission to the CRC or social worker to be contacted by the investigator and 2) the person for whom they have made decisions for died in the ICU, he or she was be mailed a letter 14 days after the patient's death. This letter (see Appendix IV) offered condolences, introduced the investigator and the study, included grief support information (see Appendices V), and informed them that the researcher would be contacting them by phone in 6 weeks to further inquire about their interest in participating in the study. The letter also stated that individuals could call or email the investigator at any time to opt out of future contact regarding the study. After 6 weeks from the mailing of the letter, the researcher contacted potential participants by phone to offer condolences, describe the study, inquire about the person's interest in participation, screen for inclusion/exclusion, and set up a time and place for the interview (see Appendix VI for call script). There was a minimum 2 month period between the time of a patient's death and an individual's interview, allowing time for acute bereavement.

Section 4: Data Collection

After signing an informed consent form (see Appendix VII), data collection ensued and included a background and demographic data form (see Appendix VIII) and a semi-structured, face-to-face interview with participants. The data collected via the background and demographic data form included age, gender, race, occupation, educational background, marital status, religious affiliation, relationship to the decedent, and whether the patient had a living will and whether he or she had designated a durable power of attorney for healthcare. The interview guide, shown in Appendix I, was

adapted from CTA interviewing techniques and probes described in Crandall, Klein, and Hoffman (2006) and was further refined with the assistance of the lead author, Ms. Beth Crandall, who was a volunteer consultant for this study. Ms. Crandall and her colleagues developed these interviewing techniques to specifically elicit from individuals how they think and make decisions in real-life situations, thus making this is an optimal interviewing framework for modeling social and psychological processes.

As described by Crandall, Klein, and Hoffman (2006), the CTA semi-structured interview consisted of 3 “sweeps” conducted by the researcher: 1) developing of a timeline of events; 2) deepening; and 3) “What if” queries. Each sweep used different questions and probes to help participants recall how they performed in the SDM role. The first sweep aimed to construct a timeline of the participant’s SDM experience noting the sequence and duration of events, actions, perceptions, and decisions. The task in this sweep was to elicit and verify the overall story in order to ensure that the participant and interviewer were working with a shared understanding of the chronology and details of events. The second sweep, called “deepening”, was guided by the overall question “What is the story behind the story?” Oriented by the timeline from the first sweep, questions in the second sweep were used to understand from the person’s perspective what they knew, how they knew it, and what they did with what they knew. The final sweep posed “What If” queries. Examples include hypotheticals (“If a [key feature] of the situation were altered, what impact would it have had?”) and potential aids (“What information might have been helpful?”).

A notable characteristic of CTA interviewing and descriptive case studies is the dynamic and evolving nature of questioning and probing from interview to interview (Crandall, et al., 2006; Yin, 2009). As initial interviews were completed and initial data analysis performed, subsequent interviews had questions and probes tailored and modified to address and verify the emerging theoretical relationships (for a good example of this in a grounded theory study, see Norton & Bowers, 2001). This was done by modifying and adding questions to the interview that queried about whether or not participants concurred with or had different views of what other SDMs identified as salient in their experiences. For example, one question asked in initial interviews stated, “How were you feeling emotionally during the time leading up to making decisions for the patient?” In later interviews, this question was followed up with the probe, “One of the things I’ve been hearing some participants say is that they experienced some degree of grief in thinking about the impending loss of the patient. What was your experience?” By allowing the interview questions to evolve in this way from participant to participant, it became possible to corroborate some of the findings from initial data analysis, which aided the development of the emerging descriptive theory and relationships between concepts (Miles, et al., 2014; Yin, 2009).

Section 5: Data Analysis

As described by Miles et al. (2014) and consistent with CTA, data analysis was guided by four concurrent processes, including: memoing, data condensation, data display, and conclusion drawing and verification. Data collection and analysis occurred simultaneously. Digitally recorded interviews were transcribed verbatim by a

professional transcriptionist and reviewed for accuracy by the researcher. Transcribed interviews were then converted into a Rich Text Format and entered into the computer assisted qualitative data analysis (CAQDAS) software program, HyperRESEARCH (Version 3.0.2). HyperRESEARCH is a software package enabling users to organize data, code and retrieve, build theories, and conduct analyses of qualitative raw data.

Analysis consisted of four iterative and mutually informing processes: 1) memoing; 2) data condensation using a coding process; 3) data display assisted by the data retrieval features of HyperRESEARCH; and 4) conclusion drawing and verification through member checking. Memos facilitated immersion into the data and were comparable to the researcher's journal entries or blogs. Memo topics included: how the researcher personally related to participants; the study's research questions; coding choices and their operational definitions; emergent codes and patterns; possible relationships between and among concepts; general direction of future interviews and data collection; the emergent theoretical model; and audit meeting notes with the researcher's dissertation committee members and consultant. In addition, a special type of memo called a case summary was composed after analysis of each individual transcript. Based on a format outlined by Miles, Huberman, and Saldana (2014), case summaries synthesized what the researcher learned from each interview including: the main themes and impressions about what happened in each case; explanations, speculations, and hypotheses regarding what happened; alternative explanations about what happened; next steps for data collection such as emendations and additions to the questions in the interviewing protocol; and implications for the current coding scheme.

These case summaries in combination with other memos documented the audit trail to the study's auditors (dissertation committee members and consultants) and illustrated in detail the reasoning and analytic steps taken in data analysis.

The process of data condensation transformed the transcribed interviews into a pithy form through a coding process that facilitated the organization of interview data in a way that was amenable to identifying recurrent patterns and relationships both within and among cases (Miles, et al., 2014). This coding process advanced through two cycles, beginning with descriptive coding (see Saldana, 2013, pp. 87-91) and progressing to pattern coding (see Saldana, 2013, pp. 209-213). In the descriptive coding cycle, a provisional "start list" of descriptive codes (shown in Appendix IX) was used that was based on the functions and processes of the conceptual model of macrocognition described previously in Chapter 2. These descriptive codes identified the general *topic* of what the participant was saying. Second cycle coding ensued after the first five transcripts were analyzed using this descriptive coding. Second cycle pattern codes were generated by the researcher by accounting for key points made in the case summaries and from other memos, salient *in vivo* instances from participant's interviews, and relevant concepts from the technical literature in social psychology. Pattern codes represented the underlying variables or concepts believed to manifest the *substance* of what participants were saying. These pattern codes were continually subject to revision, modification, deletion, and expansion as data analysis of transcripts proceeded. The cataloguing of this process was documented in the case summaries and memo log and reviewed regularly by the study's auditors (dissertation committee members).

The data condensation process described above was facilitated by two primary types of data display, matrices and path diagrams. Matrices were produced that juxtaposed codes next to all instances of raw data that exemplified the concept that the code represented. These matrices helped identify and refine the categories and concepts. Another matrix was constructed that juxtaposed theoretical relationships between concepts next to instances in the raw data where these relationships were salient. This helped identify and refine the theoretical model and conceptual relationships ultimately resulting from data analysis. A network in the form of a path diagram depicted the emerging psychological processes of surrogate decision-making using nodes representing concepts that were connected by lines designating specific kinds of relationships between concepts. Ongoing reflection and reworking of the concepts and relationships in this path diagram aided the researcher in apprehending the overall picture of the decision making process.

Tentative and finalized conclusions were drawn once common regularities and patterns, process flows, and associations among concepts emerged across participant cases. Aided by the matrices and path diagrams, key psychological concepts and processes were identified and empirically supported by participants' raw data. The verification process consisted of member checking. Upon signing the informed consent, participants had the option of receiving a member check feedback form (see Appendix X) in the mail. This form prompted participants to offer their impressions, agreements and disagreements on the tentative findings written in easy to understand terms of the psychological concepts and their relationships exemplifying the psychological processes

of SDMs. Member check forms accompanied by a cover letter (see Appendix XI) were mailed in July, 2013 to 17 participants. Nine member check forms were returned and Appendix X includes the responses from all nine SDMs who returned the feedback form.

The above four processes were employed concurrently throughout data collection and analysis until no new concepts and theoretical relations emerged from cases. After consultation with the audit (dissertation) committee, unanimous consensus was reached that data saturation had been met after 17 interviews. The interview phase was concluded after two additional interviews were conducted wherein no new concepts and theoretical relations emerged. The final report addressing the specific research aims of this study consisted of a path diagram diagrammatically depicting the decision-making process of SDMs and a rich description of the key psychological concepts and theoretical relationships characterizing how SDMs make decisions for decisionally incapacitated adults at EOL in the ICU.

Section 6: Measures to Establish Qualitative Rigor

A number of measures were undertaken to address the validity, consistency, applicability, and truth value of this study's findings. The four evaluative criteria of Lincoln and Guba (1985) including credibility, transferability, dependability, and confirmability were accounted for in this study's design. Each of these criteria along with measures used to address them is discussed in turn.

As described by Lincoln and Guba (1985), four techniques were used to establish the credibility of this study: peer and expert panel debriefing, negative case analysis, referential adequacy, and member checking. Peer and expert panel debriefing began in

the early developmental stages of this study's design and was conducted through data collection and analysis on a regular basis every 2 to 4 weeks with members of the researcher's dissertation committee and other clinician experts (e.g. nurses, advanced practice nurses, social workers, physicians, chaplains). These debriefings made explicit the researcher's biases and perspectives concerning surrogate decision-making for adults at EOL and gave the researcher an opportunity to discuss and defend the emergent concepts and theoretical relations in order to see if they seemed plausible to disinterested peers. Negative case analyses were undertaken in all participant cases and documented in all case summaries. Evidence was searched for and assessed that diverged from emergent patterns and explanations, thereby helping to refine, broaden, and corroborate concepts and the character of theoretical relationships. To facilitate referential adequacy, comprehensive definitions of all codes was kept in HyperRESEARCH and regularly referred to during encoding of the raw data. Matrices as described above were also created which documented all instances in the raw data of a concept or theoretical relation being manifest. Finally, member checking as discussed above was used to support the credibility of this study's findings.

Transferability in this study was met by incorporating "thick" description into the final report of this study's findings. Key concepts and theoretical relationships have been represented diagrammatically in a path diagram, described in written detail, and exemplified with excerpts of raw data in such a way as to allow potential appliers of the findings to make judgments about whether or not the study has implications for their particular situation and context.

Concerning dependability, an external audit committee consisting of the researcher's dissertation committee members and an external CTA consultant were consulted or convened every 2 to 4 weeks throughout the entire data collection and analysis process. Audit meetings were documented in the researcher's memos. Three of the auditors were qualitative methods experts (Drs. Danny Willis and Marie Bakitas and Ms. Beth Crandall), including a premier CTA expert (Ms. Beth Crandall). Two were content experts in the areas of decision-making, ethics, and end of life (Drs. Pamela Grace and Marie Bakitas). These auditors were 'external' to the extent that they took no part in data collection and analysis and were permitted access to all interview recordings, transcripts, memos, case summaries, and all other study materials. They critically examined the data collection and analysis process, the tentative findings, and whether or not there was adequate data to support the researcher's final report and interpretations.

The fourth and final criterion of confirmability aimed to keep in check any biases introduced by the researcher that might distort the findings. Described just previously, auditing was one strategy that was employed to help meet this aim. Reflexivity was another whereby my personal experiences, assumptions, values, and biases concerning surrogate decision making were documented in Chapter 2 and in memos. Finally an audit trail that catalogued each step of the research process from beginning to end was maintained in the form of the researcher's memos and case summaries and which was made available to auditors at regular intervals and upon request.

Section 7: Protection of Human Subjects

The research outline, recruitment protocol, informed consent form, consent process, interview guide, and background and demographic data form were all approved by the institutional review boards (IRBs) of both Boston College and Dartmouth-Hitchcock Medical Center (DHMC). Study procedures were adherent to all measures aimed at protecting participants and their confidentiality. All data were kept confidential and protected in locked cabinets or password protected computer files.

Materials obtained from participants included 1) a demographic data form; 2) a digitally recorded interview that was transcribed into written form; 3) a signed informed consent, and 4) nine participants completed and returned a member check form. With the exception of the informed consent, all of these materials were de-identified and ascribed a code. A codebook linking the participant's name with his or her designated code was privy exclusively to the researcher. The demographic and background data forms, digitally recorded and transcribed interviews, and completed member check forms were shared exclusively with the researcher's audit committee including the dissertation chair, Dr. Pamela Grace, Dr. Danny Willis (dissertation committee member), Dr. Marie Bakitas (dissertation committee member) and Ms. Beth Crandall (consultant).

At the time of the interview, an IRB approved informed consent form (Appendix VII) was presented to participants. Participants had the opportunity to read this informed consent form and ask questions. The consent form stated: the purpose and design of the research study, the potential risks, the amount of remuneration (given whether or not the participant completes the interview), how the data would be kept confidential and

anonymous, and the plans for using the results of the study. It also emphasized to the participant that he or she may at any time stop the interview for any reason and completely withdraw from the study. Questions that participants had were also addressed at this time. Willing participants then signed and dated the informed consent form and were given a copy to keep. He or she was then asked to fill out the demographic and background data form. The interview then began and the digital voice recorder activated. At the conclusion of the interview, participants were debriefed, thanked, and remunerated with a \$30 Visa gift card as a token of appreciation for their time and involvement in the interview.

Though several participants did cry at times during the interview, none of the participants became distressed to the point of needing to discontinue the interview. Participants were asked how the interview experience was for them and responses ranged from “fine” to “great” to “therapeutic”. Many reported feeling good about participating because it could contribute to helping others in the future.

Included in the 2 week mailing and given out again at the conclusion of the interview, all participants were given the grief support brochure entitled *There is no Wrong or Right Way to Grieve a Loss* (2005) published by Caring Connections (see Appendix V). Caring Connections is a program of the National Hospice and Palliative Care Organization whose mandate is offer education and resources to patients and families regarding end of life care. The brochure outlines the grieving process and details strategies to help cope with the experience of loss. Also included in this brochure is the web address to the Caring Connections online homepage and a telephone hotline that

individuals may call to speak with a staff member of Caring Connections in order to ask questions about end-of-life issues and to receive free consumer brochures and contact information for local community services. Included with the Caring Connections brochure, participants were also given a list of local and online grief and bereavement resources (also included in Appendix V) put together by the researcher in consultation with the palliative care service at DHMC.

Chapter 4

Results

This chapter presents the findings resulting from the research methods described in the previous chapter. First, the participants' demographic and background information are presented. Second and meeting Aim 1 of this study, the 27 psychological processes representing the hypothesized theoretical links amongst 20 individual psychological concepts emerging from data analysis are initially introduced and defined. Meeting Aim 2 of this study, the PREDICAMENTS (**P**psychology, **R**easoning, and **E**thics **D**emonstrated **I**n **C**hoices about the **A**ceptability of **M**edical Treatments and Patient Conditions **E**ncountered in Life **T**hreatening **S**ituations) model of surrogate decision-making is then introduced. The model in conjunction with its constituent psychological concepts and processes are then fully elucidated in succeeding sections. The chapter concludes with an overview of the responses to the member check forms and a brief summary of the findings.

Sample

The sample consisted of 19 participants who served as primary surrogate decision-makers for 19 adult patients who died in the ICU. The average time to completion of the interview and data collection process for the 19 participants was 70.3 days after the death of the patient for whom they made decisions. Nine completed and returned member check forms. Mean age of SDMs was 59 ± 11 years, 53% (n=10) were female, 100% (n=19) were white, 53% (n=10) were widowed, and 36% (n=7) had a college education or higher (Table 4.1). The sample represented a diverse range of

religious affiliation: 32% were Protestant (n=6); 21% were Catholic (n=4); 5% (n=1) were Buddhist; 10% (n=2) were “Other”; and 32% (n=6) had no religious affiliation (Table 4.1). Just over half of decedents were the SDM’s spouse (53%, n=10) while another 32% (n=6) were the SDMs’ parents.

Characteristic	Value
Surrogates (n=19)	
Age, <i>mean (SD), yr</i>	59 (11)
Female, <i>n (%)</i>	10 (52.6)
Race, <i>n (%)</i>	
White	19 (100)
Marital Status, <i>n (%)</i>	
Married	4 (21)
Living with a partner	3 (15.7)
Separated or divorced	2 (10.5)
Widowed	10 (52.6)
Education, <i>n (%)</i>	
Grammar school	1 (5)
Some high school	2 (10.5)
High school graduate	5 (26.3)
Vocational or technical school (2 year)	1 (5)
Some college	3 (15.8)
College graduate (4 year)	4 (21.1)
Masters degree (MS)	2 (10.5)
Professional degree (MD, JD, etc)	1 (5)
Religious affiliation, <i>n (%)</i>	
Protestant	6 (32)
Catholic	4 (21)
Buddhist	1 (5)
Other	2 (10)
No religious affiliation	6 (32)
Relationship (The patient was a...), <i>n (%)</i>	
Spouse	10 (52.6)
Parent	6 (31.6)
Sibling	1 (5.3)
Friend	1 (5.3)
Cousin	1 (5.3)

Table 4.2 shows demographic and background characteristics of the decedents for whom SDMs made decisions. SDMs made decisions for 19 adult patients. Decedents had a mean age of 67 ± 12.9 years, 47% were female ($n=9$), and 100% ($n=19$) were white. Just over half, or 58% ($n=11$) of SDMs reported that patients had designated a durable power of attorney for healthcare and the same number reported that patients had completed a living will.

Table 4.2 Demographic and Background Characteristics of Decedents	
Variable	Raw Value (%)
Decedents ($n=19$)	
Patient age, <i>mean [SD], yr</i>	67 [12.9]
Female patients, <i>n (%)</i>	9 (47)
Patient Race, <i>n (%)</i>	
White	19 (100)
Patient designated a DPOAH, <i>n (%)</i>	11 (58)
Patient has a living will, <i>n (%)</i>	11 (58)

The Psychological Processes of Surrogate Decision-Making and their Depiction in the Emergent PREDICAMENTS Path Model

Meeting Aim 1 of the study, 27 psychological processes representing the hypothesized theoretical links amongst 20 identified individual psychological concepts were derived from the data. The 20 individual psychological concepts are listed and defined in Table 4.3 in alphabetical order and grouped by psychological category (to be defined and explained in subsequent section). Further elaboration upon these concepts and their derivation from analysis of participant data is given in subsequent subsections.

