The dissertation of Barbara Birriel was reviewed and approved* by the following:

Lisa A. Kitko  
Assistant Professor of Nursing  
Dissertation Adviser  
Co-Chair of Committee

Judith E. Hupcey  
Professor of Nursing and Medicine  
Associate Dean for Graduate Education and Research, College of Nursing  
Co-Chair of Committee

Michelle L. McGowan  
Research Associate Professor of Women’s, Gender, and Sexuality Studies and Pediatrics  
University of Cincinnati

Susan J. Loeb  
Associate Professor of Nursing and Medicine  
Director, PhD Program

*Signatures are on file in the Graduate School.
ABSTRACT

Purpose: The purpose of this study was to explore the process of surrogate decision-making during critical illness. The specific aims of the study were to describe the process of surrogate decision-making for critically ill adult patients, including surrogate decision-makers’ cognitive and moral decision-making processes and to develop a model explaining the process.

Background: Critically ill patients are often unable to make independent decisions about their health care, requiring a family member to serve as surrogate decision-maker. Decisions made by surrogates affect not only their individual situations, but have implications for the health care system and society as a whole. The majority of work on surrogate decision-making has been related to chronic or slow progressing illness but little is known about the experiences of surrogate decision-makers during critical illness.

Methods: A prospective qualitative approach was used based in grounded theory. The setting included four intensive care units (ICUs) in a large university medical center. The sample consisted of 19 surrogate decision-makers (as identified on patient record) of critically ill patients in the acute phase of critical illness who were unable to make independent health care decisions. Participants were interviewed on enrollment and 14 days later, or at the time the patient for whom they were making decisions was transferred from the ICU if sooner than 14 days. The interviews explored participants’ cognitive and moral decision-making processes. An interview guide framed the interviews, though participants were encouraged to speak freely. Data analysis was completed per the tenets of grounded theory, beginning with the first interview and concluding when data saturation was achieved.
Results: A model of the *Process of Surrogate Decision-Making in Critical Illness* was developed, grounded in the data, to explain the process of surrogate decision-making in the context of acute critical illness. Four major themes emerged from the data and are included in the model: *Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values*. The overarching theme that explains the connections between the themes is *Integration*.

Conclusions: The findings of this study bring a new perspective to surrogate decision-making during critical illness, intertwining the cognitive and moral processes. Through integration of the four identified themes, the surrogate decision-maker reaches decisions based on a broader understanding of the factors involved. Nurses are well positioned to assist surrogates through this process during the critical illness of a family member. The model of the *Process of Surrogate Decision-Making in Critical Illness* forms a basis for education of nurses and other healthcare providers and the development of intervention studies to optimize the results of the surrogate decision-making process.
Table of Contents

List of Figures ........................................................................................................... viii
List of Tables ............................................................................................................. ix

Chapter 1. Introduction .............................................................................................. 1
  Statement of the Problem ....................................................................................... 2
  Purpose ..................................................................................................................... 3
  Theoretical Framework ......................................................................................... 4
    Decision-Making Framework ............................................................................. 5
    Bioethical Framework ....................................................................................... 5
  Research Question ................................................................................................. 6
  Theoretical Definitions ......................................................................................... 7
  Significance of the Study ...................................................................................... 9
  Chapter Summary ................................................................................................ 10

Chapter 2. Literature Review .................................................................................... 12
  Decision-Making Theory ....................................................................................... 14
    Clinical Models of Decision-Making ............................................................... 14
    Decision Theory ................................................................................................. 17
      Naturalistic Decision-Making ......................................................................... 19
    Summary ........................................................................................................... 22
  Surrogate Decision-Making Empirical Literature ............................................ 22
    Patient Preferences in Medical Decision-Making............................................ 22
      Effect of Diagnosis ......................................................................................... 23
    Surrogate Decision-Making ............................................................................... 24
      Patient Preference ......................................................................................... 24
      Surrogates Preference ................................................................................... 25
    Accuracy of Surrogate Decision-Makers ........................................................ 28
    Perceptions and Experiences of Surrogate Decision-Makers ......................... 30
    Summary ........................................................................................................... 33
  Bioethical Perspectives in Surrogate Decision-Making .................................... 34
    Justification for Surrogate Decision-Making .................................................. 35
    Ethics Guidance Principles for Surrogate Decision-Making ......................... 37
      Advance Directives ......................................................................................... 43
    Bioethical Theoretical Scholarship in Surrogate Decision-Making ............... 46
      Bioethics Theories ......................................................................................... 46
    Bioethical Conceptual Framework – Principilism .......................................... 54
    Bioethical Issues in Surrogate Decision-Making ............................................. 56
    Summary ........................................................................................................... 57
  Chapter Summary ................................................................................................ 57

Chapter 3. Research Design and Methods ................................................................ 60
  Design of the Study .............................................................................................. 60
  Protection of Human Subjects ............................................................................... 61
Sample and Setting ................................................................. 62
Participants ......................................................................... 62
Setting ................................................................................. 64
Sampling Technique ............................................................ 65
Participant Recruitment ......................................................... 65
Informed Consent .................................................................. 66
Participant Retention .............................................................. 66
Data Collection ..................................................................... 67
Interviews .............................................................................. 67
Field Notes and Memos .......................................................... 70
Data Management ................................................................ 71
Data Analysis ....................................................................... 72
Scientific Rigor ..................................................................... 75
Credibility ............................................................................ 76
Applicability ......................................................................... 76
Chapter Summary ................................................................. 77

Chapter 4. Results .................................................................. 78
Participant Demographics ........................................................ 79
Themes ................................................................................ 81
Understanding the Patient’s Values and Preferences .............. 82
Acquiring Health Care Knowledge ......................................... 86
Considering Family Perspectives .......................................... 89
Recognizing Personal Values ................................................ 91
Overarching Theme: Integration ........................................... 93
Model: Process of Surrogate Decision-Making in Critical Illness 97
Chapter Summary ................................................................. 100

Chapter 5. Discussion of Significant Findings ......................... 101
Findings in Relation to Dual Process Decision Theory .......... 101
Findings in Relation to Surrogate Decision-Making Literature 104
   Findings in Relation to Shared Decision-Making ................. 106
Findings in Relation to Biomedical Theories ................................ 108
   Ethical Basis for Surrogate Decision-Making ..................... 108
   Ethics Guidance Principles for Surrogate Decision-Making .... 110
Findings in Relation to Grounded Theory ............................. 111
Implications of the Findings .................................................. 112
Study Strengths and Limitations ............................................ 116
Recommendations for Future Research .................................. 119
Conclusions ......................................................................... 120

Chapter 6. The Bioethics of Surrogate Decision-Making in Critical Care ......................................................... 122
Approaches to Surrogate Decision-Making .............................. 122
   Traditional Approach – Three Guidance Principles ............ 122
   Other Bioethical Perspectives ............................................. 125
   Surrogate Decision-Making in Healthcare ......................... 126
List of Figures

Figure 1.1 Dual Process Model of Decision-Making ...........................................20
Figure 3.1 Screening and Enrollment .................................................................63
Figure 4.1 Process of Surrogate Decision-Making in Critical Illness ..............98
Figure 5.1 Dual Process Model of Decision-Making .........................................102
Figure 5.2 Process of Surrogate Decision-Making in Critical Illness ..............103
List of Tables

Table 1.1 Guidance Principles for Surrogate Decision-Making........................................39
Chapter 1

Introduction

Critically ill patients who are unable to participate in health care decision-making are vulnerable by virtue of incapacity. They cannot go elsewhere for care or at best have very limited choices. Critically ill patients are often unable to make independent decisions about their care because of the severity of their illness, requiring a family member to serve as surrogate decision-maker. In a study of hospitalized older adults requiring major medical decisions, almost half required at least some surrogate involvement and 23% required all decisions to be made by a surrogate (Torke et al., 2014). One could reasonably expect this to be even higher among critically ill patients.