Table 4.3 Individual Psychological Concepts Grouped by Psychological Category	
Gist Impressions	
Acceptability of medical treatment/patient condition	An internal judgment about the acceptability of some current or proposed medical treatment and/or the current or projected physical condition of the patient.
Availability of untried medical options	The perception that there were medical tests, interventions, and/or therapies that have yet to be attempted that potentially could be.
Comprehension of the medical situation	The clarity of understanding regarding the patient's medical condition and treatment regimen.
Dehumanization	The perception of how agentic and sentient the patient appeared to be.
Family consensus	The perceived agreement amongst family members concerning the acceptability of a current or proposed medical treatment or the current or projected physical condition of the patient.
Likelihood of recovery	The perceived probability that the patient would or would not return to some satisfactory state of health or wellbeing.
Patient instruction	The clarity and utility of some form of previous or current instruction from the patient.
Rebound propensity	The perception that a patient has an innate disposition or ability to recover from life threatening circumstances.
Sensory vividness of patient	The degree of clarity in one's mind concerning the physical appearance of the patient.
Service quality	The perception of the overall professional performance of the health care team.
Moral Heuristics	
Don't-do-what-the-person-would-not-have-wanted	The degree of moral obligation felt towards advocating against medical interventions and/or health states that the patient would not have wanted.
Don't-inflict-harm-if-there's-no-benefit	The degree of moral obligation felt towards not harming the patient if the likelihood of future benefit is low or nonexistent.
Don't-keep-a-person-alive-with-machines	The degree of moral obligation felt towards not sustaining a patient's life solely by artificial means.
Do-X-if-there-is-a-chance-for-success	The degree of moral obligation felt towards advocating for some current or proposed medical treatment, X, if there is some likelihood, however small, that it could bring about a positive outcome.
Meet-the-needs-of-family	The degree of moral obligation felt towards addressing the distress or wishes of family members.
Negative Emotions	
Anticipatory grieving	A feeling of sorrow concerning the impending loss of the patient.
Empathetic distress	An aversive feeling triggered by the perception that the patient is in pain or is suffering.
Service discontent	The feeling of dissatisfaction towards the perceived service quality of the health care team.
Uncertainty angst	A distressing emotion triggered by a lack of knowledge or clarity regarding aspects of the patient's medical situation.
Decision Behavior	
Expression of acceptance or rejection of medical treatment/patient condition	A communicative act, typically verbal, towards members of the health care team regarding whether or not a medical treatment and/or the patient's physical condition is acceptable.

Table 4.4 contains a list of the 27 psychological processes, or hypothesized theoretical links, that state the conjectured relationships between the individual psychological concepts listed above in Table 4.3. They are listed in the order in which they are addressed in the ensuing sections and are further elaborated upon alongside the individual psychological concepts.

Table 4.4 The Hypothesized Psychological Processes of the PREDICAMENTS Model of Surrogate Decision-Making

- 1) As the acceptability of a medical treatment and/or the state of the patient's physical condition reaches a threshold high or low point, the likelihood increases that an SDM will verbalize this acceptability or unacceptability to the healthcare team.
- 2) The less accepting an SDM is of a medical treatment and/or the patient's condition, the greater chance the SDM will feel that he or she ought to address the distress and wishes of family members.
- 3) The more strongly an SDM believes that he or she ought to meet the grieving needs of family members, the more likely that person is to esteem the importance of gaining family consensus.
- 4) As the perception of family consensus increases, the likelihood increases that the SDM will verbalize acceptance or rejection of a medical treatment and/or the state of the patient's physical condition.
- 5) The stronger an SDM feels that things ought not be done that the patient would not have wanted, the less likely it is that he or she will be accepting of a medical treatment and/or the patient's condition.
- 6) The stronger an SDM believes that harms (i.e. painful medical procedures) should not be inflicted on the patient if there is no long term benefit, the less likely it is that he or she will be accepting of a medical treatment and/or the state of the patient's physical condition.
- 7) The more strongly an SDM believes that the patient should not be kept alive with machines, the less likely he or she will be accepting of medical treatment and/or the patient's health condition.
- 8) The more strongly an SDM believes that some medical treatment *X* ought to be attempted if there is a chance of success, the more likely he or she will be accepting of a medical treatment and/or the state of the patient's physical condition.
- 9) As an SDM's empathetic distress increases, the chance increases that he or she will feel that harm ought not to be inflicted on the patient if there is no long term benefit.
- 10) The more an SDM experiences anticipatory grief, the less likely it is that he or she will be accepting of a medical treatment and/or the patient's health condition.
- 11) As an SDM's comprehension of the patient's medical situation decreases, the likelihood of an SDM experiencing uncertainty angst increases.
- 12) As the clarity and utility of a patient's past or current instructions to the SDM concerning his or her present medical situation decreases, the likelihood increases that an SDM will experience uncertainty angst.
- 13) As uncertainty angst increases, the chance increases that an SDM will perceive there to be other available untried medical options.
- 14) The more strongly an SDM feels service discontent towards the health care staff, the more likely he or she is to perceive there to be other available untried medical options.
- 15) As the clarity and utility of a patient's past or current instructions to the SDM concerning his or her present medical situation increases, the likelihood increases that the SDM will think that things ought not be done that the patient would not have wanted.
- 16) As the likelihood decreases in the SDM's mind that the patient will recover to a satisfactory state of health, the chance increases that the SDM will experience anticipatory grieving.
- 17) As the likelihood decreases in the SDM's mind that the patient will recover to a satisfactory state of health, the likelihood increases that the SDM will think that harm should not be inflicted.
- 18) As the likelihood increases in the SDM's mind that the patient will recover to a satisfactory state of health, the likelihood increases that the SDM will think that some medical intervention *X* ought to be attempted if there is some chance for success.
- 19) As the perception increases that a patient has a high propensity to rebound from life threatening situations, the likelihood increases in the SDM's mind that the patient will recover to a satisfactory state of health.
- 20) As the SDM's perception that the patient lacks agency and sentience (dehumanization) increases, the likelihood decreases in the SDM's mind that the patient will recover to a satisfactory state of health.
- 21) As the SDM's perception that there are other available untried medical options increases, the likelihood increases in the SDM's mind that the patient will recover to a satisfactory state of health.
- 22) As the SDM's perception that there are other available untried medical options increases, the chance increases that he or she will believe that some medical intervention *X* ought to be attempted if there is a chance for success.
- 23) As the sensory vividness of the patient's physical condition increases, the likelihood of the SDM experiencing empathetic distress increases.
- 24) As the sensory vividness of the patient's physical condition increases, the likelihood of the SDM to perceive that the patient lacks agency and sentience (dehumanization) increases.
- 25) As the SDM's narrative comprehension of the patient's medical situation decreases, the more likely the SDM will experience uncertainty angst.
- 26) As the SDM's perception of the service quality of the health care team increases, the more likely that he or she will have a higher narrative comprehension of the patient's medical situation.
- 27) As the SDM's perception of the service quality of the health care team decreases, the more likely that he or she will experience service discontent.

Meeting Aim 2 of study, the PREDICAMENTS Model of Surrogate Decision-Making is composed of the above psychological concepts and processes and is depicted as a path model in Figure 4.1.

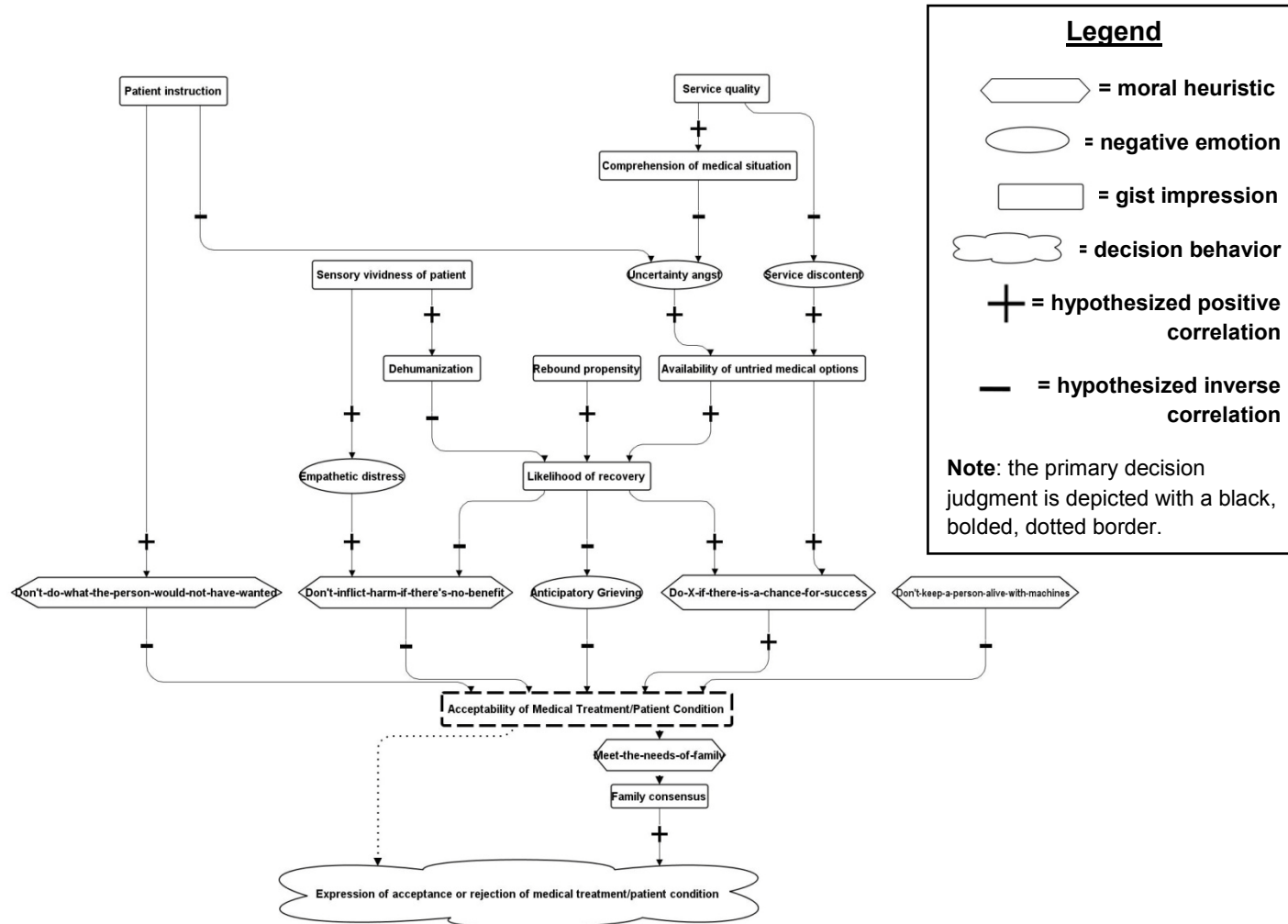


Figure 4.1. The PREDICAMENTS (Psychology, Reasoning and Ethics Demonstrated In Choices about the Acceptability of Medical Treatments and Patient Conditions Encountered in life Threatening Situations) Model of Surrogate Decision-Making, presented in the form of a path diagram. The primary decision judgment, Acceptability of Medical Treatment/Patient Condition, is highlighted with a black, bolded, dotted border. The diagram from top to bottom depicts antecedents moderating consequents.

From top to bottom, the PREDICAMENTS path model depicts antecedent psychological concepts moderating consequent psychological concepts. The arrows connecting these antecedents and consequents represent either hypothesized *correlational* relationships or hypothesized *threshold triggering* relationships. *Correlational* relationships with a negative sign indicate an inverse relationship: as the antecedent increases, the consequent decreases and, vice versa, as the antecedent decreases, the consequent increases. Correlational relationships with a positive sign indicate that as the antecedent increases, the consequent also increases or as the antecedent decreases, the consequent also decreases. *Threshold triggering* relationships are shown with a dotted line and signify that once the antecedent reaches a threshold high or low point, the consequent is then potentially activated. Introduced above, Table 4.4 contains a list of these hypothesized theoretical relationships representing the psychological processes of SDMs. These relationships are further discussed and referred to in subsequent sections.

The following subsections more fully elucidate the PREDICAMENTS Model of Surrogate Decision-Making and its constituent psychological concepts and processes supported by excerpts from the raw data. First, the four major types or *categories* of the 20 psychological concepts are described. Next, the psychological concepts functioning as the primary decision judgment and the primary decision behavior are presented, followed by an account of the moderating role of the psychological concept, family consensus, and its antecedent, meet-the-needs-of-family. Sections then follow which present the remaining psychological concepts grouped by psychological category antecedent to the primary decision judgment.

Major categories of the psychological concepts in the PREDICAMENTS model.

The psychological concepts (see Table 4.3) in the PREDICAMENTS path model are differentiated by four different shapes (refer to Figure 4.1) that correspond to the four major types of psychological categories that emerged from analysis of SDM interviews. The first psychological category (represented by the rectangle) is the *gist impression*. A gist impression is defined as a summative notion or bottom-line understanding of a perceived phenomenon or event. SDMs exhibited a number of notable perceptions and judgments in the decision-making process. These impressions were clearly meaningful and valued and yet typically lacked the precision and premeditation that typifies a more articulated and distinct propositional belief or reflective attitude. In this sense, they have been characterized as *impressions*. Because these impressions were often pithy and lacked detail, nuance, and fine gradation, they can be further qualified as *gist impressions*. SDMs acquired these bottom-line gist impressions from situations and social interactions that in the actual moment were much more complex and detailed.

The second psychological category is the *moral heuristic* (represented by the hexagon). A moral heuristic is a rule of thumb mental short cut that individuals use to make quick judgments about right and wrong when under the pressure of complex situations (Sunstein, 2005). Participants talked about making the “right” decisions and yet none reported explicitly thinking of or applying a particular abstract moral principle (e.g. the substituted judgment or best interest standard) to the situation. Rather, the detection of moral “rightness” and “wrongness” appeared to be arrived at intuitively, that

is they were immediately perceived and strongly felt. These intuitions were motivating in the sense that they prompted SDMs to form other impressions and activate decision behaviors. It was common for there to be an emotional air to these intuitions (e.g. anticipatory regret). Furthermore, these intuitions appeared to operate heuristically, meaning that individuals referred to other information in their present or past experience that they then substituted for the target attribute of “rightness” and “wrongness” in the current situation. Given the intuitive nature of these moral heuristics, participants varied on the degree to which this process was explicit in their thinking.

The third psychological category is the *negatively valenced emotion* (represented by the oval). Negatively valenced emotions are distinct affective states variously alluded to by participants as feelings, moods, and attitudes. These emotions often had an instigating cognitive component (e.g. the thought of someone dying that was very close to them) that oftentimes elicited a marked visceral reaction (e.g. heart pounding, crying, bodily tension, etc). Emotions impacting the SDM decision making process were considered negatively valenced if they had the tendency to trigger individuals to be upset, angry, fearful, avoidant, or sad.

The fourth and final psychological category is the *decision behavior* (represented by the cloud shape). Decision behaviors are those outward actions and communicative expressions triggered by a particular decision judgment that aim to make those judgments actual in a situation. In the PREDICAMENTS model, there is only one decision behavior, *expression of acceptance or rejection of medical treatment/patient condition*, which is further discussed below.

As can be noted in Figure 4.1, the model consists of ten gist impressions, four negatively valenced emotions, five moral heuristics, and one primary decision behavior. In the following subsections, each of these concepts characterized by these larger encompassing psychological categories is described along with their hypothesized relationships (listed in Table 4.3). First, I elucidate the gist impression serving as the primary decision judgment, *acceptability of current or proposed medical intervention and/or current or forecasted patient health condition*, and the primary decision behavior, *verbalization of treatment and/or patient health condition acceptability or unacceptability*. Because the relationship between these two concepts was often moderated in participant interviews by the gist impression, *family consensus*, and its antecedent moral heuristic, these concepts are then subsequently presented. Following this, I then delineate the moral heuristics, negatively valenced emotions, and gist impressions that were antecedent to the primary decision judgment while highlighting the psychological processes that bind these concepts.

The primary decision judgment and primary decision behavior.

The primary decision judgment demonstrated in the thought processes of SDMs was the gist impression: *acceptability of a current or proposed medical treatment and/or current or forecasted patient physical condition*. All SDMs reported making an internal judgment regarding the degree to which one or more medical interventions or the general physical condition of the patient was acceptable or unacceptable:

“...It would have just been more procedures that his poor body just didn’t, you know, the result wasn’t going to change anything.” (SDM013)

As the above quote illustrates, these judgments of acceptability were oftentimes targeted at medical treatments, which could be treatments that were either currently in use (e.g. currently infusing intravenous vasopressive medications) or treatments that were offered by the medical team but yet to be initiated (e.g. starting dialysis). In other cases, the target of acceptability was directed at the overall health condition of the patient.

[THE PALLIATIVE CARE PHYSICIAN] said, “Well, if we could restore her life to what it was like before this foot thing, what would that be like?” ... And that one question put it in perspective for me, because to me her life sucked before...the quality of her life was terrible before this all happened, so to restore it to sucky didn't seem like a good plan to me. (SDM030)

These judgments ranged from a medical intervention or patient condition being highly acceptable and thus to be maintained or requested, to being highly unacceptable and thus to be rejected, vetoed, stopped, or withdrawn. This concept emerged as the primary decision judgment in the decision-making process and is antecedent to the primary decision behavior.

The primary decision behavior was *the expression of either acceptance or rejection of a current or proposed medical treatment and/or the current or forecasted patient health condition*. In all cases, SDMs indicated that their decision-making role culminated at the moment or moments when they made verbally explicit to the lead members of the health care team their verdict on the accepting or rejecting of a medical treatment or patient's health condition:

We all in unison said, “No.” ... “We don't want to do that.” (SDM024)

In this example, the participant was voicing the unacceptability of having her husband undergo future cardiopulmonary resuscitation. Other participants expressed disapproval

of having current interventions continue that were already in use, such as mechanical ventilation, continuous renal dialysis, and continuously infusing intravenous blood pressure medications. Several SDMs verbalized their decision in the terms of disapproving of the patient's condition:

*I said, "I don't want him to suffer anymore. He's been through enough."
(SDM008)*

Some SDMs forecasted the future health state of the patient and in cases where this imagined health state was undesirable (e.g. being a "vegetable" and highly dependent in a nursing home), SDMs would communicate this imagined forecast and its unacceptability to the healthcare team.

The primary decision judgment triggered the subsequent primary decision behavior. Once the acceptability of a medical treatment or patient condition reached a threshold high or low level, a verdict or judgment was reached and increased the likelihood that an SDM would enact an expression of the verdict of that judgment (see Table 4.4, psychological process 1). However, as the PREDICAMENTS path model in Figure 4.1 shows, there were often two moderating psychological concepts between the primary decision judgment and primary decision behavior, family consensus and meet-the-needs-of-family.

The moderating role of the moral heuristic, meet-the-needs-of-family, and its consequent gist impression, family consensus.

Most SDMs referred to an obligation they felt to address the grieving needs of family members distressed at the potential loss of the patient, particularly if the person believed that a current or proposed medical treatment and/or the patient's health

condition was highly unacceptable (see Table 4.4, psychological process 2). This moral heuristic emerged as *meet-the-needs-of-grieving-family-members*. SDMs sensitive to this heuristic often hinted at being regretful in the future if certain steps were not taken:

...as the mother and the wife it was very difficult because my daughters weren't ready to accept that he [WAS DYING] ...So that made it difficult for me because I couldn't just say to the docs you know, "Okay, that's fine." You know, "I work in a hospital; I know the drill, so let's just do it." But I had to give my daughters a couple days to come to terms with his condition... it helped the kids see that it wasn't just me pulling the plug on their father, that he really...wasn't going to come back from this trauma. (SDM020)

As this quote illustrates, the anticipatory regret embedded in this moral heuristic appeared to compel individuals to gain some degree of consensus from family members (see Table 4.4, psychological process 3). The perception of family consensus itself became a distinct gist impression for SDMs. A majority talked about the role of agreement amongst other members of the family or close friends regarding the acceptability or unacceptability of a medical treatment or patient health condition:

"...when we had the final meeting to decide about removing life support, we had talked...to everybody prior to that about what course of action to take. So everybody was...informed." (SDM015)

'Family' included anyone who had personal ties to the patient and included close friends and non-married partners. SDMs' impressions of family consensus could be detected by individuals in several ways including explicit verbal endorsement, implied agreeability from non verbal cues (e.g. head nodding), to implied acquiescence (e.g. lack of objection from others), to outright verbal disagreement. It became apparent that as SDMs' perception of family consensus increased or decreased, the likelihood also concurrently increased or decreased that they would enact the primary decision behavior of verbalizing

the verdict concerning medical treatment and/or the patient's condition (Table 4.4, psychological process 4) to the health care team:

...there was not a consensus...about whether or not to do this operation. So I did not want to force my view on them [HIS CHILDREN]. We have to agree here as a family or we're going to do irreparable damage. And so I said to them, "I think we should have this procedure done...and we should give it at least 12 hours to see what happens. Hopefully it will be better, but not any longer than 24." And they said, "Fine." (SDM025)

Moral heuristics antecedent to the primary decision judgment.

The PREDICAMENTS path model in Figure 4.1 depicts four moral heuristics that are immediately antecedent to the primary decision judgment, *acceptability of medical treatment and/or the patient's physical condition*. This section discusses those four moral heuristics and the psychological processes that link them with the primary decision judgment.

The first moral heuristic was *don't-do-what-the-person-would-not-have-wanted*. Nearly all SDMs recounted their disapproval of medical interventions or keeping patients in medical conditions that they knew the person would not want based on some form of previously expressed instruction from the patient. Reference was made in some cases to this being a kind of pact that they were entrusted with by the patient in making decisions on their behalf:

...I basically had to make decisions based on what he had said he would want. Regardless of what my ethical or moral thoughts were on the subject. I had to do what he wanted and I was basically fulfilling what he had expressed to me over the years. (SDM020)

It was also common across many cases that SDMs framed their thinking in a way that expressed what the patient would *not* want as opposed to what they *would* want, as the following quote makes obvious:

“...they asked me, “What do you think Mom would want?” I said, “I don’t know what she would want, but I can tell you what she does not want. .. She did not want to be in an institution.” (SDM025)

This quote also exemplifies the psychological process stating that the stronger an SDM feels that things ought not be done that the patient would not have wanted, the less likely it is that he or she will be accepting of a medical treatment and/or the patient’s condition (Table 4.4, psychological process 5).

The second moral heuristic impacting the primary decision judgment was *don’t-inflict-harm-if-there’s-no-benefit*. Many SDMs reported thinking that keeping someone in an undesirable (e.g. painful, comatose) state was wrong when it was no longer thought that the circumstances of the patient were temporary but rather indefinite and that reaching a future desirable quality of life was unlikely:

...it was cruel to keep going on. It just seemed really cruel...He was never going to get better. (SDM022)

As this quote and other cases suggested, the more strongly SDMs believed that harm should not be inflicted on the patient without the possibility of long term benefit, the less likely he or she would be accepting of a medical treatment and/or the patient’s health condition (Table 4.4, psychological process 6).

The third moral heuristic was *do-X-if-there-is-a-chance-for-success*. Several participants expressed that if there was some likelihood, however small, that if some

treatment X could bring about a positive outcome, then that treatment ought to be attempted or continued:

...if there was a chance for him to live, he wanted everything done to do that... (SDM008)

SDMs often used words like ‘miracle’ and ‘hope’ to explain their thinking:

I always thought there was a chance. Maybe there was a miracle. (SDM002)

The stronger SDMs felt that some medical treatment, X , ought to be attempted if there was a chance of success, the more likely he or she was accepting of a medical treatment and/or the patient’s condition (Table 4.4, psychological process 8).

The fourth and final moral heuristic SDMs expressed was *don’t-keep-a-person-alive-with-machines*:

“I told them they could do whatever so long as it didn’t entail putting her on the machines...” (SDM014)

Several SDMs recounted rationalizing at the time of their experience that if a person’s life is being sustained solely by artificial means, then the right thing to do was to not initiate any additional treatments or stop any current life-sustaining treatments.

Participants appeared to associate the indefinite use of machines to sustain a patient’s life with becoming a “vegetable”. The artificial means were frequently referred to in a general way as “machines” and included such things as mechanical ventilators, dialysis machines, feeding tubes, and continuous IV medications. Hence the above quotes also illustrate that the more strongly an SDM believed that a patient ought not to be kept alive with machines, the less likely he or she would be accepting of a medical treatment and/or patient’s condition (Table 4.3, psychological process 7).

Negatively valenced emotions antecedent to the primary decision judgment.

Four negatively valenced emotions were antecedent in the various pathways that lead to the primary decision judgment in the PREDICAMENTS path model (refer to Figure 4.1). This section presents those four emotions from left to right in the path model and the character of the psychological processes they are hypothesized to have with adjoining moral heuristics and gist impressions. Note that several gist impressions will be referred to that are not fully explained until the next section.

The first negative emotion talked about by a number of SDMs was *empathic distress*. This was an aversive feeling prompted by their perception of patients being in pain or suffering:

...they took my husband to do another CAT Scan... When he came back he was in agony. ... I freaked out, totally lost it. (SDM022)

In some cases, the distress appeared vicarious to the extent that the feeling fluctuated in intensity based on the degree to which patient was perceived to be acutely having discomfort. This distress could also be brought on by imagining how the patient would experience future painful experiences or suffering and furthermore this distress could be brought on by perceptions of suffering in distinction from acute pain:

...would it bother her if I changed her diaper?...I mean I would have a hard time doing it, but would it embarrass her if I did it? ...it would bother her if she was aware...Insulting her abilities or what have you. (SDM002)

In this sense, patients were not necessarily experiencing bodily pain but were perceived by SDMs to have a strong negative appraisal and emotional reaction towards his or her

physical condition. Several SDMs suggested that this empathetic distress might trigger the moral heuristic, *don't-inflict-harm-if-there's-no-benefit*:

And I didn't want him to go through any more. He'd already been through enough. (SDM008)

The resultant hypothesized psychological process is that as an SDM's empathetic distress increases, the more likely he or she will be to feel that harm ought not to be inflicted without the possibility of long term benefit (Table 4.4, psychological process 9).

The second negative emotion referred to by nearly all SDMs was *anticipatory grieving*. This manifested as some degree of having had in the past or undergoing at the time of their experience a grief process in response to the impending loss of the patient. The grief manifested emotionally as anxiety, dread, helplessness, hopelessness, sadness, and feeling overwhelmed at the likelihood of the patient's looming death:

I had woken up early, early in the morning and uh, basically just bawled my eyes out. Woke everybody up in the waiting room, but um, I couldn't stop crying. And I did that for a while and I had to recompose myself and continue on until it was over. (SDM020)

SDMs would talk about their awareness that the person was dying, saying good bye and having last moments with the patient, and reflecting with others on what the person was like before serious illness:

...two days before she passed, it were during the day, we were by ourselves, and she opened her eyes wide with a little bit of a smirk on her face and she pointed at me and said very clearly, "I'll be waiting for you." And then she put her hand down. A couple of seconds later her eyes closed and she never woke up again... (SDM002)

Cases highly suggested a potential link between the degree of one's anticipatory grief and the primary decision judgment, wherein if the former was high the surrogate was more

likely to be less accepting of the medical treatment and/or the patient's condition (Table 4.4, psychological process 10):

...I just remember this stab in my heart because ...at that moment...I said, "We have to let him go." (SDM018)

A third key negatively valenced emotion described by a majority of SDMs was *uncertainty angst*. There were periods and moments during their experience when SDMs were unclear about what was happening with the person they were making decisions for:

"...And then the next couple days they were doing like weird x-rays and stuff, but they wouldn't tell me why they were doing the x-rays." (SDM020)

In this case and others, this uncertainty had an affective tone that included a combination of anxiety, worry, and fear of the unknown. As the example above alludes to, uncertainty angst could be triggered by an individual's lack of comprehension regarding the patient's medical situation (Table 4.4, psychological process 11), a gist impression further described in the next section. In these situations, SDM's often sought out or awaited more information or clarification concerning the state of the patient's medical condition:

...the other thing that bothered me was I had asked if they had done an EEG. ...For me I felt like I needed to see the EEG to see if he had any brain activity. (SDM020)

Uncertainty angst was also triggered in several cases by a lack of clarity concerning the patient's past instruction regarding their medical wishes (Table 4.4, psychological process 12):

And I'm like, "He would never talk about it." ... Um, "So what does he want us to do?" I said, "I don't know." (SDM018)

In a number of cases, uncertainty angst also appeared to arouse the notion that there were other medical interventions and courses of action that could be taken to help treat the patient's condition:

So I didn't know really what was happening. ...he made it sound like there was still efforts we could take for S---- to survive. (SDM013)

As this quote demonstrates, as uncertainty angst increases for SDMs, the chance increases that they will perceive there to be other available untried medical options (Table 4.4, psychological process 13), another gist impression that is further discussed in the next section.

The fourth and final negative emotion emerging from analyses of cases was *service discontent*. A number of SDMs reported feeling dissatisfied with the quality of the service provided by the health care team. Sources of dissatisfaction included health professional's being unfriendly, incompetent, insensitive or unresponsive to their needs or the patient's, and failing to communicate clearly, regularly, respectfully, and at a level they could understand:

"...And he said, "Do you want him to live?" And I said, "Of course I want him to live." He said, "Well then you have no choice." And I wanted to smack his face..." (SDM008)

He [EMERGENCY ROOM PHYSICIAN] was...standoffish... this doctor when I would say something "Oh no! That's not true! This, and this, and this stuff." ...So I wasn't that impressed with the ER doctor...I didn't like how he was saying his opinion... (SDM009)

SDM's also reported feeling inconvenienced by the structure of the ICU environment and hospital including for example not knowing where to use the bathroom, patient rooms

being too small or cluttered, and not knowing the procedures of when they could and could not visit in the room with the patient:

The other frustrating thing ... several times they would say, "Oh, you can come back in twenty minutes." So we'd go back in in twenty minutes. ...and then you'd come back in and you'd be there for five minutes and they'd say, "Oh, well now we've got to do something else." And you're thrown out of the room again. And I think that ...they really need a better way of communication than the system they have; which sucked. ...That was probably one of my biggest bugaboos. (SDM020)

As the above quotes illustrate, this discontent ranged from minor annoyance to outrage.

As the service discontent increased in intensity, several cases suggested that SDMs are more likely to form the impression that there are other untried medical options that could be attempted to help provide better care for the patients or for themselves:

... thing that kind of aggravated me... over the weekend nothing happened, on Monday they kept trying to do the colonoscopy, and they tried twice and I said, "For Christ's sake!" You know I understand the definition of crazy is doing the same thing over and over and expecting a different result. You know? You're not going to get the scope up there. So it's obviously pancreatic cancer so why are you dicking around? Let's do something! (SDM007)

Hence, the hypothesized psychological process that was added to the model was that as service discontent increases, the likelihood increases that he or she will perceive there to be other available untried medical options (Table 4.4, psychological process 14).

Gist impressions antecedent to the primary decision judgment.

In the PREDICAMENTS path model (refer to Figure 4.1), eight gist impressions operated in the various pathways that impacted impression formation of the primary decision judgment, *acceptability of medical treatment and/or the patient's health*

condition. This section presents those gist impressions in no particular order and the theoretical linkages that position them within the model.

The first gist impression described by every SDM in their decision-making was labeled *patient instruction*. This was the degree of clarity and/or utility of some form of previous or current instruction from the patient regarding the medical care they wished to receive should they become unable to make the decision for themselves:

“...we had talked about a lot of things surrounding him not surviving...he didn't want to be a vegetable...if he couldn't take a breath on his own and wasn't going to be able to, he didn't want to live.” (SDM013)

Patient instruction could be in the form of a formally written advance directive, a distant past conversation, or recently spoken wishes. As was noted and exemplified in the previous section regarding uncertainty angst, several SDMs exhibited how low instruction clarity from patients resulted in higher levels of this anxiety (Table 4.4, psychological process 12). Several SDMs reported that the individuals had never wanted to talk about death and dying and hence it was difficult to discern what they wanted. In these cases, SDMs inferred the patients' wishes based on past behavior and attitudes towards healthcare more generally. This was the circumstance in one case where the patient resisted talking about his wishes and so the SDM inferred instruction about his medical care based on his past non-adherence to taking medications and resistance to attending doctors' appointments:

...That's kind of how we kind of drew these conclusions because we knew that, “I'm not going in the [THE PHYSICIAN'S OFFICE] arghh!”...he'd get real grumpy and he'd growl and, “I'm not going!” (SDM018)

Unlike the instances where patient instruction was unclear or absent, when patient instructions were more salient, it was more likely that the SDMs would invoke the moral heuristic, *don't-do-what-the-person-would-not-have-wanted* (Table 4.4, psychological process 15):

...I know P-, and I know that several times he had said he would never want to go on paralyzed and unable to do anything for himself. ... "He wouldn't want this." (SDM020)

A second gist impression noted in every SDM case, *likelihood of recovery*, related how probable he or she thought it was that the patient would or would not recover to some satisfactory state of health:

...I said, "I don't think she's got a chance in hell." (SDM004)

For some, 'satisfactory' recovery meant a return of the person's health to a certain desirable quality of life. For example, several SDMs based their level of acceptable recovery on whether or not the person would be able to avoid a daily existence where they would be highly dependent in a nursing home. Other SDMs appeared to base this likelihood on a state of recovery that equated to mere biological survival seemingly disregarding projections of other quality of life aspects, such as future functional ability or cognitive status. No SDMs spoke in terms of precise numeric chances (e.g. 50%, 90%). Rather, participants expressed probability in more subjective binary terms of either believing that the patient would survive or believing that the patient would die:

...I don't think there was any doubt in our minds that he wouldn't survive this in a normal way. (SDM015)

As this quote implies, the less likely an SDM believed that a patient would successfully recover, the more likely they were to be experiencing some degree of anticipatory grief (Table 4.4, psychological process 16). Another example:

...And I wouldn't accept it and even though I knew that she probably wasn't going to make it, I never showed her that...that's why even up to the end I thought she was going to make it and then the reality hit me that she wasn't. (SDM002)

Likelihood of recovery was also antecedent to two moral heuristics. One was *don't-inflict-harm-if-there's-no-benefit*:

...there's...no guarantee that it's[CPR] even going to work." And we just didn't want him smashed up.I felt he'd been through enough suffering. Enough pain, enough suffering. (SDM024)

As this case illustrated, as the SDM's belief that the patient would recovery to a satisfactory state of health decreased, the more likely the SDM believed that harm should not be inflicted (Table 4.4, psychological process 17). The second moral heuristic also preceded by *likelihood of recovery* was *do-X-if-there-is-a-chance-for-success*:

...if...they have a very good chance of coming out of something with a quality of life then yes, I'm all for it... (SDM014)

As the likelihood increased in the SDM's mind that the patient would recovery to a satisfactory state of health, the more likely he or she would think that some medical intervention *X* ought to be attempted if there was some chance for success (Table 4.4, psychological process 18).

As the PREDICAMENTS path model shows (Figure 4.1), three gist impressions contributed to SDM's impressions of the patient's likelihood of recovery. One of these was identified as *rebound propensity*. Some SDMs made reference to an innate

disposition or ability of the patient to recover from very dire and lethal circumstances.

This was sometimes attributed to a patient based on past experiences of he or she recovering from previous situations where they were on “the brink of death”:

...years and years went by...I don't know how he did it. All the things he had against him, but he just kept fighting and kept going and kept on. (SDM018)

Others described it as a more longstanding character trait:

I just figured he'd beat it again...He was a tough old bird. (SDM024)

In these cases, as the perception increased that a patient had a high propensity to rebound from life threatening situations, the more likely the SDM believed that the patient would recover to a satisfactory state of health (Table 4.4, psychological process 19).

The second gist impression impacting the SDM's impression of likelihood of recovery was called *dehumanization*. This term from the social psychology literature (see Haslam, 2006) resonated well with SDMs' descriptions of the degree to which patients appeared sentient, emotionally responsive, communicative, autonomous, and cognitively intact:

She was...becoming less and less aware, more into a coma, deeper, and the only time she moved...was if the pain was great enough to move her body...very little moaning or anything like that. It was mainly like her body twitching, the last couple of days. ... She didn't even know I was there. (SDM002)

Patients who were perceived as highly dehumanized were seen as cold, passive, lacking in depth, emotionally and cognitively inert, and lacking agency. SDMs talked about being emotionally indifferent and detached in these cases, sometimes to the point of completely dissociating the corporeal body of the patient from the individual themselves:

“...he was basically an intubated corpse.” (SDM020)

“...he looked awful. ... He didn't even look like M- anymore. I'm pretty sure he was already gone...” (SDM013)

As the above quotes suggest, the more that SDMs perceived patients to be lacking agency and sentience, the less likely they thought patients would recover (Table 4.4, psychological process 20).

The third gist impression that affected SDMs' impressions of patients' likelihood of recovery was referred to as *availability of untried medical options*. Comments were often made by SDMs regarding whether or not they believed that there were medical tests, interventions, or therapies that had yet to be attempted that potentially could be:

...he ran out of options...He had everything going. When it started heading toward the brain there were no more options left for him. If it hadn't had that, if it hadn't started getting into the central nervous system, I think he would have kept on fighting for her. (SDM004)

As this quote illustrates, SDMs gauged whether everything was being done that could be done to give the patient a chance at survival. These untried medical options were sometimes specific in people's minds (e.g. MRI, dialysis) while at other times these options were more loosely conceived. Regardless, the more an SDM perceived there to be untried options, not only was it more likely that they thought the patient would recover (Table 4.4, psychological process 21), there was also a greater chance that they would be compelled by the moral heuristic, *do-X-if-there-is-a-chance-for-success* (Table 4.4, psychological process 22):

And the pulmonary guy was like, “...his oxygen levels are not doing so great today, and there's several things I can do. ...I was like, “Well, do whatever you have to do.” (SDM013)

Another gist impression antecedent to the primary decision judgment was *sensory vividness of the patient's medical condition*. All SDMs referred in some way to how patients appeared in person to their visceral senses, including sight, touch, smell, and hearing:

She thinks my mother was going to get better...And I'm thinking, "No, she's not." ...Because I see her, you know, I see her right here. My sister don't see her. I see her. (SDM023)

...I come from an animal background where I can tolerate just about anything, but this woman's urine was so horrendous that, you know, I had to leave the room. (SDM030)

It was notable in a few cases how the lack of this sensory information had a major impact on the course of decision-making. In these cases, individuals were shocked at how much their view of the patient's medical condition changed once they were in the physical presence of the patient:

...[MY FAMILY] saw things I didn't see because they were there. ...I think I was in denial when I went up there when they asked me to come. I guess in the back of my mind I knew that but I wasn't admitting it to myself if that's what they wanted me there for. And when it hit me it was a ton of bricks. (SDM018)

This quote demonstrated, as sensory vividness of the patient increased, the likelihood of empathetic distress also increased (Table 4.4, psychological process 23). Additionally, because the cues that triggered SDMs to have a stronger impression of dehumanization were also largely based on what people saw and heard, the psychological process emerged that higher sensory vividness of the patient's condition made it more likely that one perceived the patient to be lacking agency and sentience (Table 4.4, psychological process 24).