Methods of patient or surrogate decision-making range from paternalism to autonomy (Cook, 2001). More recently, shared decision-making has become the preferred model as recommended by the American Medical Association (AMA, 2014), the American College of Critical Care Medicine, and the American Thoracic Society (Davidson et al., 2007; Kon, Davidson, Morrison, Danis, & White, 2016). In the shared decision-making model, decision responsibility is shared between the provider and the patient or family surrogate decision-maker. Anderson, Arnold, Angus, and Bryce (2009) found an association between passive decision-making and higher levels of anxiety and depression in relatives of critically ill patients. Stress has been noted as one of the most common negative effects on the surrogate decision-maker (Wendler & Rid, 2011), raising the question of its effect on decision-making.

Decisions made by surrogates have numerous implications. There are direct effects on patient treatment and therefore, outcomes and costs. There are indirect effects on the surrogate’s relationship with other family members and the patient. There are also effects on the surrogate
decision-makers themselves as they go through the process of making critical decisions for another person. From a broader perspective, these decisions and the process by which they are made have implications for health care systems and society as a whole in terms of professional guidelines and legislation.

Understanding the process of surrogate decision-making is the first step to developing methods to minimize negative effects and maximize positive effects in all of these areas. This study aimed to describe the process of surrogate decision-making during the critical illness of a family member and identify factors that may impact the decision-making process and ultimately, the decision-maker and the patient.

**Statement of the Problem**

Little is known about the process of surrogate decision-making during a family member’s critical illness. Previous work in surrogate decision-making mainly has been in the context of chronic illness or illnesses with longer trajectories, such as cancer. Decision-making during critical illness is different, often requiring rapid decisions in acute life-threatening situations. Additionally, there is rarely a pre-existing relationship between the patient or family and the critical care clinician resulting in the absence of baseline trust and rapport. Previous studies have been done retrospectively, affecting reliability and validity, as recall of the process is affected by the lapse in time and uncertainty is less likely to be captured since the outcome is known. Other studies have been done at a single point in time during the patient’s critical illness. The quantitative studies in this area are observational, resulting in an inability to determine with certainty the direction of the relationship between variables. Qualitative studies have not explored surrogates’ preferences in making decisions.
There is a lack of sufficient knowledge regarding the surrogate decision-maker experience during critical illness. There is a complete absence of knowledge about their process of decision-making and the ethical basis for their decisions. This large gap in theoretical understanding of the surrogate decision-making process limits our ability to develop evidence-based interventions that effectively assist the surrogate decision-maker and optimize outcomes for the surrogate, the patient, and the larger systems of health care and society. This study begins to fill this gap in the literature through a prospective qualitative design in which surrogate decision-makers were interviewed at prescribed data collection points during the patient’s critical illness.

**Purpose**

The purpose of the study was to explore the process of surrogate decision-making during critical illness. Specifically:

- What do surrogates know about the patient’s care preferences?
- How do they make decisions?
- What type of decision-making model is used?
- What is the ethical basis for their decisions?
- What resources have been used or could be used to assist the surrogate in the decision-making process?

The specific aims of the study were to describe the process of surrogate decision-making for critically ill adult patients, including participants’ cognitive and moral decision-making processes and to develop a model explaining the process. This study makes a significant contribution to practice through describing of the process of surrogate decision-making during the acute phase of critical illness. This new knowledge informs critical care practice and
provides foundational insights for the development of targeted interventions to assist surrogate decision-makers in individual situations. By understanding the factors considered by family surrogates in the decision-making process, clinicians can develop methods and systems to ensure that each is acknowledged and discussed with the surrogate. Knowledge emerging from this study also forms a basis for development of relevant professional guidelines and policies related to care of the critically ill, supporting truthful sharing of information, routine family meetings, and shared decision-making including perspectives of the patient, healthcare team, family, and family surrogate decision-maker. Critical care clinicians, caring for both patients and families, have an obligation to be involved in optimizing the surrogates’ decision-making process and capabilities, and therefore the outcomes for all stakeholders.

**Theoretical Framework**

Use of a theoretical framework is not supported in grounded theory studies such as this (Corbin & Strauss, 2015). The theoretical frameworks identified here were chosen based on their fit with the current literature on surrogate decision-making in critical illness. They were not used as strict guides in study methodology or analysis.

The theoretical framework for the study includes both decision-making and bioethical frameworks. The decision-making framework is the dual process model of decision-making that combines rational and intuitive reasoning to reach a decision. The bioethical framework is based on principlism, the ethical model most commonly used within healthcare. Both of these areas are integral to organizing a thoughtful process of surrogate decision-making. An overview of the decision-making and bioethical frameworks is presented here. Chapter 2 includes a more detailed discussion of the chosen and competing frameworks.
Decision-Making Framework

The decision-making framework for this study is the basic dual process model of decision-making. The dual process model, developed in the field of psychology, combines both cognitive rational and normative intuitive models of decision-making. Multiple studies indicate that surrogate decision-makers use both rational and intuitive thinking in making health care decisions (Braun, Beyth, Ford, & McCullough, 2008; Gries, Curtis, Wall, & Engelberg, 2008; Jeffers, 1998; Kirchhoff et al., 2002; Majesko, Hong, Weissfeld, & White, 2012; Schenker et al., 2012; Swigart, Lidz, Butterworth & Arnold, 1996). As these processes are occurring together, a dual process model is well suited to conceptually frame the study.

Bioethical Framework

Multiple bioethical theories or schools of thought must be considered in a discussion of any aspect of health care, including surrogate decision-making. Each of these theories provides a different perspective from which to consider the process of surrogate decision-making. The most prominent bioethical theories include virtue ethics, consequentialism, deontology, ethics of care, casuistry, and principlism.

When considering surrogate decision-making, each of the bioethical theories approaches the process from a different perspective. Virtue ethics expects that the surrogate makes decisions as a good person based on normative standards of good moral character (Beauchamp & Childress, 2013; Pellegrino, 1995). Consequentialism requires that the decision be based on which result achieves the highest good for the greatest number of people (Beauchamp & Childress, 2013; Mill, 1879). Deontology considers the surrogate’s duty to the patient (Beauchamp & Childress, 2013; Kant 1785). Ethics of care is concerned with care and compassion for the patient (Baier, 1987; Gilligan, 1982). Casuistry is based in exemplar cases of
similar situations (Beauchamp & Childress, 2013). Principlism balances aspects of autonomy, nonmaleficence, beneficence, and justice (Beauchamp & Childress, 2013).