A seventh gist impression antecedent to the primary decision judgment, *comprehension of the medical situation*, was defined as the degree to which SDMs understood, processed, and acted on medical information helping them to have a coherent sense of the patient's medical condition. SDMs high on this construct clearly understood why and how it was that the patient got into the health state that they were in. These participants often correctly used medical terms, understood the rationale and purpose of lab tests and diagnostic procedures, and understood the roles and responsibilities of different types of health professionals. This SDM demonstrated high comprehension of the patient's medical situation:

The tumor was so big that it covered her pancreas all across her abdomen and it collapsed her colon. That's why she was constipated...The tumor was wrapped about her artery and it was wrapped around a bunch of nerves that come out of the lumbar spine. It was just inoperable.
(SDM007)

SDMs with a lesser grasp of the patient's medical situation sometimes did not understand that the medical circumstances of the patient were such that death was imminent, as was the case for this participant:

...see in my mind I'm thinking, "Oh yeah, we'll try this for a couple days and, you know.", but I didn't get it that that was the end of her life...
(SDM030)

In this particular case and in other cases, having a poor understanding of what was going on with the patient often resulted in some degree of uncertainty angst (Table 4.4, psychological process 25).

The eighth and final gist impression antecedent to the primary decision judgment was identified as *service quality*. All SDMs made statements in reference to their

impressions of the professional performance of the health care team, which included physicians, nurses, social workers, care managers, chaplains, emergency responders, and others:

I appreciated that doctor that called me and spent that time to explain things to me, and talk to me. ...[THE ICU RESIDENT] was very professional and kind and patient, so good at what he did. (SDM018)

As is evident from this quote, many SDMs who experienced or perceived there to be high service quality were more likely to have a higher comprehension of the patient's medical situation (Table 4.4, psychological process 26). SDMs also spoke about several different aspects of service quality. One aspect was communication, as the quote above depicts, entailing that SDMs felt their needs and perspectives were listened to and that they were spoken to in a respectful and sensitive manner and in language they were able to understand. SDMs also talked about the responsiveness and accessibility of the healthcare staff and the degree to which they had easy, timely, and reliable access to physicians, nurses, and others:

...I went out to the nurses...said I wanted a priest for my wife's last rites. And I want him here and now cause we're getting her off [THE VENTILATOR]. The nurse never questioned. So they rounded up a priest...he went in and did a beautiful job of giving her last rites. (SDM004)

Another aspect of service quality SDMs mentioned was the healthcare team's trustworthiness and sincerity in having the patient's and their own best interests as a prime concern:

...I was certainly made comfortable. I was offered coffee...one of the interns had come in and he said, "Would you like me to go and get you something for lunch?" And I was like, "No, I'm all set. Thank you."

...everybody made sure that they were constantly checking in...they made sure I that I had whatever I needed (SDM014)

Lastly, a number of SDMs described service quality in terms of environmental characteristics of the hospital and ICU facilities including such features as cleanliness, spaciousness, orderliness, comfort, and noise level.

The nursing station was just loud...the nurses...they would like all congregate around there and it was just loud. Like laughing and talking and yelling to each other. (SDM022)

As cases clearly demonstrated, the lower one's experience or perception of service quality, the more likely it would trigger the negative valenced emotion *service discontent* (Table 4.4, psychological process 27).

Participant Responses to Member Check Forms

Of 17 member check forms that were mailed, 9 were returned and Appendix X includes the responses from those participants who returned the feedback form. For the majority of psychological processes, responses indicated support for the findings. There were two findings however that appeared to have little to no resonance with the nine responding participants (see Appendix X, responses to items 10 and 18). Common among these 2 items was the gist impression, *availability of untried medical options*. Further discussion of this observation will be made in Chapter 5.

Summary

In summary, qualitative analysis of interview data from 19 participants addressed the two specific aims of this study: 1) to identify and describe the psychological processes of individuals recently acting as a primary SDM for an adult at EOL in the ICU and 2) to develop a theoretical model of the psychological processes of SDMs.

Interviews yielded rich, thick descriptions of SDMs' decision-making experiences. Meeting Aim 1 of this study, data analysis yielded 27 psychological processes representing the hypothesized theoretical links amongst 20 individual psychological concepts. Meeting Aim 2 of this study, the PREDICAMENTS model (**P**Psychology, **R**Reasoning, and **E**Ethics **D**Demonstrated **I**In **C**Choices about the **A**Acceptability of **M**Medical Treatments and Conditions **E**Encountered in Life **T**hreatening **S**Situations) of surrogate decision-making was constructed from those 27 psychological processes and 20 concepts. The model depicts a complex web of psychological processes wherein SDMs ultimately express acceptance or rejection of medical treatments and/or the patient's condition based on their perception of the acceptability (or lack thereof) towards medical treatments and/or the patient's physical condition. This perception of acceptability is preceded by a number of psychological concepts categorized as moral heuristics, negative emotions, and gist impressions. The relationship between an SDM's perceived acceptability of a medical treatment and/or the patient's physical condition and his or her expressive acts to manifest this verdict to the health care team is moderated by psychological concepts related to family member needs and family consensus.

In the next and final chapter, the results reported above are situated within the greater empirical literature and the implications of the PREDICAMENTS model for research, practice, and ethics are discussed.

Chapter 5

Discussion

Recognizing nursing's obligation to assist patients and families in making optimal health care decisions (American Nurses Association, 2010), the aims of this descriptive multiple case study were to identify and describe the psychological processes of SDMs who had made decisions for adults around EOL in the ICU (Aim 1) and to develop a theoretical model of these processes (Aim 2). Using a CTA interviewing approach, a purposive sample of 19 participants who recently acted in the SDM role for adults who died in the ICU provided rich descriptions of their decision-making experiences.

Analysis of these descriptions resulted in the PREDICAMENTS Model of Surrogate Decision-Making (Figure 4.1) (Aim 2) and 27 constituent psychological processes (Table 4.4) (Aim 1) consisting of 20 individual psychological concepts (Table 4.3). In the PREDICAMENTS model, 4 moral heuristics, 4 negatively valenced emotions, and 8 gist impressions interact to influence an SDM's perception of the acceptability of medical treatment and/or the patient's physical condition. When this perception reaches a threshold high or low point, an SDM is often compelled to attain family consensus before expressing his or her judgment of the acceptability or lack thereof of the patient's medical treatment and/or physical condition to the health care team.

The PREDICAMENTS model is in need of further testing. However, it offers an initial understanding of the psychological processes of surrogate decision-making for adults at EOL in the ICU and attempts to redress the gaps noted in Chapter 3 concerning models of surrogate decision-making identified in the literature. First, the

PREDICAMENTS model is a path model that attempts to relate the complexity of the constructs and their relationships that operate in surrogate decision-making while still retaining the theoretical modeling virtue of parsimony (Fawcett, 2005). Second, the nature of relationships between key constructs is more fully characterized and diagrammatically depicted than in other models. Third, ethical constructs are emphasized in this model along with how they operate in the decision-making process. Fourth, this model was designed to clearly demarcate areas where interventions could be developed and tested as discussed in more depth later. Finally, the PREDICAMENTS model represents a middle range theory that was developed in part from a grander conceptual model of decision-making, namely macrocognition (discussed in Chapter 3).

The remainder of the chapter discusses in more depth the psychological processes (Table 4.4) and concepts (Table 4.3) of the PREDICAMENTS model (Figure 4.1). These processes and concepts are discussed in the same order as presented in the previous chapter and are situated in the context of existing theoretical and empirical literature. Suggestions for future research are addressed concurrently. Following this discussion, implications for nursing practice and health care ethicists are presented. Finally, the limitations of this study are disclosed followed by a summary statement of the chapter.

The Primary Decision Judgment and the Primary Decision Behavior

The primary decision judgment demonstrated by the expressed thoughts of SDMs was the gist impression: *acceptability of a current or proposed medical treatment and/or current or forecasted patient physical condition*. Several existing theoretical models of surrogate decision-making as reviewed in Chapter 3 also identified this psychological

concept or constructs very similar in nature (see Buckey & Abell, 2010; Caron, et al., 2005; Limerick, 2007). However this is the first study of its kind to identify that this primary judgment is not isolated to the current or proposed medical treatment but sometimes also to the overall state of the patient's physical condition. Moreover, the SDM's impression of the patient's physical condition was not limited to current status but sometimes included projections of the patient's physical condition in the future, which is another unique finding of this study. More research is needed to understand this finding in preparation for the development of interventions.

SDMs' primary decision behavior was *the expression of either acceptance or rejection of a current or proposed medical treatment and/or the current or forecasted patient health condition*. Casting the decision judgment and the decision behavior as two discrete concepts is apparent in several SDM decision-making models (Colclough & Young, 2007; Limerick, 2007) For example, in Colclough and Young's (2007) model of surrogate decision-making, they describe the decision-making process as including a decisional phase and an executional phase. Other grander models of decision-making, such as Prochaska's (2008) transtheoretical model of behavior change and Beach and Mitchell's (1987) image theory of decision-making, also demarcate a distinction and yet close relationship between an internal decision-making process and resultant manifested behaviors. In image theory, options are adopted into action by decision makers so long as these options do not surpass a decision-maker's rejection threshold (Beach & Mitchell, 1987). Similarly in the PREDICAMENTS model, as the primary decision judgment

reaches a threshold high or low point, the likelihood increases that an SDM will manifest the primary decision behavior (see Table 4.4, psychological process 1).

Family Consensus and Its Antecedent Moral Heuristic

The gist impression, *family consensus*, and its antecedent moral heuristic, *meet-the-needs-of-family*, appeared in most SDM cases to moderate the relationship between the primary decision judgment and the primary decision behavior. The less accepting an SDM was of a medical treatment and/or the patient's condition, the greater the chance that the SDM would feel that he or she ought to address the distress and wishes of family members (Table 4.4, psychological process 2). Supporting these findings, a number of qualitative studies have reported that SDMs describe an ethical obligation to address the distress or wishes of family members before expressing a decision to the health care team regarding the withdrawing/withholding of life sustaining treatment for patients at EOL (Braun, Beyth, Ford, & McCullough, 2008; Colclough & Young, 2007; Fritsch, Petronio, Helft, & Torke, 2013; Meeker & Jezewski, 2009; Schenker et al., 2012; Wiegand, et al., 2008). A qualitative study of 30 SDMs in the ICU by Schenker et al. (2012) not only identified the need to preserve family wellbeing as a key concern for SDMs, but also found that it often triggered the coping mechanism of sharing decisions with family members. This is consistent with the finding in this study that the more strongly an SDM believed that he or she ought to meet the grieving needs of family members, the more likely that person would esteem the importance of gaining family consensus (Table 4.4, psychological process 3). As the perception increased that there was agreement amongst family members concerning the unacceptability of a medical treatment and/or of a

patient's physical condition, the more likely an SDM would verbalize rejection of a medical treatment and/or the state of the patient's physical condition to the health care team (Table 4.4, psychological process 4). From a psychological standpoint, this finding is not wholly surprising in light of classical psychological experiments that have shown the powerful effect that one's desire for group integration and acceptance can have on that person's choice of action (Asch, 1956; Milgram, 1963).

Moral Heuristics Antecedent to the Primary Decision Judgment

Four moral heuristics were immediately antecedent to the primary decision judgment in the PREDICAMENTS model. The first of these was *don't-do-what-the-person-would-not-have-wanted*. Although other qualitative studies of SDMs have found a similar theme (Meeker & Jezewski, 2009), the findings from this study suggest that this heuristic is almost always expressed as a rejection: SDMs expressed what patients' would *not want* as opposed to what they *would* want. Weighting choices by negative features results in a "rejection" of options in contradistinction to decisions where options are "chosen" based on positive features (Baron, 2008). An SDM may *reject* options on a patient's behalf because the negative features of the situation (e.g. patient's sickly appearance, the patient's unconscious state, perceived pain, etc.) are more salient to the SDM than the beneficial features. In the PREDICAMENTS model, the more strongly an SDM endorses *don't-do-what-the-person-would-not-have-wanted*, the less likely it is that he or she will be accepting of a medical treatment and/or the patient's condition (Table 4.4, psychological process 5). This might reflect an omission bias (Hardman, 2009)

whereby SDMs are more reluctant to endorse a continued or new course of action that risks further harm to the patient or other negative outcomes.

The second moral heuristic that impacted the primary decision judgment was *don't-inflict-harm-if-there's-no-benefit*. SDMs exhibited a moral obligation to not harm or continue harming patients if the likelihood of future benefit was low or negligible. The *do-no-harm* or nonmaleficence heuristic has been recognized and discussed by moral psychologists (Sunstein, 2005), however the instance of the heuristic in this study and situation was unique in that it had the added qualifier about future benefit. Though ultimately intended to be of future benefit to the health of the patient, many medical interventions in the ICU setting are themselves invasive, painful, and unpleasant (e.g. injections, foley catheters, central lines, surgery, etc.) or induce a state of unconsciousness (e.g. sedatives). In the PREDICAMENTS model, the stronger an SDM feels compelled that the harms introduced by these medical interventions should not be inflicted if the patient is unlikely to benefit in the future, the less likely it is that he or she will be accepting of a medical treatment and/or the state of the patient's physical condition (Table 4.4, psychological process 6).

The third moral heuristic was *do-X-if-there-is-a-chance-for-success*. This is the degree of moral obligation felt towards advocating for some current or proposed medical treatment, *X*, if there is some likelihood, however small, that it could bring about a positive outcome, which for SDMs typically meant survival. The high end of this spectrum would appear to echo the technological imperative wherein all attempts at rescue are to be attempted no matter how small the likelihood of benefit (Beauchamp &

Childress, 2009). In the PREDICAMENTS model, the more strongly an SDM believes that some medical treatment X ought to be attempted if there is a chance of success, the more likely he or she will be accepting of a medical treatment and/or the state of the patient's physical condition (Table 4.4, psychological process 8). The *do-X- if-there-is-a-chance-for-success* heuristic is also hypothesized to be highly linked in the model to its antecedent, *likelihood of recovery* (Table 4.4, psychological process 18). Even if this perceived likelihood is low, SDMs may still be triggered by this heuristic. In a study by Zier, et al. (2012) of 80 SDMs where they were asked to interpret a patient's survival probability based on numeric prognostic statements, the authors found that surrogates tended to greatly overestimate statements that conveyed a low risk of survival. The prognostic statement "a 5% chance of survival" was interpreted on average by participants to mean a 20-25% chance of survival. Zier, et al. attributed SDMs' misinterpretation of dire prognostic information to an optimism bias, which may explain some of the mechanism behind this moral heuristic.

The fourth moral heuristic SDMs expressed was *don't-keep-a-person-alive-with-machines*. In the model (Figure 4.1), the more strongly an SDM believes that the patient should not to be kept alive with machines, the less likely he or she will be accepting of medical treatment and/or the patient's health condition (Table 4.4, psychological process 7). Studies looking at preferences documented in advanced directives have found that the majority of individuals do not wish to receive life sustaining treatment in situations where they would be in a permanent vegetative or minimally conscious state (Hawkins, Ditto, Danks, & Smucker, 2005; Yung, Walling, Min, Wenger, & Ganz, 2010). Such strong

aversion to having diminished cognitive capacity could explain why SDMs utilize this heuristic so as to avoid this outcome.

Negatively Valenced Emotions Antecedent to the Primary Decision Judgment

Four negatively valenced emotions were antecedent in the various pathways that lead to the primary decision judgment in the PREDICAMENTS path model (refer to Figure 4.1). The first negative emotion was *empathic distress*, an aversive feeling triggered by the perception that a patient is in pain or suffering. Evidence from psychology supports the occurrence of this phenomenon whereby individuals experience somatosensory discomfort themselves when witnessing the pain of others (Morrison, Tipper, Fenton-Adams, & Bach, 2013; Osborn & Derbyshire, 2010). In the PREDICAMENTS model, as an SDM's empathic distress increases, the chance increases that he or she will feel that harm ought not to be inflicted on the patient if there is no long term benefit (Table 4.4, psychological process 9). This may help to explain findings such as in Pruchno, et al.'s (2006) study of 291 hemodialysis patients and their SDMs where they found that SDM decisions to discontinue dialysis were positively correlated with their perceptions of patients having a negative affect or quality of life. Further testing will be needed to confirm the link between an SDM's distress over the perceived discomfort of the patient and decision-making outcomes.

The second negative emotion identified in this study, *anticipatory grieving*, was a bereavement experience associated with the thought of an impending loss. A number of qualitative studies on surrogate decision-making for adults at EOL have identified and described themes similar in character (Meeker & Jezewski, 2009). The

PREDICAMENTS model hypothesizes that the more an SDM experiences anticipatory grief, the less likely it is that he or she will be accepting of a medical treatment and/or the patient's health condition (Table 4.4, psychological process 10), a link which others have noted (Kacel, Gao, & Prigerson, 2011).

Uncertainty angst, a third negative emotion described by a majority of SDMs, has been noted in several studies of this group (e.g. Braun, Beyth, Ford, & McCullough, 2008; Chambers-Evans & Carnevale, 2005; Hickman, Daly, & Lee, 2011) and is a central concept in naturalistic decision-making (Klein, 1998). Consistent with a recently proposed taxonomy of different triggers of uncertainty (Han, Klein, & Arora, 2011), two key antecedents appeared to elicit this uncertainty in the PREDICAMENTS model: low comprehension of a patient's medical situation (Table 4.4, psychological process 11) and low clarity of a patient's past or current instructions (Table 4.4, psychological process 12). Corroborating the latter, Braun, et al. (2008) conducted focus groups with 44 SDMs and found that much of the burden of decision-making was due to uncertainty regarding the patient's wishes. In the psychology literature, uncertainty has been found to prompt decision avoidance and feelings of vulnerability (Anderson, 2003; Han, et al., 2011). This helps to explain why, in the model, as uncertainty angst increases, the chance increases that an SDM will perceive there to be other available untried medical options (Table 4.4, psychological process 13). Other studies have reported a similar finding, particularly noting that SDMs who are uncertain often search for more information and delay making decisions (Chambers-Evans & Carnevale, 2005; Fritsch, et al., 2013).

The fourth and final negative emotion identified in this study was *service discontent*. A number of reports have described SDM's dissatisfaction with the service quality of the health care team (Abbott, Sago, Breen, Abernethy, & Tulskey, 2001; Meeker & Jezewski, 2009; Radwany, et al., 2009). The impact that service discontent has on the decision-making process itself of SDMs appears less well described in the literature. In the PREDICAMENTS model, the more strongly an SDM feels service discontent towards the health care staff, the more likely he or she is to perceive there to be other available untried medical options (Table 4.4, psychological process 14). This could relate to SDMs believing that more could be done for patient to give them a fair chance at survival. Evidence in psychology suggests that anger, even anger caused by events unrelated to a particular situation, tends to elicit a more critical minded stance from individuals making them more likely to evaluate, criticize, and disbelieve the viewpoints of others (Gino & Schweitzer, 2008; Wiltermuth & Tiedens, 2011). In the context of surrogate decision-making, one might postulate that this kind of anger might trigger SDMs to be critical of information communicated by the health care team and compel them to seek out more information or other options. Further research will be needed to explore this link.