These and other bioethical perspectives have been used to consider surrogate decision-making. Despite the multiplicity of bioethical theories, knowledge and application of those theories remains largely within the disciplines of bioethics and philosophy. Historically, health care providers have been trained to consider ethical theory based on principlism (Davis, Tschudin, & de Raeve, 2006; Goldberg, 2009). As a result, the terminology of principlism is found even throughout the lay literature, i.e., books, periodicals, and other material written for those who are not experts in either health care or ethics. Principlism was chosen as the ethical framework for this study based on the expectation of provider and surrogate decision-maker familiarity with the terminology. As the framework most familiar to critical care providers, study findings would be well positioned to be applied to clinical practice. Surrogate decision-maker familiarity with the terminology increased the likelihood that they would describe their decision-making using those terms.

**Research Question**

The overall research question for this study is: What is the process of surrogate decision-making for critically ill adult family members? The question is purposely broad to capture the full scope of the decision-making process, including both the cognitive and bioethical perspectives. The cognitive perspective describes the mental processes involved in making decisions. The bioethical perspective describes the moral considerations underlying the decisions. Together, these provide a stronger representation of the surrogate decision-making process.
Theoretical Definitions

Terminology related to surrogate decision-making varies in the literature, though the meanings remain fairly consistent. Key terms used throughout this paper are defined here, presented in order of relation to clinical status, surrogate decision-making, decision theory, and ethical decision-making.

- **Acute critical illness**: The acute phase of critical illness is an acute condition of physiologic instability requiring constant monitoring and intervention (Girard & Raffin, 1985; Wienczek & Winkelman, 2010).

- **Chronic critical illness**: Chronic critical illness is a condition characterized by ongoing physiologic abnormalities and dependence on technology that continues beyond several weeks from onset (Wienczek & Winkelman, 2010).

- **Surrogate**: Surrogate means to put in place of another or to appoint as successor, deputy, or substitute for oneself (Merriam-Webster, 2003).

- **Surrogate decision-maker**: The surrogate decision-maker is a person who makes health care decisions for a family member, as designated by the family member and/or state law. An alternate term is substitute decision-maker.

- **Surrogate decision-making**: Surrogate decision-making is the process of making health care decisions for a family member. An alternate term is substitute decision-making.

- **Reliant decision-making**: This is a decision-making process in which the decision is left to the provider with little to no input from the surrogate decision-maker.

- **Shared decision-making**: This is a decision-making process in which there is input into the decision by both the surrogate decision-maker and the provider.
• **Independent decision-making:** This is a decision-making process in which the decision is made by the surrogate decision-maker with little to no input from the provider.

• **Dual process theory:** Dual process is a theory of reasoning in which both intuitive and rational processes are used and balanced (Croskerry, 2009; J. S. Evans, 2003; Osman, 2004).

• **Dual process theory System 1:** System 1 is the intuitive process arm of dual process theory of reasoning. Decisions are made based on prior experience with little or no conscious thought (Croskerry, 2009; J. S. Evans, 2003; Osman, 2004).

• **Dual process theory System 2:** System 2 is the rational process arm of dual process theory of reasoning. Decisions are made based on conscious consideration of facts and options (Croskerry, 2009; J. S. Evans, 2003; Osman, 2004).

• **Ethics:** Ethics refers to the broad moral considerations of the topic discussed (Beauchamp & Childress, 2013).

• **Bioethics:** Bioethics is a more recent term than ethics. The former is used to refer to moral issues in the realm of health (Beauchamp & Childress, 2013).

• **Advance directive:** An advance directive is a formal written document completed by a competent patient to direct decisions about medical care should they become incapacitated (Buchanan & Brock, 1986).

• **Substituted judgment:** The substituted judgment principle states that the surrogate should make the decision that the patient would choose given the current circumstances based on prior knowledge of the patient’s wishes (Buchanan & Brock, 1986).
• **Best interest standard**: The best interest principle states that the surrogate should make the decision by considering all aspects of the patient’s interests to determine the greatest benefit (Buchanan & Brock, 1986).

**Significance of the Study**

Nursing’s Social Policy Statement (American Nurses Association [ANA], 2010) requires the refinement and expansion of nursing’s knowledge base by partnering with individuals and families. Issues to be addressed include the experience of illness, disease, and death; meanings ascribed to illness; decision-making and the ability to make choices; as well as relationships and role performance. The American Nurses Association Code of Ethics for Nurses (ANA, 2015) requires nurses to include “surrogate decision-makers in discussions, provide referrals to other resources as indicated, identify options, and address problems in the decision-making process” (p. 3). It is difficult to accomplish these mandates without fully understanding the surrogate’s decision-making process.

This investigation of surrogate decision-making during critical illness of a family member has both short and long term significance. In achieving the aims of this study, the process of surrogate decision-making during critical illness is more fully understood, including the process itself and the needs of the surrogate. With these issues identified, specific interventions can be developed to provide support to the surrogate through the decision-making process and potentially moderate the negative physical and psychological effects that are described in the empirical literature (Iverson et al., 2014; McAdam & Puntillo, 2009; Schenker et al., 2012; Wendler & Rid, 2011).

Description of the decision-making processes and moral reasoning used by surrogates in critical care are areas that have not been described to date in the literature. The model developed
in this study aids nurses and other clinicians in understanding the decision-making process of the individual surrogate, but also the process as common to all surrogate decision-makers during the critical illness of a family member. An understanding of these processes can contribute to the development of appropriate institutional, professional, and legislative policy by providing evidence of how surrogates make decisions. Nurses and other clinicians are in a position to use the model developed in this study to educate all levels of healthcare professionals, improve clinical practice and guide future studies and interventions to support the surrogate through the decision-making process and optimize patient outcomes.

The description of the ethical reasoning used by surrogate decision-makers in critical care provides a fresh perspective of how they use the ethics guidance principles for surrogate decision-making (advance directives, substituted judgment, and best interest). Understanding of this process provides nurses and other clinicians with insight and direction regarding how to best assist the surrogate through their decision-making responsibilities.

**Chapter Summary**

As the population ages, we can expect to see an increase in chronic illness resulting in hospitalizations and critical illness. Over 5 million people are admitted to intensive care units annually just in the United States. Advances in health care technology further expand our capability to provide treatment for patients with critical illness and injury. The result is an increasing population of critically ill persons, many of whom require a surrogate decision-maker to voice their decisions. Though the current literature provides a glimpse of the issue, not enough is known about surrogate decision-making during a patient’s critical illness. Surrogate decision-making in the context of critical illness is different than surrogate decisions made in
other circumstances. A major difference is that decisions must be made urgently and in concert with clinicians who typically have no prior relationship with the patient or family.

Understanding the process of surrogate decision-making is the first step to develop methods to minimize the negative effects and maximize the positive effects – for the patient, the surrogate, the health care team, the institution, and society. Investigating the decision-making process of surrogate decision-makers uncovers opportunities for health care providers to support the surrogate and improve outcomes for both the patient and family. Knowledge gained from this study can inform a future intervention trial to improve the process of surrogate decision-making in critical care to the benefit of all involved.

In Chapter 2, varied decision-making models are discussed and justification provided for the dual process model as a theoretical framework for this study. Next, an analysis of current literature on surrogate decision-making is presented. Finally, bioethical concepts and theories of bioethics are discussed as they related to surrogate decision-making. In the context of this qualitative study, it is acknowledged that both the decision-making and bioethical theoretical frameworks were purely speculative. The true nature of surrogate decision-making in critical illness is determined in analysis of the data as described in Chapters 4 and 5.
Chapter 2

Literature Review

Surrogate decision-making in healthcare requires a family member to make decisions for the patient who is unable to do so independently. Critically ill patients, in particular, often rely on a family member or other close associate to make decisions when they are physiologically incapacitated. An understanding of the background and research literature in the area of surrogate decision-making is vital to investigating the process by which surrogates make decisions and factors affecting their ability to make those critical decisions.

Authors using different terms for the same concept complicate identification of related literature. The literature search was completed using PubMed, CINAHL, EthxWeb, and Academic Search Complete. Inclusion criteria were English language, human population, and professional literature in journals or scholarly books. No date parameters or other restrictions were placed on the search. The initial literature search was related to surrogate decision-making using the terms surrogate decision-making, surrogate decision-maker, substitute decision-making, substitute decision-maker, and proxy decision-making. A separate literature search was conducted related to decision theory using the terms decision-making theory, dual process decision-making, and naturalistic decision-making. In addition, the bioethics literature was searched by adding the terms ethics and bioethics to each of the terms in the surrogate decision-making search. The bioethical perspective on surrogate decision-making was almost completely absent in the standard literature search. Inclusion criteria were modified to include works of theoretical scholarship in bioethics. The body of literature reviewed was expanded based on reference lists from papers in the initial search as well as personal recommendations from experts in bioethics, critical care, and surrogate decision-making. The literature search was repeated on
multiple dates as the study progressed and was last updated in April 2017. Empirical work in surrogate decision-making demonstrated an increasing trend through the 2000s but had declined since 2012. More recent publications do indicate some growth in work on surrogate decision-making in the critical care setting.

Research studies within the body of literature were reviewed using the Grading of Recommendations, Assessment, Development and Evaluation (GRADE) methodology (Appendix A). The GRADE methodology provides a systematic approach to judging the strength of evidence in the literature. The method considers factors other than study design, which is important in this review of surrogate decision-making that includes both quantitative and qualitative studies. The GRADE system is currently used by the Society of Critical Care Medicine/American College of Critical Care Medicine, supporting its use in the current study of a critical care population.

Understanding the current state of knowledge about surrogate decision-making in the context of critical illness involves three topical areas. First, decision theory is discussed concluding with support for the use of Dual-Process Theory as a theoretical framework for this study. Next, the empirical literature on surrogate decision-making is considered. The empirical literature includes investigation of patient preferences in decision-making, patient and surrogate preferences in surrogate decision-making, the accuracy of surrogate decisions (congruence of decisions made by surrogates with those made by the patient), and surrogates’ perceptions and experiences. Finally, the bioethical perspectives applicable to surrogate decision-making are explored, including guidance principles, related theoretical scholarship, and bioethical issues in surrogate decision-making. The rationale for use of principlism as a bioethics theoretical framework in this study is discussed.
Decision-Making Theory

There is a vast amount of literature related to making decisions in popular publications, trade magazines, and scholarly journals and books. The former two publication types primarily consist of series of anecdotes in which the process of decision-making is explored and explained (Groopman, 2007; Lehrer, 2009). These publications do not propose a model to organize the decision-making process, but rather discuss the factors involved in individual situations. The scholarly literature on decision-making can be found in the realms of mathematics, psychology and medicine. The models can be divided into two general groups. The cognitive or rational models are based on fact and evidence. The normative or intuitive models are based on prior identified patterns, experience, and intuition. Unfortunately, the terms used across publications and disciplines are inconsistent which may lead to confusion regarding the types of models. The following sections will describe clinical models of decision-making, decision theories, and the decision-making conceptual framework for this study.

Clinical Models of Decision-Making

In the past, paternalism was the prominent model for medical decision-making. The patient or surrogate was passive and decisions were directed by the physician (Cook, 2001). Beginning in the 1980s, there was a shift to a model of autonomy, at least in the United States, in which the patient or surrogate assumed responsibility for making final decisions (Cook, 2001). Each of these extremes could be harmful. Paternalism can result in treatment decisions that do not consider the patient. Autonomy can result in increased pressure on the patient or surrogate, particularly in critical situations that are beyond their comprehension.

More recently, the model of shared decision-making has been recommended by major critical care professional organizations (Carlet et al., 2004; Davidson et al., 2007; Kon et al.,
2016; Lanken et al., 2008; B. T. Thompson et al., 2004) as a component of patient-centered care. The shared decision-making model applies to surrogate decision-makers as well, when the patient is unable to make independent decisions. The American College of Critical Care Medicine (ACCM) and American Thoracic Society (ATS) endorse the Informed Medical Decisions Foundation (2015) definition of shared decision-making as “a collaborative process that allows patients or their surrogates, and clinicians to make health care decisions together, taking into account the best scientific evidence available, as well as the patient's values and preferences.” In the context of surrogate decision-making, shared decision-making requires that clinician and surrogate develop a partnership. The clinician provides emotional support; provides information on the patient’s medical condition and prognosis; assesses the surrogate’s role preference; and explains treatment options, highlighting that there is a choice. The surrogate provides information on the patient’s values and preferences. Together, the clinician and surrogate come to a decision about the treatment plan (Kon et al., 2016). The shared decision-making model does not define the role the surrogate assumes, so the process may in reality range anywhere from paternalism to autonomy.

The research literature on decision-making uses slightly different terminology in describing the continuum of decision-making models. Perhaps because of the strong societal shift from paternalism to autonomy, the term paternalism has been replaced by passive or reliant decision-making. This refers to a decision-making process in which the decision is left to the provider with little to no input from the patient or surrogate decision-maker. The term autonomy remains in use, usually as autonomous or independent decision-making. This refers to a decision-making process in which the decision is made by the patient or surrogate decision-maker with little to no input from the provider. The research literature generally uses the term
shared decision-making to imply equal input into the decision by both patient or surrogate and the provider.

Decision aids may be considered another type of clinical model of decision-making but are actually tools to lead a patient or surrogate decision-maker through the steps of making a decision. Since the decisions aids are developed by another (usually by someone involved in health care), the content is naturally biased toward the developer and does not reflect the decision-making process of the user. There has been some support for using decision aids to enhance or improve the informed consent process (Pope & Hexum, 2013) but provision of information alone does not ensure that the user follows all of the steps in the model and thinks only within the model provided. Decision aids that predict the treatment option an incapacitated patient would choose based on the individual’s characteristics and values are being evaluated (Rid & Wendler, 2014a, 2014b). Challenges remain in terms of predictive accuracy and acceptance by patients, surrogates, and providers. The Ottawa Decision Support Framework (ODSF) is one of the most well known decision aids and can serve as an exemplar (Ottawa Hospital Research Institute, 2015).