Gist Impressions Antecedent to the Primary Decision Judgment

In the PREDICAMENTS path model (refer to Figure 4.1), eight gist impressions operate in the various pathways preceding the primary decision judgment, *degree of acceptability of medical treatment and/or the patient's health condition*. The first gist impression was *patient instruction*, representing the degree of clarity and/or utility of

some form of previous or current instruction from the patient regarding the medical care they wished to receive or not receive should they become unable to make decisions for themselves. This finding is not surprising given the centrality that patient instructions, whether written in an advance directive or verbal, have to very essence of the surrogate decision-making role. Correlational studies have shown that prior knowledge of patient wishes increases decision making confidence (Buckey & Abell, 2010; Majesko, Hong, Weissfeld, & White, 2012) , however, it is unclear if this increased role confidence is tantamount to abiding by a moral injunction to adhere to patient wishes. Thus, what bears more testing is whether higher clarity and utility of patient instructions lead to SDMs using the *don't-do-what-the-person-would-not-have-wanted* moral heuristic over others (Table 4.4, psychological process 15).

How probable an SDM thought it was that the patient would or would not recover to some satisfactory state of health, or *likelihood of recovery*, was a key concept noted in previous qualitative studies of SDMs (Meeker & Jezewski, 2009) and has been the focus in several studies that have specifically looked at the impact that patient prognosis has on surrogate decision-making (Apatira et al., 2008; Boyd, et al., 2010; Zier et al., 2008; Zier, et al., 2012). In the PREDICAMENTS model, an SDM's impression of the *likelihood of recovery* is antecedent to two of the moral heuristics (previously discussed) and to anticipatory grieving. Resonating with the psychological process that was identified in this study (Table 4.4, psychological process 16), Limerick's (2007) grounded theory study of 17 SDMs also found that surrogates tended to grieve as their perception of the patient's prognosis declined.

Three gist impressions contributed to SDM's impressions of the patient's likelihood of recovery including *rebound propensity*, *dehumanization*, and *availability of untried medical options*. One interesting observation about this group of antecedents is what is absent, specifically physician communicated predictions of survival and mortality. Boyd, et al.'s (2010) mixed methods study of 179 SDMs found that less than 2% reported that their impression of the patient's prognosis was based on physician projections. Rather Boyd, et al. found that SDMs' perceptions of the patient's individual strength of character and will to live did contribute favorably to prognosis. Similarly, a study of 80 SDMs by Zier, et al. (2012) found that SDMs interpretations of prognostic statements were partly influenced by their belief that patients' fortitude would result in better than expected outcomes. These studies corroborate this study's finding of *rebound propensity* and its impact on the SDM's impression of the patient's likelihood of recovery (Table 4.4, psychological process 19). As noted by Zier, et al., this may be explained by a psychological bias called illusory superiority that causes individuals to overestimate their own or others' chances of success.

Dehumanization was another gist impression contributing to SDM's impression of the likelihood of recovery. This is the first study to suggest the specific role played in decision-making by how agentic and sentient patients appeared to be from the perspective of SDMs. Haslam (2006) performed an integrative review of the concept of dehumanization and proposed that one of the main forms of dehumanization was *mechanistic* in character. In mechanistic dehumanization, the person is viewed as inert, lacking emotional depth, cold, rigid, fungible, and lacking agency. Hence, this form of

mechanistic dehumanization would appear to resonate well with what occurred in the minds of SDMs in this study. In the PREDICAMENTS model, as the SDM's perception of a patient's state of dehumanization increases, the less likely the SDM believes that the patient will recover (Table 4.4, psychological process 20). This kind of finding may help to explain findings, such as Gao, et al.'s (2012), whose regression analysis of 221 advanced cancer patient-caregiver dyads found that cognitive impairment was associated with less intensive EOL care. Further research will be needed to further explore the impact of dehumanization on SDMs' decision-making.

The third gist impression affecting SDMs' impressions of patients' likelihood of recovery was *availability of untried medical options*, or the perception that there were medical tests, interventions, and/or therapies that have yet to be attempted that potentially could have been. This finding appears understudied in the SDM population. In delineating his rational-emotional model of decision-avoidance, Anderson (2003) reviews evidence in the psychology literature that suggests that a person's present choices can be influenced by the awareness of alternative future choices that are precluded if certain decisions are made in the present. If a person believes that possible future choices may be superior to the current set of alternatives, then the most regret-minimizing choice is the one that leaves open the possibility of taking advantage of those future alternatives. This helps explain why in the PREDICAMENTS model, as the SDM's perception that there are other available untried medical options increases, the chances increase that he or she will believe that some medical intervention *X* ought to be attempted if there is a chance for success (Table 4.4, psychological process 22). Further testing is needed to

corroborate the relationship between an SDM's perception of the availability of untried medical options and the patient's likelihood of recovery (Table 4.4, psychological process 21).

Of interest is that this gist impression was not endorsed by the nine participants who returned their member check forms. There are two possible explanations for this discrepancy between SDMs' narratives and their lack of endorsement when presented with this finding. First, they may not have understood it as described in the member check form. Second, a growing amount of research in psychology suggests that much of how we act and make decisions occurs below our level of conscious awareness (Kahneman, 2011), which may account for why participants may not have been aware of this factor in their thinking. It may also indicate that this impression is better recognized by individuals as the perception that there have been insufficient efforts put forth to help rescue the patient (and therefore more available untried options). This finding deserves greater exploration in future research.

The sixth gist impression operating in the PREDICAMENTS path model antecedent to the primary decision judgment was the *sensory vividness of the patient's medical condition*. The presence and impact that the physical appearance of the patient has on the SDM experience has been noted in a number of studies (Boyd, et al., 2010; Colclough & Young, 2007; Hansen, Archbold, Stewart, Westfall, & Ganzini, 2005; Meeker & Jezewski, 2009; Wittich, Williams, Bailey, Woodby, & Burgio, 2013). In the PREDICMENTS model, *sensory vividness of the patient's medical condition* is associated with the SDM's impression of *dehumanization* (Table 4.4, psychological

process 24), which in turn relates to the SDM's beliefs about the likelihood of recovery (Table 4.4, psychological process 20). These links are supported by Boyd, et al.'s study in which 64% of SDMs (n=114) used interpretations of the patient's physical appearance to ascertain prognosis. In the PREDICAMENTS model, it is hypothesized that this sensory vividness of the patient's medical condition does moderate *likelihood of recovery* but is mediated by the gist impression *dehumanization*. *Sensory vividness of the patient's medical condition* is also hypothesized by the model to moderate empathetic distress (Table 4.4, psychological process 23). Lending credence to this finding, studies in psychology have found that one of the primary determinants of empathetic detection of another's pain is by the observed person's facial expressions of pain as well as other nonverbal cues (Goubert et al., 2005).

The seventh gist impression antecedent to the primary decision judgment was the SDM's *comprehension of the medical situation*. The importance of the SDM's comprehension of the patient's medical condition including treatment regimens has been noted in a number of studies (Allen, Allen, Hilgeman, & DeCoster, 2008; Radwany, et al., 2009) and reviews on end of life decision making (Hancock et al., 2007; Meeker & Jezewski, 2009; Parker et al., 2007). Given this amount of attention, SDMs' comprehension of the patient's medical situation is an important component of the PREDICAMENTS model. This finding also reflects the concepts of sensemaking, problem detection, and mental simulation and story building in the conceptual model of macrocognition discussed in Chapter 3. In naturalistic decision-making, decision-makers must be able to make sense of and prioritize the key elements of a present situation in

order to build a story of what's happening and why (Klein, 1998). This allows decision-makers to mentally project what different actions will mean for the future (Klein, 1998). The less decision-makers are able to make sense of what is going on in a situation, the more likely they are to experience uncertainty (Klein, 1998). This helps to explain why, in the PREDICAMENTS model, as the SDM's comprehension of the patient's medical situation decreases, their experience of uncertainty angst increases (Table 4.4, psychological process 25).

Representing the eighth and final gist impression in the PREDICAMENTS model antecedent to the primary decision judgment is *service quality*, or an SDM's perception of the overall professional performance of the health care team. This concept was found to consist of a tightly knit group of dimensions including quality and timeliness of health care provider communication, respectfulness and sensitivity, responsiveness and accessibility, trustworthiness and sincerity, health care team competence and thoroughness, and environmental orderliness and salubriousness. The literature on these dimensions and the general concept is vast and well supported (Majesko, et al., 2012; Meeker & Jezewski, 2009; Torke et al., 2012). However, this is the first study to suggest that all of these various and seemingly disparate dimensions of service quality are strongly associated in a decision-maker's mind. This could be explained by psychological biases known as the halo and pitchfork effects whereby people tend to base favorable and unfavorable *overall* views of a person or group based on a single or limited number of positive and negative attributes of that person or group (Baron, 2008). Further testing will be needed to corroborate how *service quality* impact an SDM's

comprehension of the patient's medical situation (Table 4.4, psychological process 26) and the degree to which he or she experiences service discontent (Table 4.4, psychological process 27).

Limitations

There were several limitations in this study. First, the PREDICAMENTS model of surrogate decision-making is based upon qualitative data from a small, purposive sample of SDMs (N=19), which limits generalizability to the population. Larger samples of SDMs will be needed in future quantitative studies to corroborate the psychological concepts and processes proposed by this model.

Second, all 19 participants in the study were white, which was expected given the demographic homogeneity of the Upper Valley of Vermont and New Hampshire. Minority SDMs, particularly African-Americans, do tend to request life-sustaining treatments at a rate higher than that of the general population and are less likely to have completed advance directives (Barnato, Anthony, Skinner, Gallagher, & Fisher, 2009), suggesting that the psychological processes of decision-making may differ by race. However, an Institute of Medicine (2009) report focusing on health literacy and race disparities stated that much of the variability in health outcomes may be better accounted for by differences in health literacy than by differences in race. If this holds true in surrogate decision-making for adults at EOL, then differences in race would likely be mediated in the PREDICAMENTS model by *comprehension of the patient's medical situation*, which resembles the concept of health literacy. Supporting this claim, a study by Allen, et al. (2008) of 81 adults (47% African American, 49% Caucasian) in a two-

group between subjects design found that African-Americans given enhanced information about life-sustaining treatments resulted in less desire for those treatments in hypothetical scenarios. Despite this line of thinking, future testing of the PREDICAMENTS model will need to be done with a more racially heterogeneous sample of SDMs to corroborate this claim.

Third, the data collected to describe SDMs' moment by moment decision-making processes was based on participants' recall of that experience. It has been noted that recollections of past experiences can be highly inaccurate due to the biasing effects of reflection and selective recounting (Baron, 2008). The design of this study attempted to compensate for this limitation by interviewing SDMs as soon as possible after the death of patients; by explicitly prompting participants repeatedly during the interview to describe what actually happened at various time points in their experience; and by using non-judgmental probes and non-leading questions in order to minimize socially desirable responses. In addition, a question on the member check form asked: "During the interview, did you feel able to express your true thoughts and feelings?" Responses unanimously indicated that participants did feel able to talk about what happened in a truthful and open manner. Regardless, the findings should be interpreted in light of this possibility.

Fourth, it is likely that there are other gist impressions, moral heuristics, emotions, and decision behaviors as well as relations among them operating in the decision making processes of this population that are not represented in the PREDICAMENTS model. It should be emphasized that this is a newly proposed model of surrogate decision-making,

making it amenable to revision and emendation as its constructs and associations are studied in future research.

Implications for Nursing Practice

The PREDICAMENTS model suggests a number of implications for nurses who interact with surrogates in the adult ICU. First, nurses and other members of the health care team need to recognize the ethical obligation that many SDMs feel towards meeting the needs and wishes of not just the patients, but other family members. Many SDMs fear having future guilt and regret related to not satisfactorily addressing family needs, concerns, and perspectives (Braun, et al., 2008; Colclough & Young, 2007; Fritsch, et al., 2013; Meeker & Jezewski, 2009; Schenker, et al., 2012; Wiegand, et al., 2008). Hence, SDMs will often be compelled to wait until some degree of family consensus is reached before formally expressing medical decisions to the health care team. This could potentially lengthen the amount of time that a terminally ill patient lingers in an undesirable and potentially harmful condition. To preempt this situation, there are several ways ICU nurses can facilitate the process of building family consensus. First, nurses should assess what SDMs understand their role to be and inquire who among a patient's family and friends would want to be present or made aware of the person's critical condition and the possibility of his or her not surviving (Berger, et al., 2008). Nurses might consider encouraging SDMs to contact these individuals as soon as possible and offer to help assist contacting them. Second, besides asking SDMs how they wish to proceed with making decisions for the patient, nurses should also assist SDMs in asking other family members how they wish to be involved. Third, at the first sign of family

conflict regarding choices about the patient's medical care, nurses should advocate for or request an ethics and/or palliative care consult or other form of mediation to help explore and navigate through disagreements.

A second major way nurses can assist SDMs in the decision-making process is to prompt surrogates to think through and articulate their moral reasoning when weighing choices on behalf of patients. SDMs are likely to be unfamiliar with the formalized ethical principles of expressed wishes, substituted judgment and best interest standards. Rather, they will be using one or more rule of thumb, mental short cuts to adjudicate the best course of action for patients. Because these moral heuristics often operate at an intuitive level, they are highly subject to framing effects (Kahneman, 2011), meaning that SDMs will tend to think of different moral heuristics depending on how questions and information are presented. Given the preeminent importance in nursing of upholding patient preferences, the moral heuristic that nurses should be most focused on triggering SDMs to think about and employ is the *don't-do-what-the-person-would-not-have-wanted* heuristic. Nurses should ask SDMs specifically about what the patients' instructions were that they recall: "Tell me about conversations you've had in the past with _____ regarding his/her wishes." As the PREDICAMENTS model depicts, having SDMs recall what a patients' instructions were may trigger surrogates to consider this heuristic. In addition, nurses should ask SDMs not "What do you think _____ would have wanted in this situation?" but rather "What do you think _____ would *not* have wanted in this situation?" The first question triggers SDMs to think of specific medical treatments, which can be difficult for them to fully

understand, whereas the latter question targets the patient's overall health and physical condition. Surrogates tend to have a much clearer conception of what health state a patient would reject in comparison to what medical treatments a patient would accept.

Third, nurses should anticipate and be prepared to respond to the negative emotions that SDMs can experience. Nurses should help SDMs verbalize and make sense of how they feel: "How are you feeling about _____'s situation and the medical treatment he/she is receiving?" An SDM's response to this question can help nurses assess what elements of the decision-making process are most impacting the SDM's impression of the acceptability of medical treatment and/or the patient's physical condition. In particular, SDMs expressing uncertainty may need the nurse to help them think about what the patient's previously expressed instructions were or may need someone to explain to them what's going on with the patient's medical situation.

Fourth, nurses need to be mindful of the various antecedents that impact an SDM's impression of the patient's likelihood of recovery, given the potential moderating effects this impression has on whether or not an SDM believes a medical treatment or patient condition is acceptable or unacceptable. In light of this, SDMs should be highly encouraged by nurses to be physically present at the patient's bedside (Critchell & Marik, 2007). Being present at the bedside allows SDMs to assess the cognitive status of patients which thereupon impacts their estimation of recovery. Nurses and other health care professionals should also be aware that should the SDM believe there to be other available untried medical options, he or she will mostly likely increase their subjective estimation of the patient's recovery. Thus, medical options should not be presented to

SDMs if they are not medically indicated but are offered rather as an expression of condolence or as a symbolic expression of everything being done. Most SDMs will not be able to discern the difference between medically ineffective and effective treatment options and will thus feel obliged by the *do-X-if-there-is-a-chance-for-success* heuristic so that they feel that they tried everything possible to give patients a chance at recovery (Fritsch, et al., 2013). Nurses should remind surrogates that withholding/withdrawing life-sustaining treatments does not mean that they are responsible for the patients' death but rather that patients' underlying illnesses have simply progressed beyond medicine's ability to cure.

Implications for the Ethics of Surrogate Decision-Making

This study offers insight to the discussion regarding the ethics of surrogate decision-making for adults at EOL in the ICU. In Chapter 1, the central ethical issue was raised regarding whether it was psychologically realistic to obligate SDMs to have perfect or near perfect concordance with patients regarding their medical preferences. SDMs are often inaccurate when predicting patients' wishes (Shalowitz, et al., 2006) thus suggesting that this concordance criterion may not be psychologically realistic and thus ethically unreasonable to demand. Furthermore, the 3-standard hierarchy including the patient's known wishes, the substituted judgment, and the "best interest" standard was held suspect as a sufficient set of principles to guide SDMs in meeting this concordance criterion.

What this study found was that most SDMs do in fact attempt to apply patient's past or current instructions via the *don't-do-want-the-person-would-not-have-wanted*

moral heuristic. This heuristic resonates with the substituted judgment and expressed wishes principles of surrogate decision-making. However, the use of this heuristic does not guarantee that SDMs' and patients' medical choices were actually perfectly concordant despite this being the SDMs' intent. Though most SDMs in this study made reference to this heuristic, a systematic review of studies by Shalowitz, et al. (2006) found that SDMs predicted patients' treatment preferences with only 68% accuracy. This raises the question of what accounts for the over 30% discordance. Part of the explanation this study offers relates to potential confounding effects of the moral heuristic, *meet-the-needs-of-family*, which is a consideration that may not be immediately obvious to individuals in advance care planning who are informing SDMs of their wishes.

This then raises the question: is it ethical for an SDM to consider family members' needs (including their own) when making choices about a patient's medical care? One might argue that this is unethical because it violates patient autonomy by failing to uphold the patient's preferences. However, this position may oversimplify the situation. First, part of the patient's wishes may expressly stipulate that the SDM take into account the perspective of family members. A recent systematic review by Kelly, Rid, and Wendler (2012) of 14 qualitative and 26 quantitative studies of surrogate decision-making found that involving family members in the decision-making process was among the top three goals that individuals expressed with respect to decisions being made on their behalf. Second, patients have been found to express great concern about burdening loved ones with medical decisions to such an extent that they want SDMs to take this factor into consideration when making medical decisions on their behalf (Winter

& Parks, 2012). Third, many individuals tend not to perceive deviations from their wishes as major violations of their autonomy (Fins et al., 2005) and are often willing to give SDMs leeway or margin for error when making decisions on their behalf (Berger, et al., 2008; Kelly, et al., 2012). Taking into account these three considerations, it does not appear to be the case that patient autonomy and concern for family wellbeing are always and necessarily conflicting. Ethicists should urge nurses and other clinicians that ethical dilemmas involving tensions between patient and family needs can be circumvented by addressing these three considerations as early as possible in advance care planning discussions.

Summary Conclusions

Using a descriptive, multiple case study design, this study identified 27 psychological processes representing the hypothesized theoretical links amongst 20 individual psychological concepts that in combination formed the PREDICAMENTS model (**P**psychology, **R**easoning, and **E**thics **D**emonstrated **I**n **C**hoices about the **A**ceptability of **M**edical Treatments and Conditions **E**ncountered in Life **T**hreatening **S**ituations) of Surrogate Decision-Making. This model exhibits significant and previously understudied underlying psychological constructs and relationships operating in the decision-making of SDMs for adults at EOL. This model helps explain why SDMs do not always adhere to patients' wishes and why the decision making experience is burdensome for many. As early as possible, nurses and other members of the health care team should assess and help SDMs verbalize their thought processes, emotions, and ethical concerns and involve other key family stakeholders in the decision-making

process. Further research is needed to test and corroborate the constructs and linkages in this model in order to solidify the groundwork for theory-based decision support interventions. Ethicists need to further consider the role that concern for and involvement of family members has on the normative ethical standards expected of SDMs.

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Appendix I: Interviewing Protocol

Interviewing Protocol: “Generating a Theoretical Model of the Psychological Processes of Surrogate Decision Making at Adult End-of-Life in the Intensive Care Unit”

Introduction:

“Hi [participant’s name]. Thank you so much for meeting with me today. My name is Nick Dionne-Odom and I’m a doctoral student in nursing at Boston College. I am also a critical care unit nurse and I currently work in the cardiac ICU at Dartmouth-Hitchcock Medical Center. For my dissertation research, I am exploring how individuals go about making decisions for others who die in the ICU. These individuals are commonly referred to as proxies or surrogate decision makers. Are these terms you’ve heard before? [If “no” then briefly explain that a surrogate decision maker makes medical decisions for someone who cannot due to illness or medication]

Given that you’ve told me during our initial conversation over the phone that you were recently a surrogate decision maker for someone at the end of their life, I am interviewing you today to get a clearer understanding of your experience. I realize this experience was likely very difficult for you and I once again want to offer my condolences for your loss. The aim is that by talking with individuals like yourself who have recently been in this role, I can get a clearer sense of the situations and dilemmas faced when making these decisions.

It is important that I get as accurate a description as possible of what you thought and experienced. I will do my best to listen and understand what you have gone through. I recognize that many people have found the role of surrogate decision maker to be very difficult and that the loss of someone close to you can be distressing. People can have different experiences and what feels right to one person can be different for another.

I will share what I learn from these interviews with the greater world of nursing and health care. In doing so, I believe we can help nurses and other health care professionals to come up with better ways to support individuals who are faced with the responsibilities of making decision for others who are dying.

I hope to have one to two hours of your time...is that what you expect? What time do you need to finish by?

I will not use any specific names including specific places in reporting what I learn from these interviews, or identify you or anyone you mention in any way.

I have a short form for you to fill out that asks questions about who you are and the situation surrounding your experience. I also have an informed consent form for you to read over and sign before we get started. This will give me permission to interview you. I will give you a copy of the informed consent form to keep.

[When they have finished with the demographic data form and informed consent form...]
As I mentioned when we spoke over the phone, I will be recording the interview; however I will not share this recording with anyone besides individuals who are consulting on my dissertation research. I also want to emphasize that you may stop at any time and for any reason during the interview and I may occasionally check in with you to see if you are okay to continue.

Do you have any questions for me before we start the interview and the recorder is turned on?

OK, let's get started...[Recorder turned on]

I. Background and Warm up Questions [Goal: Build rapport, establish comfortable and unthreatening conversational space, gain general sense of the background story and of the history of the relationship between the participant and the patient] **(5 to 20 minutes)**

To begin, I would just like to hear a little bit about yourself and the situation surrounding your experience.

What do/did you do for a living? How would you describe yourself to someone who doesn't know you?

Tell me a little bit about [patient's name]...how would you describe her/him? How long had you known each other? In general, how would you describe your relationship with this person before s/he became ill?

Did [patient's name] become ill suddenly or was s/he sick for a long time? Were you involved at all in helping [patient's name] manage his or her health before being admitted to the hospital?

[Interviewer will take note of responses on demographic data form regarding advance directives] *Had you ever talked with [patient's name] about dying and what to do in case s/he couldn't make decisions for her/his self? Did s/he have a living will that stated what s/he would want in the event that s/he was dying and couldn't speak for his/herself?*

II. First sweep [Goal: Develop a timeline of events and reach consensus with the participant regarding the details of the incident. Identify the best time point to start getting specific details.] **(20-40 minutes)**

Okay great, thank you for telling me a little bit about yourself. The rest of the interview has three "sweeps" or sets of questions. In the first sweep I will ask you about the general, overall story of your role as a decision-maker without going into too much

detail. In the second sweep, I will ask you questions about the specific details of your experience. And in the third sweep, I will ask you several “what if” questions. These questions get you to think about whether you might have thought or done something differently if some part of your experience had been different.

Does this make sense?

So now, I would like you to give me an overview of your experience as a surrogate decision maker for [patient’s name]. It would help me most here in this first sweep, if you could give me a quick outline of the story of your experience so that I have a sense of what happened from beginning to end. I will be drawing a timeline on paper and taking some notes to help me understand as we go along.

[Construct a timeline on paper as the participant recalls the specific incident]

So, now let me repeat back to you what I have heard you say so far. [Recount the incident] Do I have the sequence and the details of the story right so far?

[Continue detailing the timeline on paper as the participant verifies the details of the story. List key individuals involved in the decisions and note critical points where the participant experienced a major shift in his or her understanding of the situation, particularly when they knew the patient was dying, when they understood they had a role to play as a decision-maker, and what decisions they made and how they expressed them. I will have them see what I am doing and how I am labeling things. I will engage him or her in the task by asking: “Do I have this right? About where on the timeline should we put _____?”]

III. Second sweep [Goal: Discover the story behind the story. At this point, I will know what happened and who did what. In this sweep, participants will be asked what they knew, when they knew it, how did they know it, and what did they do with what they knew. Using the timeline account as a guide, I will proceed segment by segment and learn everything I can about the participant experience particularly centering upon their ICU experience. The probes listed below are examples of generic questions that will be selectively used in this section of the interview. However, so as not to constrain and bound the goal of this sweep, their choice and wording will be tailored to the issues and events identified within each individual interview.] **(30 to 90 minutes)**

Okay great. Now that I have a sense of the overall story and timeline of what happened, we will move on to the second “sweep” where I will be asking you questions about the specific details of your experience.

What was it about the situation at this point that told you what was going on/what was going to happen? What were your overriding concerns at that point? What information

did you use in making this decision/taking this course of action? How and where did you get this information, and from whom? [Information and Situation Assessment]

So at this point, was there anything striking or that “stood out” about what you saw or heard? What was your gut telling you about the situation, at that exact point in time? [Cues]

Did you feel particularly “in sync” or “out of sync” with [a key individual, e.g. the patient, another family member, a nurse, a physician, the “healthcare team”] at this point in the event? What let you know that? What did you think [a key individual] knew or was thinking or was feeling then? What do you think [key individual] was expecting from you at this time? [Interpersonal dynamics and maintaining common ground]

Did you seek guidance at this point? What did that guidance do for you? [Guidance]

How were you feeling emotionally and physically? What or who caused you to feel this way? How did you handle these emotions? How do you think they affected what you thought or what you did? [Affectivity]

Was anything at that time preventing you/helping you to do what you thought was right? [Moral assessment and action]

At this point in the incident, what were your specific goals [or] what were you focusing on? What did you hope/intend to accomplish? What was making it difficult/easy to do that? What was the most important thing to figure out/decide/do, right then? [Goals and priorities]

Did you have sense or a picture in your mind of what was going to happen next/in the future? Was there a point in the situation where you had to reinterpret what was going on, because things weren't what you had originally thought? [Mental modeling]

How did you come to make the decision you made? Did your decision feel right at this point? Was there anything that would have led you to make the decision differently? What kinds of pressure were involved in making this decision? [Decision making]

What other courses of action did you consider? Were other options available to you? How did you choose this action? At the time, why did you reject other options? Was there a principle or rule that you were following in choosing this action/making this decision? [Identifying leverage points]

Were you reminded of any previous experience? What about that previous experience seemed relevant here? Was there any past experience or training that was helpful in this instance? Did you feel prepared to handle this event? [Experience and Analogs]

What did you know 'for sure' and what were you uncertain about at this point? How did you deal with not knowing [unknown data, e.g. whether or not the patient was really dying, how machines in the ICU worked]? [Uncertainty and risk management]

IV. Third sweep [Goal: Pose “What if” queries and gain further insight into the participant’s thinking, reasoning, and action processes. As with the previous sweep, the probes listed below are example questions that will be selectively used in this section of the interview. However, so as not to constrain and bound the goal of this sweep, their choice and wording will be tailored to the issues and events identified within each individual interview.] **(10-30 minutes)**

Okay great. I think you have given me a pretty rich description of your experience. In this third and final sweep, I want to ask you some “what if” questions. As I mentioned before, these questions trigger you to think about what you might have thought or done differently if some part of your experience had been different.

[For any of the info they described in the sections above...]

If [a hypothetical person, e.g. someone with better/worse knowledge of/relationship with the patient, someone older, someone younger, someone with better/worse family relationships] had been in your situation at this particular point in the story, what kinds of things do you think s/he would have struggled with and why? Would they have noticed what you noticed? Would they have known to do X?

If [key feature] of the situation had been different, what impact would it have had on your decision/assessment/actions/plans?

What training/knowledge/information/tools might have offered an advantage in this situation?

Is there anything you wished you would have known or been paying more attention to...in retrospect? What do you think kept you from putting your attention there, what was the barrier?

VI. Closing questions and debriefing

Okay, we have reached the end of the interview guide. Do you feel ready to conclude our conversation or is there anything else you would like to bring up at this time?

How was this interview for you?

Okay, thank you. I am going to stop the recorder now.

VII. Grief Support Information

Before I leave today, I would like to give you a few resources that you might find helpful if you would like to talk to someone about the loss of [patient's name].

The first is a grief support brochure entitled "There is no Wrong or Right Way to Grieve a Loss." This is published by Caring Connections, which is a program of the National Hospice and Palliative Care Organization. This brochure outlines the grieving process and points out some things you can do to help cope with the experience of your loss. Also included in this brochure is the web address to the Caring Connections online homepage and a 24 hour telephone hotline that individuals can call to speak with a staff member of Caring Connections. You can ask questions about the grieving process and receive free consumer brochures. They can also link you with local community services.

The second item I want to give you is a list of grief and bereavement resources put together for this study. One of the first things listed is the contact information for the Bereavement Coordinator of the Visiting Nurse Association and Hospice of Vermont and New Hampshire. This coordinator offers free bereavement services and can also link you with other community services local to this area making it a particularly good resource of the ones listed here.

Do you have any questions about these grief support resources?

Appendix II: DHMC and Boston College IRB Approval Letters

Trustees of Dartmouth College • Dartmouth-Hitchcock Medical Center
COMMITTEE FOR THE PROTECTION OF HUMAN SUBJECTS

Howard Hughes, PhD, Chair CPHS A
 Thomas Ward, MD, Chair CPHS B and D
 Jack van Hoff, MD, Chair CPHS C

63 South Main Street • HB 6254 • Hanover, NH 03755-1404
 Telephone (603) 646-6482 • Fax (603) 646-9141

Date: 09/19/12 **Submission:** Response to Previous IRB Notification

To: JamesN Dionne-Odom **Action:** Response Approval

Department: Nursing **Action Date:** 09/18/12

From: The Committee for the Protection of Human Subjects **Expiration Date:** 09/17/13

CPHS #: 23560 **Review Type:** Expedited Review

Study: Generating a Theoretical Model of the Psychological Processes of Surrogate Decision Making at Adult End-of-Life in the Intensive Care Unit using Cognitive Task Analysis

Comments: Approved:
 - CPHS Study Plan v. 8/7/2012 with attachment: M
 - Main Consent form v. 8/9/12, stamped with CPHS approval date 9/18/2012
 - Grief Support Recruitment letter v. 9/18/2012
 - Other study materials provided for review

+ The PI is a graduate student at Boston College; the IRB at Boston College will also review this study.

The Committee determined future renewals of this study qualify for expedited review under:
 - Category #6: Collection of data from voice, video, digital, or image recordings made for research purposes
 - Category #7: Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies. (NOTE: Some research in this category may be exempt from the HHS regulations for the protection of human subjects. 45 CFR 46.101(b)(2) and (b)(3). This listing refers only to research that is not exempt.)

Notes: + The enrollment of potentially pregnant women in this study is incidental and acceptable.
 - Study participation involves no more than minimal risk

The Committee for the Protection of Human Subjects (CPHS) has reviewed your response to the previous IRB notification regarding the above-referenced study. The CPHS now approves this study and the final versions of the study materials submitted for CPHS review. This approval is based on an appropriate risk/benefit ratio and a study design wherein risks have been minimized.

Please be reminded that informed consent is a process beginning with a description of the research and including an evaluation of comprehension by the researcher. Once the consent form has been signed, each participant should receive a copy. Assessment of each participant's consent by the researcher should continue throughout a research study.

Date Stamped CPHS Consent Form:

The CPHS "date stamps" final approved consent form(s). The stamped approved consent form accompanies this approval letter. Please photocopy and use only the CPHS date stamped consent form for this project.

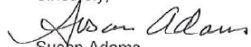
Any revision to previously approved materials must be approved by the CPHS prior to initiation. Please use the Revisions or Addition Review form for this procedure.

Unanticipated problems involving risks to subjects or others as well as certain adverse drug events and medical device effects should be promptly reported to the CPHS. Please refer to the information and forms to make these reports on the CPHS web site at www.Dartmouth.edu/~cphs. In addition, please promptly report to the CPHS office any known instances of noncompliance and complaints made by subjects in connection with this study.

Based on the risks, this project requires Continuing Review by the CPHS on an annual basis.

If you have any questions, please direct them to CPHS.Tasks@Dartmouth.edu.

Sincerely,



Susan Adams
CPHS Director (Designee for Chair, CPHS "A")

cc: Marie Bakitas, DNSc; Pamela Grace



BOSTON COLLEGE
Institutional Review Board
Office for Research Protections
Waul House, 3rd Floor
Phone: (617) 552-4778, fax: (617) 552-0498

IRB Protocol Number: 13.012.01

DATE: October 3, 2012

TO: James Dionne-Odom

CC: Pamela Grace

FROM: Office of Research Protections

RE: Generating a Theoretical Model of the Psychological Processes of Surrogate Decision-Making at Adult End-of-Life in the Intensive Care Unit using Cognitive Task Analysis

Notice of IRB Review and Approval
Full Board Review [Title 45 CFR Part 46.108 (b); 46.109]

The project identified above has been reviewed and approved by the Boston College Institutional Review Board (IRB) for the Protection of Human Subjects in Research. The protocol was reviewed by the fully convened IRB in accordance with HHS regulations requiring the IRB to employ additional criteria when reviewing research that does not qualify for an Expedited Review. The approval is based on the assumption that the materials you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

This approval is given with the following standard conditions:

1. You are approved to conduct this research only during the period of approval cited below;
2. You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
3. You will immediately inform the Office for Research Protections (ORP) of any injuries or adverse research events involving subjects;
4. You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;
5. You will only use the informed consent documents that have the IRB approval dates stamped on them (approved copies enclosed).
6. You will give each research subject a copy of the informed consent document;


7. You may enroll up to 24 participants. You may not enroll more than this number of participants without seeking IRB approval. To do so will be a violation of the conditions of IRB approval and, if federal funding is involved in your project, a matter of non-compliance that we must report to the federal government. This could significantly and negatively impact your research.

Any research personnel that have not completed an acceptable education/training program should be removed from the project until they have completed the training. When they have completed the training, you must submit a Protocol Amendment Form to add their names to the protocol, along with a copy of their education/ training certificate.

Boston College and the Office for Research Protection appreciate your efforts to conduct research in compliance with Boston College Policy and the federal regulations that have been established to ensure the protection of human subjects in research. Thank you for your cooperation and patience with the IRB process.

Approval Period: October 3, 2012 to October 2, 2013

Sincerely,



Stephen Erickson
Director
Office for Research Protections

Enclosures

Confidential

ooc

Appendix III:

Appendix III: CRC/SW Script for Approaching Potential Participants

[CRC/SW WILL HAVE ALREADY ESTABLISHED INITIAL RAPPORT WITH POTENTIAL PARTICIPANTS RELATED TO THEIR NORMAL WORK DUTIES]

CRC/SW: “Mr./Ms. _____, I would like to tell you about a research study that is happening here at DHMC that you may qualify for and might be interested in participating in. The study is about making decisions for patients in the ICU who can’t make decisions for themselves. Could I take a minute to tell you a little bit more about the study?”

[IF INDIVIDUAL RESPONDS YES, THEN...]

CRC/SW: “The study is being conducted by a researcher here at DHMC who is also a nurse. His name is Nick Dionne-Odom and he is a doctoral student in nursing at Boston College. He also works here at Dartmouth in another critical care unit. He is interviewing people about their experiences as decision-makers for patients who have been in our ICU. Would it be okay if I gave him your name, telephone number, and mailing address so he could contact you to tell you more about the details of the study and to see if you might be interested in participating?”

[IF INDIVIDUAL RESPONDS YES, THEN...]

CRC/SW: “Okay great. Could you give me a phone number and mailing address where Nick could contact you?” [GET CONTACT INFO]

CRC/SW: “Thank you for that information. And just to let you know, he is unable to contact everyone who is interested in participating, so there is a chance he will not contact you at all. Thanks again Mr./Ms. _____.”

[IF INDIVIDUAL RESPONDS NO OR IS UNSURE, THEN...]

CRC/SW: “Okay, well thank you for considering it. If you change your mind, just let me know.”

Appendix IV: Sympathy and Grief Support Letter

[DATE]

[INDIVIDUAL'S NAME AND ADDRESS]

Dear Mr./Ms. _____,

My name is Nick Dionne-Odom and I am sending this letter to you today in response to your interest in the research study about making decisions for someone in the intensive care unit.

Firstly and most importantly, I want to let you know how deeply sorry I am to hear about your recent loss. I hope you are managing as best you can in this difficult time.

I also want to thank you for your interest in hearing more about this study. I am a doctoral student in nursing at Boston College and I also work in the cardiovascular critical care unit at Dartmouth-Hitchcock Medical Center. I have been a critical care nurse for 10 years and am interested in understanding people's experiences in making decisions for others around the time of their end of life in the intensive care unit. Having a better understanding of experiences like yours may help us provide better support for others who are faced with making decisions for loved ones who are critically ill.

I will be recruiting between 15 and 25 people to participate in this study. For individuals who choose to participate in the study, I will schedule one or two, face to face, voice recorded interviews with them, focusing on their experiences as a decision-maker. The interviews will be conducted at participants' homes or places of their choosing and should last 1 to 2 hours. Because I want to be very sensitive about individuals' needs to process and mourn their recent losses, interviews are scheduled about 6 weeks from when you receive this letter. At the time of the interview, I will ask participants to read over and sign an informed consent and complete a demographic data form that asks about things like age, educational background, etc. You will also have a chance to ask questions before enrolling.