The ODSF consists of counseling, decision tools, and decision coaching. Optimally, all three of the components would be used. The Personal Decision Guide is most applicable to patient and surrogate decision-making in healthcare. It is a general guide that leads the person to consider the positive and negative aspects of the choice, and to consider what they need in terms of knowledge, values and support to make a decision. The Decision Aids are less helpful in the setting of critical illness due to its complexity and urgency.

The Cochrane Review of decision aids in health care indicates that use of decision aids did improve knowledge and patient-clinician communication. Satisfaction with decision-making
and preparation for decision-making showed either increased satisfaction or no change. (Stacey, et al., 2014) The findings do not demonstrate a clear benefit and there is no data on patient outcomes. The study samples included only patients (no surrogates) and were not in a setting of critical illness.

**Decision Theory**

Though these clinical models of decision-making describe which individuals participate in the decision-making process, none of them describe the actual process that the patient or surrogate goes through to make the decision. Similarly, the various decision aids may prompt a person to consider certain aspects of a decision but they do not determine or describe the person’s cognitive process in making the decision. Many major universities now have decision laboratories for both the cognitive and physiologic study of decision-making. Even these advanced programs of study do not address decision-making in health care, particularly in real situations and with surrogate decision-makers. There is not a universally accepted decision theory for surrogate decision-making in health care. Recall that decision theory is primarily based in mathematics, psychology, and medicine. Mathematical decision theories based on strict probabilities do not fit well with health care decision-making involving individual preferences and values. Decision theories in psychology and medicine have been applied to health care decision-making.

Werner (1995) defines a universal process by which clinicians make decisions under uncertainty. The process involves making a choice of action to reduce uncertainty. However, it also includes multiple strategies for making the choice. Mazur (2012) describes the development of Bayesian inference in medical decision-making. This has progressed from identification of the need for evidence to the use of probability and inverse probability. In a white paper for the
Agency for Healthcare Research and Quality, Ebell (2010) proposes the development of decision-making rules that integrate information to provide quantitative data regarding the estimate of risk for a particular outcome. He notes some degree of physician resistance to this model even when it is informed by the clinical context. Resistance is likely due to the perception that all aspects of the patient cannot be considered, which challenges the clinician’s ability to reason independently.

Though there are multiple models of decision-making, these have not been applied to the situation of surrogate decision-making in healthcare. Additionally, decision-making models described in the literature may or may not apply to decision-making in the scenario of critical illness. Because surrogates in healthcare are essentially being asked to make medical decisions, it is logical to use models that have been used in medical decision-making. However, the surrogate most often has far less depth of medical knowledge than health care providers from which to make decisions. The literature as described above supports the notion that even clinicians, with a strong knowledge base, do not choose to make decisions purely based on logic and calculation. Multiple studies have reported that surrogate decision-makers rely on both rational and intuitive thinking when making healthcare decisions (Braun et al., 2008; Gries et al., 2008; Jeffers, 1998; Kirchhoff et al., 2002; Majesko et al., 2012; Schenker et al., 2012; Swigart et al., 1996). There is support for a similar rational and intuitive process when making moral judgments. Haidt (2012), a social psychologist, describes the process of moral judgment as a dual process system in which moral judgment is first influenced by emotion and then moderated by reasoning. Naturalistic Decision-Making and Dual Process Theory both describe this combination of reasoning processes, merging the cognitive/rational and normative/intuitive models.
**Naturalistic Decision-Making.** Naturalistic decision-making describes how people make decisions in real-world contexts that have meaning and familiarity with an emphasis on prior experience (Lipshitz, Klein, Orasanu, & Salas, 2001). The Recognition-Primed Decision Model is the prototypical model of naturalistic decision-making (Schulz, Lingle, Chubon, & Coster-Schulz, 1995). Though there are several variations, all rely on experience to guide decision-making. Relevant experience is necessary to suggest expected outcomes associated with decisions to guide action (Klein, 2008). Naturalistic decision-making describes patient decision-making but does not apply as well to surrogate decision-making where prior experience is often lacking.

**Decision-Making Conceptual Framework - Dual Process Theory.** Dual Process Theory applies to surrogate decision-making by describing factors in addition to experience that influence decisions. It considers that thought processes are completed by two different systems. System 1 processes involve heuristics, rely on prior knowledge and experience, and are often made without conscious thought. System 2 processes involve conscious thought, weighing multiple facts and observations to come to a decision (Croskerry, 2009; Djulbegovic, Hozo, Beckstead, Tsalatsanis, & Pauker, 2012; J. S. Evans, 2003; Osman, 2004; Reyna, 2004).

Historically, Plato was the first to develop a dual process theory of the mind (Frankish, 2009). Contemporary dual process theories were developed in the 1960s and 1970s by Schneider and Shriffin (1977) in social cognition, by Reber (1993) in learning, and by Wason and Evans (1975) in reasoning. These varied branches of psychology developed their versions of dual process theory over similar time periods. This reflects movement from a positivist to a post positivist paradigm in the field. System 2 thinking alone is purely positivist as it relies on facts. System 1 is post positivist as it is more flexible than System 2, considering the influence of prior
experience and intuition. Combining both Systems into a dual process model pulls the entire model into post positivism. It acknowledges the multiple ways of knowing and arriving at a decision.

Dual Process Theory was not developed as a model to describe surrogate decision-making and has not been applied in this realm as of 2015. Cognitive-emotional decision-making (Power, Swartzman & Robinson, 2011) describes a framework for patient medical decision-making and utilizes the concepts of dual process theory. Croskerry’s (2009) Universal Model of Diagnostic Reasoning describes a dual process theory for clinician medical decision-making. Dual Process Theory could readily be adapted to describe the combined reasoning and interactions that occur in surrogate decision-making in the context of critical illness (Figure 1).

**Figure 1.1 Dual Process Model of Decision-Making**
**Major Concepts.** There are two major concepts that describe the processes by which decisions are made: System 1 and System 2. System 1 can be defined as the intuitive approach to decision-making and System 2 as the analytical approach.

“System 1 processes” are greatly influenced by prior experience. It involves heuristics and other mental shortcuts. These processes are useful when something about the situation is familiar or recognized. Consciously or subconsciously, the decision-maker considers characteristics of the patient, the illness, the environment and the situation. The influence may come from prior experience, prior conversations with the patient or guidance from an advance directive. System 1 is more prone to errors (making a decision later considered to be ‘not the best decision’ by the surrogate), but allows for more rapid decision-making.

“System 2 processes”, on the other hand, are useful when the situation is not recognized. The decision-maker evaluates the options utilizing education, intellectual ability, and critical thinking. New learning may be required either from healthcare providers or outside information. This is a slower, resource intensive process. Because it requires purposeful deliberation among options, System 2 is less prone to error (more likely considered to be ‘the best decision’ by the surrogate).