In about 6 weeks, I will contact you by phone to see if you are interested in participating in the study and to schedule an interview. If you have any questions, please do not hesitate to contact me. My phone and email are listed at the end of this letter. If you do not wish to participate, please just let me know by either phone or email.

I have also included with this letter some information you might find helpful if you feel you would like to talk to someone about your loss or need help coping. The first is a grief support brochure called *There is no Wrong or Right Way to Grieve a Loss*. This is published by Caring Connections, which is a program of the National Hospice and Palliative Care Organization. This brochure outlines the grieving process and points out some things you can do to help cope with the experience of your loss. Also included in this brochure is the web address to the Caring Connections online homepage and a 24 hour telephone hotline that individuals can call to speak with a staff member of Caring Connections. You can ask questions about the grieving process and receive free consumer brochures. They can also connect you with local community services.

The second item is a list of grief and bereavement resources put together with the help of the palliative care team at Dartmouth Hitchcock Medical Center. One of the first items listed is the contact information for the Bereavement Coordinator of the Visiting Nurse Association and Hospice of Vermont and New Hampshire. This coordinator offers free bereavement services and can also link you with other community services local to this area, making it a particularly good resource of the ones listed.

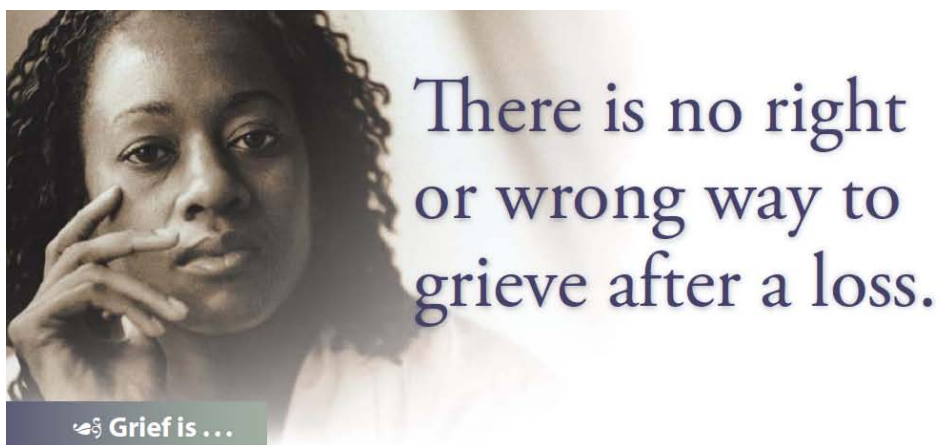
Thank you for your time Mr./Ms. _____ and I look forward to speaking with you in 6 weeks. Again, I offer you my sincerest condolences and wish you everything you need to get through this challenging time.

Sincerely,

A handwritten signature in black ink, appearing to read 'Nick Dionne-Odom', written in a cursive style.

Nick Dionne-Odom, MSN, RN
Doctoral Candidate
William F. Connell School of Nursing
dionneod@bc.edu
(603) 305-8668

Appendix V: Bereavement Flyer and Grief Support Resources



☞ Grief is ...

- The normal response of sorrow and emotions, thoughts and behaviors that follow the loss of someone or something important to you
- A natural part of life
- A typical reaction to death, divorce, illness, job loss, a move away from family and friends or any life-changing experience
- Very personal—it is different for everyone—there is no right or wrong way to grieve

☞ Grief reactions may include ...

- Feeling empty and numb, as if you are in a state of shock
- Physical responses such as nausea, trouble breathing, crying, confusion, lack of energy, dry mouth, or changes in sleeping and eating patterns
- Anger—at a situation, a person or in general
- Guilt about what you did or did not do
- Withdrawal from family, friends and common activities
- Difficulty focusing, working or making decisions
- Questions about faith or spirituality; challenges to the meaning, value and purpose you find in life

☞ Grief lasts ...

- As long as it takes to adjust to the changes in your life after your loss
- For months, or even years. Grief has no timetable; thoughts, emotions, behaviors and other responses may come and go



Caring Connections

a program of the
National Hospice and Palliative Care Organization



Experiencing Grief

It is important to experience all of the thoughts and emotions that come up, as painful as they may be, and to treat yourself with patience and kindness.

Talk about your loss

Take the time to talk to family, friends or a counselor. You can also find support by joining a hospice or community support group. Let them know you need to share your memories and express your sadness.

Forgive yourself

For everything you believe you should have said or done. Also forgive yourself for emotions such as anger, guilt or embarrassment you may feel while grieving.

Eat well and exercise

Grief is exhausting. It is important to maintain a balanced diet and rest. Exercise is also important to keep up your energy. Find a routine that you enjoy – clear your mind and refresh your body.

Indulge yourself

Take naps, read a good book, listen to your favorite music, go to a ball game, rent a movie. Do something that is fun, distracting and that you find comforting.

Prepare for holidays and anniversaries

Many people feel especially “blue” during these periods, and anniversary dates (of important family celebrations, a diagnosis, death) can be especially hard. Even when you have moved forward in your grief, these dates may bring back some painful feelings. Make plans to be with friends and family members with whom you feel comfortable. Plan activities that give you an opportunity to mark these important times.

How will I know when I’m finished grieving?

After a loss, you may be overwhelmed by the grief reactions you are experiencing. In time, you will learn to adjust to living with your loss. Eventually, you will start to draw comfort rather than experience pain from the memories. In a sense, you are never “finished grieving.” With a loss, there will always be moments when you will remember the loss and you may experience moments when your grief is “triggered.”

*There is no right way to grieve. It is an individual process.
Life won't be the same after a loss, but experiencing your grief
will allow you to adjust to life after loss.*

For more information, Contact Caring Connections:
HelpLine 800.658.8898 • Multilingual Line 877.658.8896
www.caringinfo.org • caringinfo@nhpco.org

Grief and Bereavement Resources

Visiting Nurse Association and Hospice of Vermont and New Hampshire

Offering bereavement services, programs and support throughout the Upper Valley. For more information, please call us and ask to speak to the Bereavement Coordinator. Our services are free and open to anyone in the community who is grieving the loss of a loved one.

Lebanon office: (603) 298-8399

Palliative Care Program at Dartmouth-Hitchcock Medical Center

We help those who have experienced the death of someone they love cope with the grief that naturally follows.

Lebanon, NH (DHMC): (603) 650-5402

http://patients.dartmouth-hitchcock.org/palliative_care.html

New Hampshire Hospice and Palliative Care Organization

Website lists numerous books and videos related to bereavement and loss.

<http://www.nhhpco.org/resourcesbooks.htm#m>

Association for Death Education and Counseling

Website lists a compiled set of educational resources for individuals experiencing a death-related loss. The site also offers searchable database of counselors trained to work with the bereaved.

http://www.adec.org/Coping_With_Loss_New_/3469.htm

Hospice Foundation of America

The Hospice Foundation of America provides leadership in the development and application of hospice and its philosophy of care with the goal of enhancing the U.S. health care system and the role of hospice within it. The web link below provides information, videos, and direction for finding support groups related to grief.

<http://www.hospicefoundation.org/grief>

Helpguide.org

In collaboration with Harvard Health Publications, Helpguide.org International is a nonprofit 501(c)(3) charitable organization that offers information, articles, videos, and self-guided toolkits to help individuals cope with grief and loss.

http://helpguide.org/mental/grief_loss.htm

Appendix VI: 6-Week Follow-up Phone Script

Primary investigator: “Mr./Ms. _____, my name is Nick Dionne-Odom and I am calling in response to your interest in the research study about making decisions for someone in the ICU. I sent you a letter in the mail about 6 weeks ago and I had said in the letter that I would call you around this time to see if you were still interested in participating in the study. Is this a good time to speak with you?”

Potential participant: “Yeah, sure.” [IF NO, ASK WHEN A GOOD TIME TO CALL BACK WOULD BE]

Primary investigator: “Firstly, I want to again offer you my condolences for the recent loss of _____. As the letter I sent you mentioned, I am a doctoral student in nursing at Boston College. I also work in the cardiovascular critical care unit at Dartmouth-Hitchcock Medical Center and have been a critical care nurse for 10 years. I am interested in understanding people’s experiences in making decisions for others around the time of their death in the intensive care unit. By having a better understanding of experiences like yours, we may be able to think of better ways to support people who are faced with making decisions for loved ones who are critically ill.

Potential participant: “Um hm.”

Primary Investigator: “I will be recruiting between 15 and 25 people to participate in this study. For individuals who qualify and decide to participate in the study, I will schedule one or two, face to face, digitally recorded interviews with them, focusing on their experiences as a decision-maker. The interviews will be conducted at participants’ homes or places of their choosing and should last 1 to 2 hours. At the time of the interview, I will ask participants to read over and sign an informed consent and complete a demographic data form that asks about things like age, educational background, etc. You will also have a chance to ask us questions before enrolling. At the completion of each interview, participants will be given a \$30 Visa gift card for their time and effort. Does all this make sense? Does this study seem like something you would be interested in if you qualify?”

Potential participant: “Sure, what do I need to do?” [IF NO, THEN THANK THEM FOR TIME AND WISH HIM OR HER AND THEIR FAMILY WELL]

Primary investigator: “In order to ensure that I am enrolling appropriate individuals to meet the purposes of the study, I need to ask you specific questions to see whether or not you qualify. Is this okay?”

Potential participant: “Sure.”

[INCLUSION/EXCLUSION CRITERIA QUESTIONS]

Primary investigator: “Are you 21 years of age or older?”
YES [] OR NO []

Primary investigator: “Did you consider yourself the primary decision maker for a patient who died in the ICU at Dartmouth Hitchcock Medical Center?”
YES [] OR NO []

Primary investigator: “Are you currently a health professional or have you ever been employed as such?”

YES [] OR NO []

[IF THEY ASK FOR CLARIFICATION, ASK ABOUT WHETHER OR NOT THEY HAVE EVER WORKED IN A HOSPITAL AND WORKED DIRECTLY WITH PATIENTS]

[IF PARTICIPANT RESPONDS “YES” TO THE FIRST THREE QUESTIONS AND “NO” TO THE LAST QUESTION THEN...]

Primary investigator: “Okay, based on those responses you qualify for the study. The next step involves scheduling a time and place for the interview. Again, the interview would occur in your home or other place of your choosing and would take anywhere from 1 to 2 hours. Would you like to schedule an interview with me at this time?”

Participant: “Yeah that sounds good.”

Primary investigator: “Great. Would it be okay if I came to your home or is there another location you would prefer?” **[CONFIRM LOCATION AND ADDRESS]**

Primary investigator: “Thank you for that information. In general, are there particular days and times of the week that might be good for you to meet for an interview lasting up to two hours? **[AGREE UPON DATE AND TIME TO MEET]**

Primary investigator: “Well Mr./Ms. _____, it has been a pleasure speaking with you today. I will look forward to our interview at **[ADDRESS OF INTERVIEW]** on **[DATE AND TIME OF INTERVIEW]** Do you have any other questions that I might be able to answer for the time being?”

Potential Participant: “No.”

Primary investigator: “Okay, well if you think of anything, feel free to call or email. You can reach me by phone at 603 305 8668 or by email at james.n.dionne-odom@bc.edu. Be well and take care, good bye.”

[IF INDIVIDUAL RESPONDS “NO” TO ONE OR MORE OF THE FIRST THREE QUESTIONS OR “YES” TO THE LAST QUESTION, THEN...]

Primary investigator: “Mr./Ms. _____, thank you again for your time today. Based on your responses, you don’t qualify for the study at this time because you stated **[NOTE CRITERION/CRITERIA THEY DID NOT MEET]**. The study criteria require that I be very specific about who I can enroll. However, I very much appreciate your interest and the time you gave me today. Again, I offer you my sincerest condolences for your recent loss. Thank you again and I wish you well. Good bye.”

Appendix VII: Informed Consent Form

CONSENT TO TAKE PART IN RESEARCH

Study Title: *Generating a Theoretical Model of the Psychological Processes of Surrogate Decision-Making at Adult End-of-Life in the Intensive Care Unit using Cognitive Task Analysis*

Primary Investigator: Nick Dionne-Odom, MSN, RN
Doctoral Student
William F. Connell School of Nursing
Boston College
603.305.8668
dionneod@bc.edu

Introduction: You are being asked to take part in a research study. Taking part in research is voluntary.

You are being invited to participate in a study about how people make medical decisions for seriously ill adults who died in the intensive care unit (ICU). Such people are called proxies, durable power of attorneys for healthcare (DPOAH), or surrogate decision makers. You are being asked to take part in this study because you recently acted in this role.

Please ask questions if there is anything about this study you do not understand.

What is the purpose of this study?

The purpose of this study is to understand how people make medical decisions for seriously ill and dying patients who cannot make these decisions for themselves. Knowing this information may help doctors and nurses better assist people who must make these decisions for others in the future.

Will you benefit from taking part in this study?

You will not personally benefit from being in this research study. We hope to gather information that may help other people in the future.

What does this study involve?

- (1) Completing a short background and demographic data form.
- (2) Participating in 1 or 2, one to two hour, voice recorded interviews.

(3) (Optional) Reviewing a summary of the study results to provide more written feedback to the researchers that can be returned in a self-addressed stamped envelope.

What are the risks involved with taking part in this study?

You may feel inconvenienced by the time taken to take part in the interview. A second interview can be arranged if you feel unable to finish the first interview. You may also feel sad or angry when talking about your experience. You are free to pause or stop the interview at any time for any reason.

Other important items you should know

Leaving the study:

Your participation in this study is voluntary. You are under **no** obligation to participate. You have the right to withdraw *at any time for any reason*.

Funding:

This study is funded by a grant from the American Association of Critical Care Nurses and Sigma Theta Tau International.

Number of people in this study:

It is expected that 15 to 25 people who have had a family member in the ICU at Dartmouth Hitchcock Medical Center will enroll in this study.

How will your privacy be protected?

Information collected as data for this study includes:

- (1) a background and demographic data form;
- (2) a digitally recorded interview;
- (3) a word for word paper copy of the interview;
- (4) a signed informed consent; and
- (5) an *optional* feedback form.

We are careful to protect the identities of all participants in this study. We will store all the above information in a locked file cabinet in a research office at Dartmouth. Except for this consent form, all data for this study will be given a random code so that your name will not be linked to the information you share. Your identity will not be revealed to others at any time during or after the study.

Specific people and places you mention will also not be revealed and will be removed from the data. Data will be maintained for 5 years after completion of the study.

The information collected for this study will be used only for the purposes of research as stated earlier in this form.

Whom should you call about this study?

If you have questions about this study, Mr. Dionne-Odom will be happy to answer them. He can be contacted at (603) 305-8668 during normal business hours or emailed at dionneod@bc.edu.

Questions regarding the rights of human subjects research may be directed to the Office of the Committee for the Protection of Human Subjects at Dartmouth College (603) 646-3053 during normal business hours. You may also contact the Boston College Office of Human Research Participant Protection (617) 552-4778 during normal business hours.

Will you be paid to take part in this study?

Yes. After the interview, you will be given a \$30 Visa gift card. If you stop the interview or cannot finish, you will still be given the \$30 Visa gift card. If you participate in a second interview, you will be given an additional \$30 Visa gift card.

CONSENT

I have read the above information about *Generating a Theoretical Model of the Psychological Processes of Surrogate Decision-Making at Adult End-of-Life in the Intensive Care Unit using Cognitive Task Analysis*. I have also been given time to ask questions. I agree to take part in this study and I have been given a copy of this signed consent form.

Participant's Signature and Date

PRINTED NAME

I do ___do not___ wish to receive a feedback form by mail. The feedback form can be mailed to: _____

Street

City/Town

State

Zip

I have explained this study to the above participant and have sought his/her understanding for informed consent.

Researcher's Signature and Date

PRINTED NAME

Appendix VIII: Background and Demographic Data Form

1. **What is your current age?** _____

2. **What is your gender?** ___ male ___ female

3. **What is your ethnic background?** ___ Not Hispanic or Latino ___ Hispanic or Latino

4. **What best describes your race? (Circle one)**
 - White
 - Black or African American
 - Asian
 - Native Hawaiian or other Pacific Islander
 - American Indian or Native Alaskan
 - Other (Please specify) _____

5. **What is your current marital status? (Circle one)**
 - Never married
 - Married
 - Living with a partner
 - Separated or divorced
 - Widowed

6. **What is your highest level of education? (Circle one)**
 - Grammar School
 - Some high school
 - High school graduate
 - Vocational or Technical School (2 year)
 - Some college
 - College graduate (4 year)
 - Masters Degree (MS)
 - Doctoral Degree (PhD)
 - Professional Degree (MD, JD, etc)
 - Other (please specify) _____

7. **What is or was your main occupation?** _____

8. What best describes your religious affiliation? (Circle one)

- Buddhist
- Catholic
- Hindu
- Islamic
- Jewish
- Protestant (*please specify*) _____
- No religious affiliation
- Other (*please specify*) _____

9. Which best describes your relationship to the person from whom you made decisions?

This person was my... (Circle one)

- Spouse
- Sibling
- Parent
- Child
- Grandparent
- Friend
- Other (*please specify*) _____

10. In your opinion, how long before this person's death was he or she aware that they were dying? (Circle one)

- Never aware
- One week before death
- 2-4 weeks before death
- 2-6 months before death
- 6-12 months before death
- Greater than 12 months
- Don't know

11. Did the patient for whom you made decisions complete a durable power of attorney for healthcare (DPOAH)?

Yes (If yes: who was the designated DPOAH? (*check one*) ___Me___Someone else___Don't know)

- No
- Don't Know

11a. If you answered "Yes" above, did the medical team have a copy? (Circle one)

- Yes
- No
- Don't know

12. Did the patient for whom you made decisions complete a living will describing his or her wishes for medical care should he or she become unable to speak? (Circle one)

Yes (If yes, did the medical team have a copy? (*check one*) ___Yes___No___Don't know)

- No
- Don't know

Appendix IX: Start List of Descriptive Codes with Operational Definitions

Descriptive Code/Concept	Operational Text Analysis Definition
Process-Maintaining Common Ground	When participant mentions acting in a way that maintained or sought to attain a shared understanding or awareness of a situation with others.
Process-Developing Mental Models	When participant states an instance where he or she thought about or attempted to comprehend a then <i>present</i> state of a situation using a mental schemata of abstract concepts and principles.
Process-Mentally Simulating and Storybuilding	When participant states an instance where he or she mentally projected or imagined a then <i>future</i> state of affairs or possible futures, possibly based on a mental model that offered a causal explanation of how situations would come about.
Process-Managing Uncertainty and Risk	When participant states an instance where he or she had to deal with not knowing something important or critical. This uncertainty could be a result of missing data or facts, data or facts of unclear accuracy or conclusiveness, competing or conflicting situation assessments, and situation complexity that interferes with sensemaking.
Process-Identifying Leverage Points	When participant states an instance where he or she identified options in a situation and turned them into courses of action.
Process-Managing Attention	When participant states ways or processes that they used to discriminate between important versus unimportant or less important information.
Function-Naturalistic Decision Making	When participant states an instance where he or she made a decision to pursue a concrete course of action
Function-Sensemaking	When participant states an instance where he or she acquired an altered view of a state of affairs, which could take several forms including but not limited to: expanding an existing account of a situation, questioning whether an existing account is accurate, explaining away inconsistent data, contrasting the merits of different accounts of the same data, replacing one account with another, and constructing a novel account.
Function-Planning	When participant states an instance where he or she undertook or modified his or her actions or behaviors in order to transform a current state of affairs into a targeted desired future state.
Function-Adaptation	When participant states an instance where he or she modified, adjusted, or replaced a plan that was in the process of implementation. Adaptation is often necessitated when the intended goals of a plan are in a state of negotiation or change.
Function-Problem Detection	When participant states an instance where he or she spotted potential problems at an early stage before significant consequences were met. May be preceded by a particular cue that triggered a reassessment of the situation.
Function-Coordination	When participant states how a group of individuals (including his or herself) orchestrated their actions and relationships in order to perform a task.
Process-Ethical/Moral Deliberation	When participant states an instance where he or she contemplated concepts, principles, or schemata of good and bad or right and wrong
Mediator-Ethical/Moral Assessment	When participant states an instance where he or she interpreted

	situations or courses of action through the perceptual lens of good and bad or right and wrong
Mediator- Emotions	When participant states an instance or period of time where he or she experienced an affective, psychophysiological state, such as but not limited to fear, anger, sadness, happiness, excitement, and tenderness
Process-Managing Emotions	When participant states an instance or period of time where he or she undertook ways to manage or control his or her affective, psychophysiological states

Appendix X: Participant Feedback Form with Responses from 9 Participants

Instructions: This form gives you a chance to comment on the findings of this study. These findings sum up the major points talked about by all participants as a whole. These findings are listed in the **LEFT COLUMN**. In the **RIGHT COLUMN**, space is provided for you to write down your thoughts on the findings. Not all findings will relate to your experience and that is OK. If the finding does not relate your experience, just write that this was not true in your case.

Study Finding	Your Feedback
<p>1. Part of my belief that my family member or friend was NOT able to think, make decisions, and be aware of their surroundings was based on seeing them in person.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i></p> <p>I found my beautiful wife in her bed room in a coma. EMTs transported her right to hospital (SDM004)</p> <p>Yes (SDM007)</p> <p>My family member could hear and understand (SDM008)</p> <p>Absolutely true-He was unconscious at first and had a breathing tube in his mouth later (SDM015)</p> <p>Aware of his surroundings and what was going on. When not sedated he was very scared & couldn't even grasp who I was. His wife of 23 years. (SDM022)</p> <p>Not true in my case (SDM024)</p> <p>36 hrs. before the death of their mother our four children could not agree what to do. I agree with this finding (SDM025)</p> <p>True-and as I reflect, I realize it was present for a long time. It also added to the pressure of wanting her closer to home (SDM030)</p>
<p>2. Seeing my family member or friend in person made it more likely that I would feel distressed about his or her suffering or pain.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i></p> <p>Seeing my M- in this state was wicked hard. She never regained consciousness. I stayed with her right until after life support was taken off her. I hurt more than I can describe (SDM004)</p> <p>Yes (SDM007)</p> <p>I couldn't stand to see him suffering (SDM008)</p> <p>Yes I agree - but was even more aware of the amount of artificial means to relieve pain by being there (SDM015)</p> <p>More distressed but it was necessary to make the decisions I made (SDM022)</p> <p>Not true in my case (SDM024)</p> <p>Seeing my wife and mother made a profound difference in our emotions and decisions. I agree with this finding (SDM025)</p> <p>Absolutely-hence this struggle to get her back to this area (SDM030)</p>

<p>3. When a current or proposed medical treatment or medical condition seemed <u>unacceptable</u>, it was important to get family consensus or agreement before expressing a decision to the health care team.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i></p> <p>No I am her husband and had constant contact with treating doctors/treatment team (SDM0004)</p> <p>Yes (SDM007)</p> <p>Yes I waited for my daughter and we made decision together (SDM008)</p> <p>Agree - we wanted to be as inclusive as possible and be the eyes and ears of family members who were unable to be there (SDM015)</p> <p>I didn't really have any input or support from his or my family (SDM022)</p> <p>Not true in my case (SDM024)</p> <p>We delayed the final decision for 24 hours because our adult children did not initially reach a consensus. I strongly agree with this finding (SDM025)</p> <p>Two weeks after court appointed guardianship-a decision whether to amputate her leg. (SDM030)</p>
<p>4. Part of my belief that my family member or friend would not survive was based on their condition of NOT being able to think, make decisions, and be aware of their surroundings.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i></p> <p>No the pneumonia and staph infection wouldn't let her live. M- never regained consciousness (SDM004)</p> <p>Yes (SDM007)</p> <p>No we made decision on medical findings (SDM008)</p> <p>We actually thought too many organs were too irreversibly distressed for him to survive regardless of this mental state (SDM015)</p> <p>Very true. He was terminal, not able to think and being kept alive by drugs & machines only prolonged the suffering (SDM022)</p> <p>Not true in my case (SDM024)</p> <p>I "knew" my wife was dying before the children did. How did I "know". 25 years as a surgeon taught me how to approach this sort of issue. In many ways, being a physician made this much more difficult for me. (SDM025)</p> <p>Truly an ethical dilemma! (SDM030)</p>
<p>5. I began thinking about the possible death of my family member or friend when I realized that they were NOT able to think, make decisions, and be aware of their surroundings.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i></p> <p>The feeling began about 2 wks after here last admission in Oct. 2012 (SDM002)</p> <p>I met with the social worker several times and doctors (SDM004)</p> <p>Yes (SDM007)</p> <p>Dr.'s opinion and diagnosis were deciding factors (SDM008)</p> <p>Yes, that awareness contributed (SDM015)</p>

	<p>Very true. I, (we) first began thinking of hospice, then I knew it was worse & thought about nursing home care, and then accepted his pending death (SDM022)</p> <p>Not true in my case (SDM024)</p> <p>No, our children simply had differing views. I do not agree with this finding (SDM025)</p> <p>I began thinking about her death <u>years</u> ago as I watched her destroy her body by ignoring her health issues, like overeating, smoking, lack of exercise etc. (SDM030)</p>
<p>6. There came a point that I became distressed about my family member's or friend's pain and suffering and thought we should not cause any more pain if there was not going to be any long term benefit.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i></p> <p>We talked about this when she was first told about the cancer and when we would stop treatment if needed. No one else was involved in our talks (SDM002)</p> <p>The doctors said that the disease was going into the central nervous system she would be brain dead (SDM004)</p> <p>Yes (SDM007)</p> <p>Yes, we knew we had to make a decision (SDM008)</p> <p>Yes, agree (SDM015)</p> <p>What I said above (SDM022)</p> <p>Not true in my case (SDM024)</p> <p>Yes, I agree. In the end it was clear and a consensus was achieved. Later, as time passed, two children wish we had waited at least another day. (SDM025)</p> <p>I come from an "animal background" where death with dignity is much easier to access. This human way causes me ethical conflict (SDM030)</p>
<p>7. The more strongly I believed that my family member or friend would not survive, the more I began grieving the loss of this person.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i></p> <p>Even seeing her worsening I ignored the possibility of her dying (SDM002)</p> <p>I started grieving the second I found M- in bed (SDM004)</p> <p>Yes (SDM007)</p> <p>True (SDM008)</p> <p>Agree (SDM015)</p> <p>Very true (SDM022)</p> <p>Not true in my case (SDM024)</p> <p>Yes, I agree with this (SDM025)</p> <p>Yes...and by doing this I was ready for her death. In fact, I was happy for her. Is that weird? (SDM030)</p>
<p>8. As I began grieving the potential loss of my family member or friend, I began to think that their medical</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i></p> <p>At no time did we question treatment and put our faith & trust in Dr. H- & nursing staff (SDM002)</p>

<p>treatments and/or medical condition was <u>unacceptable</u>.</p>	<p>Never doubted had the best treatment team in the country (SDM004) Yes (SDM007) We were provided with medical opinions that survival was unlikely (SDM008) We thought it was unacceptable because it was unproductive (SDM015) Very true (SDM022) Not true in my case (SDM024) The staff had suggested to us that technology could keep my wife and mother "alive" for many days. Suddenly the line between "living" and dying became unclear (SDM025) What I truly found "unacceptable" was "the systems" directing my mother for services she didn't need-For example "skilled nursing" vs. hospice care etc. (SDM030)</p>
<p>9. Believing that my family member or friend had survived life threatening circumstances in the past or was "a fighter" made me think they had a higher chance of surviving.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> until her last admission <u>we</u> both had faith that we would beat this. (SDM002) No she was too weak from other past surgeries most of M-'s stomach had been removed. M- only weighed 87 lbs (SDM004) No (SDM007) No, there was no hope (SDM008) This was not our experience or believe (SDM015) In the beginning. When first diagnosed, N- wanted to everything to prolong his life. This is why I thought the breathing tube was a good decision. (SDM022) This statement is 100% true (SDM024) I do not especially like the "fighter" metaphor to describe an unconscious intubated patient on life support. I do not find comfort in the "fighting" metaphor (SDM025) I never thought of my mother as a "fighter", more like a luck survivor. I describe her as not very "gritty", not a lot of "try", always the road of least resistance—that was her. The fighter part was my job—and I did it for her all my life (with her). (SDM030)</p>
<p>10. The more strongly I believed that there were other medical options that could have been attempted, the more I believed that my family member or friend could have possibly survived.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> We both had complete faith in our medical team (SDM002) No (SDM004) No (SDM007) N/A (SDM008) We did not have that belief based on staff opinions and our own observation (SDM015) I knew from the beginning he was terminal. Survival wasn't</p>

	<p>possible. It was just about time. (SDM022) Not true in my case (SDM024) 24 hours before death, I felt strongly that there were no other options that would alter the inevitable outcome (SDM025) By the time I became POA most options that might have changed the outcome were well past being options (SDM030)</p>
<p>11. There were times when I became upset with a health care professional and suspected that there were other medical options that could have been tried to help the situation of my family member or friend.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> No (SDM002) No M- had the best of everything medicine had to offer (SDM004) Yes, the surgery should have been done sooner (SDM007) N/A (SDM008) We at no time felt that way (SDM015) This was my <u>biggest</u> complaint. He had a terrible nurse at 1 point (a day) (SDM022) Not true in my case (SDM024) Before the transfer to D- in L- I had concerns. Once we got there I never had any concerns that any option would change things. (SDM025) Again—not so much individuals as the system itself. (SDM030)</p>
<p>12. I felt I had a good understanding of what was going on with my family member or friend when the healthcare team was friendly, professional, compassionate, reliable, and spoke in words I understood.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> I can not begin to state how much the nursing staff helped both of us thru this ordeal (SDM002) Yes we had several conversations and everything was clear (SDM004) Yes (SDM007) Yes, the team was honest and very caring (SDM008) Agree completely (SDM015) Very true, again, what I said above. (SDM022) This is a very true statement. Everyone was very caring and helpful. The best. (SDM024) The Palliative Care doctor and the staff were wonderful. We couldn't have asked for anything more (SDM025) At D-, they were great—other experiences at the local hospitals & nursing homes <u>sucked!</u> (SDM030)</p>
<p>13. There were points where I felt uncertain and anxious because I didn't understand what was going on medically with</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> No I was informed on everything (SDM004) No (SDM007) No, everything was explained thoroughly (SDM008)</p>

<p>my family member or friend.</p>	<p>We were anxious and uncertain but not because of lack of medical information (SDM015) Once, briefly. I was so overwhelmed with the minute to minute decisions that I shut down & couldn't make any (SDM022) Not true in my case (SDM024) No-I had a very good understanding as to what was happening (SDM025) It was not that I did not understand—it was more that I was not informed or did not see her enough to "get it" for myself. Sometimes it was extremely challenging to wade through the "bullshit" and jump through the hoops. (SDM030)</p>
<p>14. There were moments when I felt uncertain and anxious because I did not have a clear sense of what my family member or friend would actually have wanted.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> No (SDM002) No M- always stated she didn't want to die in a nursing home unable to know anything or anyone (SDM004) No (SDM007) N/A (SDM008) This is true in our case (SDM015) I always felt clear that I was making the decisions N- would have wanted (SDM022) Not true in my case (SDM024) No I knew, or I thought I knew, what my wife wanted (SDM025) *Especially having her leg amputated. (SDM030)</p>
<p>15. I had a clear sense of my family member's or friend's wishes which made me think that we should not do things I know this person would not have wanted.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> Yes we talked in depth on the subject until the last 2-3 wks (SDM002) Yes stated prior she never wanted to be brain dead (SDM004) Yes (SDM007) Very true (SDM022) We as a family wanted every one of his wishes met and they were (SDM024) I agree. Above all else my wife did not want to be chronically ill and forced to exist in an institution (SDM025) Yes—to an extent. She was clear about not wanting to be intubated, paddled etc. None of us could have predicted the difficulty of the decision to amputate her leg. (SDM030)</p>
<p>16. Because I felt that we shouldn't do things that my family member or friend would not have</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> Yes, R- was alert the day we told staff to stop treatment (SDM002)</p>

<p>wanted, there was a point where I felt that we should stop or not start certain medical treatments.</p>	<p>No I worked closely with the doctor (SDM004) Yes (SDM007) True. The last procedure was draining the fluid (and blood) from around his heart. He had a blood clot in his lung & when given heparin & starting bleeding in his stomach. That was when I said <u>enough</u>. (SDM022) Not true in my case (SDM024) Agree-See #15 (SDM025) Yes! (SDM030)</p>
<p>17. I had a strong feeling that we should not keep my family member or friend alive with machines and so I felt that their medical treatment or medical condition was unacceptable.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> Towards the end the only treatment we wanted was for pain (SDM002) No M- was rapidly deteriorating (SDM004) Yes (SDM007) very true (SDM022) Not true in my case (SDM024) "unacceptable" is too strong. The situation required delicate, painful, and emotionally wrenching decisions (SDM025) Fortunately that part was clear. (SDM030)</p>
<p>18. There were times when I felt anxious and uncertain which made me think there might be other potential medical options that could be attempted to help my family member or friend.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> No (SDM002) No (SDM004) No (SDM007) No. I knew everything that could be done was done. (SDM022) Not true in my case (SDM024) This was an area of disagreement on the first day these issues were evident. I did not act until the children reached consensus. (SDM025) The anxiety and uncertainty I felt was more over the lack of options. (SDM025)</p>
<p>19. There were times when I felt anxious and uncertain about my family member's or friend's medical condition which led me to think that their treatment was okay for the time being.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> The doctor/medical team did everything possible for M- (SDM004) No (SDM007) There were times. But I was able to see the bigger picture which was that my husband was terminal. It was just a matter of time and how much more suffering he would endure if we kept the machines going (SDM022) We as a family knew D- would do everything they could to save him. (SDM024)</p>

	<p>I was anxious but my anxiety had little to do with any specific treatment in the end, damaged physiology outstripped 21st century technology (SDM025) At D-, I felt she was safe (SDM030)</p>
<p>20. There were times when I agreed to or wanted a medical treatment done for my family member or friend because I thought that if there was some chance or hope for success, then we should try it.</p>	<p><i>Do you have any thoughts about this statement? If so, please explain.</i> Yes once the doctor thought he could save M- (SDM004) No (SDM007) No such time occurred for us (SDM015) Yes with the draining of the fluid around his heart & the breathing tube. This thought of a chance or hope was very short lived. (SDM022) I wanted all that could be done to save him as that is what he wanted (SDM024) I acted to stay the course until the children (all were adults) reached a consensus (SDM025) This was the "million dollar" question? As Man is physically & mentally failing, losing the will to live, Do we amputate her leg to prevent death from gangrene. A democratic vote from 5 players. (SDM030)</p>

21. Do you have any other final thoughts about the findings of this study?

8 mos after R-'s passing I am still having a rough time accepting our lost [?] I really have no family or friend to help me thru my ordeal and spend most of my time alone with R-'s passing on my mind. (SDM002)

The social worker was extremely helping me with final funeral arrangements for M- (SDM004)

No I think you have it. (SDM007)

I commend you for taking the time to examine these issues (SDM025)

I found the process helpful to healing. (SDM030)

22. Do you have any additional thoughts about your experience as a decision-maker that was not mentioned above?

No (SDM002)

No (SDM004)

Yes, how hard it is to make the decision (SDM007)

I don't think my family or his has any idea how hard it was to make the decisions I made & how hard it is for me to live with them. I know my husband is proud of me & grateful for doing what I did. But it still sucks. (SDM022)

Thank you - no. (SDM025)

Personally I think it's important to remember as one accepts the responsibility for someone else— Decisions are to be made as the incapacitated person would choose. That can cause personal and ethical conflict. (SDM030)

23. Please describe what the overall interview experience was like for you.

I was hopeful that our ordeal would help others thru their loss (SDM002)
 The interview was very helpful (SDM004)
 Easy (SDM007)
 Very conscious of my feelings, respectful and kind (SDM008)
 Positive experience – made me reflect on the process (SDM015)
 Very helpful. It reaffirmed my decisions (SDM022)
 I wanted to do whatever I could to help the next person in my place. (SDM024)
 Very professional, respectful, and friendly (SDM025)
 It was great—Discussing it helped me put it in perspective and “get on” with the healing process.
 (SDM030)

24. During the interview, did you feel able to express your true thoughts and feelings?

I did the best I could under the circumstances but as today I have a impossibly hard time accepting my loss and feel like my life is in turmoil & unable to focus on anything (SDM002)
 Yes (SDM004)
 Yes (SDM007)
 Yes I was honest (SDM008)
 Yes – in as much as words could describe true feelings (SDM015)
 Yes thank you N- [PRIMARY INVESTIGATOR]. Your work is very important & it was a pleasure meeting you. (SDM022)
 Always (SDM024)
 Yes I did (SDM025)
 Yes, N- [PRIMARY INVESTIGATOR] was personable and friendly. (SDM030)

Please return this form in the included stamped and addressed envelope by:

MONDAY, AUGUST 5TH

Thank you!!

Appendix XI: Member Check Form Cover Letter

July 15th, 2013

[PARTICIPANT'S NAME AND ADDRESS]

Dear [PARTICIPANT'S NAME],

I hope this letter finds you well. And thank you again for participating in my study to help better understand how individuals make medical decisions for others in the intensive care unit.

You indicated on the informed consent form during our interview that you would be willing to receive a summary of the study's results and provide comments.

In this letter, you will find:

- 1) A feedback form. The instructions for commenting on the study's findings are included on the form. Any and all comments are very much appreciated and strengthen the study's findings.
- 2) An enclosed stamped envelope. Once you have finished completing the participant feedback form, please use this envelope to send your feedback form to the study's project coordinator, Ms. Daphne Ellis.

The deadline for including your feedback into the study's findings is **Monday, August 5th, 2013.**

Do not hesitate to contact me by phone or email regarding any questions you may have.

Thank you [PARTICIPANT'S NAME] and I look forward to receiving your feedback on the study's findings.

Sincerely,

Nick Dionne-Odom, MSN, RN
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William F. Connell School of Nursing, Boston College
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