**Relationship of the Concepts.** The unidirectional arrows in Figure 1 demonstrate the relationship between the major concepts of the theory. The problem requiring a decision leads System 1 and System 2. If it is recognized, the model flows into System 1. If it is not recognized, the model flows into System 2. In the simplest of situations, thought processes from both System 1 and System 2 move toward calibration where all of the data are considered and a decision is reached. In more complex situations, a variety of interactions between System 1 and System 2 are possible.
Summary

Clinical models of decision-making define who participates in making decisions. From a clinical perspective, decisions take place on a spectrum of shared decision-making ranging from a paternalistic reliant model to an autonomous independent model. Mathematical models cannot manage the individualistic criteria involved in health care decisions. The decision-making model that appears to be the best fit for surrogate decision-making was developed within psychology. Dual process theory acknowledges the rational and intuitive processes that surrogates have been shown to use when making decisions. It has been used in theories of both patient medical decision-making and clinician medical diagnostic decision-making. The basic dual process theory is the conceptual framework for this study of surrogate decision-making in critical illness.

Surrogate Decision-Making Empirical Literature

An initial description of patient preferences in medical decision-making is included to determine what and how patients decide when they are capable of making their own decisions. Both patient and surrogate preferences regarding surrogate decision-making follow. Since the surrogate decision-maker is making a decision for another, the congruence of decisions between patient and surrogate is reviewed. Finally, the effects of acting as a surrogate are discussed.

Patient Preferences in Medical Decision-Making

Knowledge of how patients make their own medical decisions could be useful to surrogate decision-makers. An early descriptive study of 459 health maintenance organization members (S. C. Thompson, Pitts & Schwankovsky, 1993) found that younger, more educated individuals preferred a higher degree of involvement in making medical decisions. A later descriptive study with a representative sample (n=2765) of the U.S. population (Levinson, Kao,
Kuby & Thisted, 2005) also found that an active decision-making role was preferred by younger, more educated individuals and also by women and healthier individuals.

Other observational studies have described the decision-making preferences of patients with chronic diseases. Outcomes have been consistent in multiple countries. In the United States (Arora & McHorney, 2000) and Germany (Hamann et al., 2007), younger, more educated, and female patients desired more active roles in decision-making. In the United Kingdom (Garfield, Smith, Francis & Chalmers, 2007), younger patients and those belonging to a higher social class chose higher degrees of involvement. Education level was not described, but it is likely that patients of higher social class were also more educated. These studies describe a group of factors associated with patient preference for an active role in medical decision-making. It is not known, however, whether these factors might influence the surrogate.

Effect of Diagnosis. The diagnosis being treated and the type of medical decision required were significantly associated with patient desire for involvement in the decision in several studies. S. C. Thompson et al. (1993) found that patients wanted a higher degree of participation for decisions that did not require a high degree of medical knowledge. A group of 459 health maintenance organization members responded to the Autonomy Preference Index (API; decisions requiring higher degree of medical knowledge) and the Desire for Involvement Questionnaire (DIQ; decisions requiring less medical knowledge but having greater effect on quality of life). Regardless of age or education level, participants desired more involvement in decisions having greater effect on quality of life. Arora and McHorney (2000) reported on 2197 patients from the Medical Outcomes Study, a longitudinal study of chronically ill patients. Using patients with only mild hypertension as the referent group, those with severe diabetes and mild heart disease were less likely to prefer an active role in medical decision-making (diabetes:}
OR = 0.62, 95% CI 0.39 - 0.97; heart: OR = 0.45, 95% CI 0.23 - 0.86) while those with depression were more likely to prefer an active role in medical decision-making (OR = 1.64, 95% CI 1.16 - 2.30). Garfield et al. (2007) reported that in a study of 516 outpatients, those with rheumatoid arthritis preferred more involvement in decisions about starting, changing doses, or stopping medicines than patients with diabetes. The findings of these studies suggest that patients choose a higher degree of participation in decisions about conditions perceived to be more related to comfort and quality of life, such as rheumatoid arthritis and depression. They choose less involvement in decisions to treat more abstract medical problems in which they perceive no current symptoms. It is not known whether this trend would be consistent in more acute or critical illnesses.

**Surrogate Decision-Making**

**Patient Preference.** It is important for the surrogate to understand the role that patients expect to be played on their behalf. B. Kelly, Rid and Wendler (2012) completed a systematic review of individuals’ goals for surrogate decision-making. Forty articles reporting 14 unique qualitative and 26 unique quantitative studies were reviewed. Only nine studies occurred in the context of serious acute illness. The majority of individuals wanted family members to serve as surrogates, primarily because of a belief that families understood what they would want. If they were incapacitated, their major goals were to have family involved in care and decisions, have treatment consistent with their own wishes, and decrease the burden on their family surrogate. A more recent study supports those findings. Of 1169 participants (inpatient and outpatient), 78.2% with a designated surrogate wanted the surrogate to make treatment decisions for them in the event of incapacity and 66.1% without a designated surrogate wanted their family to make treatment decisions. The most common reason given for the choice was the belief that their
surrogate and/or family knew their treatment preferences (Wendler, Wesley, Pavlick, & Rid, 2016).

Sharma et al. (2011) studied patient preferences for family involvement in a cross-sectional survey of 52 dyads of patients with pancreatic cancer or amyotrophic lateral sclerosis and their family members. The survey included two scenarios (one in which the patient was conscious and one unconscious) and a recent event identified by the patient in which a decision had to be made about their care. In identifying the patient’s preference for family involvement in decision-making (independent, shared, or reliant on physician), agreement was 56% in the conscious scenario and 46% in the unconscious scenario. Family members often felt they should decide independently when in fact the patient preferred they use shared or even reliant decision-making with the physician.

Surrogates Preference. The majority of research on surrogate decision-making focuses on healthy individuals or those with chronic disease. In the investigation of surrogates’ preference of decision-making model, the great majority of studies have been in intensive care units and most were published in the last ten years. This likely reflects a growing awareness of the issues faced by surrogate decision-makers during acute and critical illness when life-changing decisions must be made urgently. It may also reflect the knowledge that situations in which surrogates have difficulty with decision-making or achieving consensus often result in increased length of stay and costs (Davidson et al., 2007).

The surrogate needs adequate information from clinicians to understand the patient situation in order to make an informed decision. Clinicians may find it difficult to provide sufficient information so that the surrogate can make an informed decision while not imparting so much detailed and technical information that the surrogate becomes overwhelmed. The
following two studies examined surrogates’ preferences about provision of some types of clinical information. D. B. White, Evans, Bautista, Luce, and Lo (2009) studied 169 surrogates of critically ill patients. After viewing standard videos in which the physician provided a clinical update and either recommended limiting life support or made no recommendation about life support, there was no consensus among participants regarding their preference for either presentation. The majority (56%) expressed preference for the presentation in which the physician made a recommendation while 42% preferred not to receive a recommendation and 2% did not report a preference. The result could possibly have been affected by the fact that the video depicted a standard scenario that did not necessarily relate to their personal situation. In a study of 179 surrogates of critically ill patients, L. R. Evans et al. (2009) found that 87% preferred to hear the physician’s prognosis even if it was uncertain as long as the uncertainty was explained. Since exemplars were not used, the participants relied on their personal situation when deciding whether they preferred to hear prognosis and treatment recommendations from the physician.

As described previously, patients often prefer that their surrogates use shared decision-making or even rely on the physician for decision-making. The medical culture is moving toward sharing decisions with both patients and their surrogates as the preferred model for medical decision-making. In an evaluation of overall decision-making, 81.2% of intensive care unit surrogate decision-makers preferred a model of shared decision-making with the physician (Heyland et al., 2003). An examination of shared decision-making during physician-family intensive care unit conferences showed that only 2% of the conferences met all of the criteria for shared decision-making (D. B. White, Braddock, Bereknyei, and Curtis, 2007). Audiotapes of 51 conferences were reviewed using a 10-item tool that had previously been shown to reliably
indicate the presence of shared decision-making in health care situations. The poorest correlation was found with families of lower educational levels. Higher levels of shared decision-making were associated with greater family satisfaction with communication \((p = .03)\), reinforcing its importance to patients and families.

There is some evidence that surrogates prefer more decision control in value-laden versus strictly medical decisions, closer to an independent decision-making process than a shared or passive decision-making process (S. K. Johnson, Bautista, Hong, Weissfeld & White, 2011). The study included two artificial scenarios: a value-laden decision scenario and a technical medical decision scenario. The value-laden scenario involved a life support decision about discontinuing ventilator support for the patient. The technical medical decision scenario involved a choice between medications for treatment. In a study of 230 surrogates of critically ill patients, 55% preferred final decision control for life support decisions, while 40% preferred shared decision-making. Significantly more control was preferred in the value-laden life support decision than in the technical decision about choice of medication. This is similar to the findings of S. C. Thompson et al. (1993), Arora and McHorney (2000), and Garfield et al. (2007) who report a patient preference for higher level of control in situations that were perceived to be related to quality of life and symptom management in contrast to strictly medical issues. The desire for increased control in value-laden decisions may be explained, at least in part, by surrogate decision-makers’ doubt about physicians’ ability to predict medical futility. In a mixed methods study of the surrogate decision-makers of 50 critically ill patients given a hypothetical scenario, 64% expressed doubt about the physician’s futility prediction, 32% chose to continue life support given a \(< 1\%\) survival estimate, and 18% chose to continue life support when informed that the patient had no chance for survival (Zier et al., 2009).
Accuracy of Surrogate Decision-Makers

Accuracy of surrogate decision-makers refers to the congruence of their decisions with decisions made by the involved patient. Studies evaluating the congruence of decisions made by patients and surrogates during critical illness would be logistically difficult as those patients are unable to express their wishes. To investigate the congruence between patients and surrogate decision-makers, studies have used hypothetical scenarios in populations of well (Corke, Lavery & Gibson, 2005), chronically ill (Seckler, Meier, Mulvihill & Paris, 1991; Sulmasy et al., 1998) or stable hospitalized patients (Suhl, Simons, Reedy & Garrick, 1994). A systematic review on accuracy of decisions made by surrogates as measured by congruence of decisions within the surrogate-patient dyad given hypothetical scenarios or vignettes demonstrated that surrogates’ decisions reflected the true wishes of the patient only 68% of the time (Shalowitz, Garrett-Mayer, and Wendler, 2006). The findings across the studies reviewed were consistent. Seckler et al. (1991) reported that chronically ill patients expressed the belief that their physicians (90%) and family (87%) would be able to correctly predict their wishes given a hypothetical cardiopulmonary resuscitation scenario under conditions of current health and progressive dementia. Neither physician nor family correctly predicted the patient decision in both scenarios (kappa < 0.3 in all scenarios; percent agreement range 59 – 88%). Interestingly, more physicians would have withheld care that the patient wanted, but family discordance with patient responses showed no consistency in the direction of the discrepant responses. Corke et al. (2005) presented a hypothetical end-of-life scenario to 30 elderly people and their potential surrogate decision-makers. Patients reported they would not want intensive treatment (83%). A majority of surrogates (i.e., 76%) concluded that the treatment was inappropriate; however, all surrogates
opted to treat the patient. The most common reasons given for choosing treatment were the need to get the family together, achieve family consensus, and be more certain of the prognosis. The literature indicates significant discordance between patient and surrogate decisions, perhaps with a trend toward more aggressive treatment choices by the surrogate though this finding is not consistent. The lack of concordance may be due to the absence of prior discussion about the patient’s wishes, the surrogate’s fear of being responsible for the patient’s death, a desire to pursue any chance of recovery (Schenker et al., 2012), or a yet unidentified reason. One study did show concordance between surrogates and patients. Emergency department patients (who were not having a neurological event) and their surrogate decision-makers were presented two hypothetical scenarios in which the patient presented with a stroke. Given a choice of tPA or no treatment, there was 96% agreement for tPA; given a choice of invasive clot removal procedure or tPA, there was 87% agreement for tPA (Bryant, Skolarus, Smith, Adelman, & Meurer, 2013). It is possible that the scenarios presented less uncertainty to the participants due to education of the general public about stroke symptoms and treatment with ‘clot busters’.

Advance directives may be helpful to surrogates. Silveira, Kim, and Langa (2010) retrospectively studied 435 individuals who were enrolled in the Health and Retirement Study, had an advance directive, and required surrogate decision-making near the time of death. Those who requested limited care by advance directive received all possible care only 7.1% of the time. Those who requested all care possible by advance directive received limited care 50% of the time. These findings are inconsistent with those of Corke et al. (2005) who found that surrogates chose to approve treatment for patients even when the patients did not want intensive treatment and Ditto et al. (2001) who found that even interventions using advance directives did not
improve congruence of decisions. None of the studies provide information to account for the discrepancy.

A single study investigated congruence of surrogate decisions with patient decisions in the scenario of actual critical illness. Eleven patients who survived liver transplant following surrogate consent for the operation due to the patient’s physiologic incapacity were queried by questionnaire. Ten of eleven agreed with the surrogate’s decision to consent. All patients believed that the surrogate should not be able to decline consent for transplant if it was recommended by the physician (Brewster, Palmatier, Manley, Hall, & Brems, 2011). This is consistent with other studies demonstrating patient desire for physician involvement in decision-making. Other studies have also shown that congruence between patient and surrogate is related to the degree of certainty of the prognosis (Corke et al, 2005; Hinderer, Friedmann, & Fins, 2015). The high congruence in the face of severe liver failure may be influenced by the certainty of death, as well as by the fact that it was only possible to query survivors.

**Perceptions and Experience of Surrogate Decision-Makers**

The initial work describing the experiences of surrogate decision-makers was done retrospectively, from weeks to years following the event of the decision or the patient’s death. At this time in 2017, the majority of these studies are over ten years old (Abbott, Sago, Breen, Abernethy & Tulsky, 2001; Jeffers, 1998; Kirchhoff et al., 2002; Tilden, Tolle, Garland & Nelson, 1995; Tilden, Tolle, Nelson & Fields, 2001; Vig, Taylor, Starks, Hopley & Fryer-Edwards, 2006), raising the question of whether the surrogate experience is different as a result of changes in health care systems, societal perceptions and expectations. A systematic review addressed symptoms experienced by family members of patients in intensive care units, finding the most frequent symptoms to be stress, depression, and anxiety (McAdam & Puntillo, 2009).
Another systematic review (Wendler & Rid, 2011) of the effect of decision-making on surrogates also noted stress as the most common symptom. Within the systematic reviews, the results were consistent across the time span of the 1990s to the present. The most commonly described negative effects of decision-making on the surrogates were stress, guilt, and doubt about making the right decision.

More recent work related to the experience of surrogate decision-makers has been completed in the critical care environment. This likely reflects the heightened awareness of the importance and increase in surrogate decision-making required in the high technology environment. Gries et al. (2008) found that increased family satisfaction with decision-making was associated with withdrawal of life support and documentation of palliative care measures. One retrospective study focused on intensive care nurses’ interactions with and support of families serving as surrogate decision-makers (Lind, Lorem, Nortvedt & Hevroy, 2012). The nurses were perceived by family members as vague, evasive, and non-participants in meetings with family and physicians. Since the study was conducted in Norway, this could reflect cultural norms of Norwegian nurses but further investigation is warranted.

Surrogates experienced high levels of stress related to the conflict between the desire to make decisions as the patient would want and to pursue any hope of recovery so as not to feel responsible for the patient’s death (Schenker et al., 2012). Surrogate decision-makers of critically ill patients also described stress related to uncertain outcomes and lack of clear, consistent information from providers (Iverson et al., 2014). Among 449 family members of critically ill patients, 51.7% had a significant degree of learned helplessness, as did 50% of those family members who were designated as surrogate decision-makers (Sullivan et al., 2012). The degree of learned helplessness was positively correlated with stress level and inversely related to
education level. The presence of an advance directive or a do not resuscitate order was associated with lesser degrees of learned helplessness, perhaps because the decision was already in place. Surrogates who had less confidence in their role as decision-maker were significantly less likely to have experience as a surrogate or to have had a prior discussion with the patient about their wishes, and were more likely to have had poor communication with the critical care physician (Majesko et al., 2012).

Coping style has been shown to have some association with depressive symptoms. A study of 210 family surrogate decision-makers of chronically critically ill patients, those with a coping style classified as ‘monitors’ on the Miller Behavioral Style Scale had higher degrees of depression (Hickman, Daly, Douglas, & Clochesy, 2010). Avoidant and problem-focused coping 30 days after hospitalization were associated with increased posttraumatic stress in 77 family decision-makers of adult critical care patients (Petrinec, Mazanec, Burant, Hoffer, & Daly, 2015). Coping style has also been shown to have an association with health care decisions made by surrogates. Three coping profiles were identified in a study of 345 participants: adaptive copers, maladaptive copers, and disengaged copers. When presented with a vignette-based simulated ICU experience, disengaged copers (15%) were more likely to refuse dialysis treatment for an adult sibling than adaptive copers (7%) or maladaptive copers (5%) ($p=0.03$).

Anxiety and depression are high among surrogates and family members of critically ill patients. Several studies that measured anxiety and depression also asked the surrogate to identify the type of decision-making process that they preferred or that was employed during their experience. Passive decision-making refers to a paternalistic model in which the physician makes medical decisions. Independent decision-making refers to a process in which the surrogate makes decisions without physician input. Shared decision-making refers to a process
in which there is discussion and finally agreement between the physician and the surrogate, though the relative contributions of each to the decision may vary. Azoulay et al. (2004) reported that among the family members of 357 patients in a French intensive care unit, 73% had significant anxiety, 35% had depression, and 35% had poor comprehension of the patient’s status. Shared decision-making (with the physician) was desired by 47% of participants but only occurred in 15% of cases. Anderson et al. (2009) found that passive decision-making (physician driven), as opposed to use of independent or shared decision-making, was associated with higher rates of anxiety (88% vs. 42%) and depression (50% vs. 8%). The question was raised whether the higher rates of anxiety and depression might be related to being denied shared decision-making (their preference) rather than to the use of passive decision-making itself. This could be true in the Azoulay’s (2004) study as well, since in that case there is documentation of the discrepancy between the type of decision-making desired by the surrogate versus what occurred. Additionally, it is not clear from these studies whether the anxiety and depression experienced by surrogates was related to the burden of decision-making, regardless of method, or solely to the illness of the family member. There is also some evidence of decisional conflict and regret experienced by surrogate decision-makers for the chronically critically ill (Hickman, Daly, & Lee, 2012). This is another possible contributing factor to developing anxiety and depression. The quantitative methodology of these studies does not allow for determination of the direction or cause of the relationships.

**Summary**

The empirical work on surrogate decision-making during critical illness is primarily observational, retrospective, or reliant on the use of hypothetical scenarios. During critical illness, surrogates prefer provider involvement in decision-making but desire control over value-
laden decisions such as terminal extubation. Congruence between patient and surrogate
decisions is poor even when the surrogate knows the patient’s wishes from prior conversation or
an advance directive. The responsibility of surrogate decision-making during critical illness has
multiple negative effects (stress, anxiety, depression) on surrogates that extend beyond the time
of the event. There are suggestions that factors such as advance directives, communication
between patient and family, previous interaction or communication with providers to establish
rapport, and others could improve the process of decision-making for the surrogate. The current
studies, however, do not deliver sufficient data to support cause and effect and the development
of intervention studies.

Bioethical Perspectives in Surrogate Decision-Making

Review of the bioethics literature presents some challenges for those trained in clinical
professions. The first challenge is determining how bioethics and bioethicists are defined in a
particular paper. The second is determining what constitutes bioethics scholarship versus the
opinion of the author.

The field of bioethics is interdisciplinary in educational background and flexible in
requirements for defining who is a bioethicist. The variety of primary disciplines contributes to
the ongoing discussion of whether bioethics exists as a distinct profession, who it represents, and
what its goals are or should be (Callahan, 2014; J. H. Evans, 2012; J. H. Evans, 2014a; J. H.
Evans, 2014b; Flamm & Kodish, 2014). Consequently, one cannot determine whether a paper
represents the bioethical perspective based on the background or credentials of the author.

An early focus of bioethics was medical ethics. The origins of medical ethics lie in the
intersection of philosophy and ethics. Philosophical analysis was used “to clarify common
ethical dilemmas through the application of ethical theory, casuistic reasoning and logical
analysis” (Pearlman, Miles, & Arnold, 1993, p. 197). As empirical researchers began to investigate those same ethical problems, philosophers found it necessary to discuss the contributions and limitations of empirical research to bioethics (Pearlman et al., 1993). Empirical researchers must also consider the contributions and limitations of bioethical analysis. Care must be taken to differentiate analysis by application of ethical theory from authors offering only their opinions.

The work discussed here includes both empirical studies and theoretical scholarship in bioethics. First, a case is made to justify surrogate decision-making. Following are discussions of the ethics guidance principles for surrogate decision-making, bioethical theoretical scholarship including ethical theories, and bioethical issues in surrogate decision-making.

**Justification for Surrogate Decision-Making**

It is generally accepted that people have the right to make their own healthcare decisions. Respect for an individual’s autonomy related to health care is based in the rulings from the Nuremberg trials (The Nuremberg Code, 1996) and statements of human rights in the Declarations of Helsinki (WMA General Assembly, 2013) and the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). From a legal perspective, the courts have upheld the rights of patients to refuse interventions (*Fosmire v. Nicoleau*, 1990; *Stamford Hospital v. Vega*, 1996). When a person loses decisional capacity, whether due to mental or physiological reasons, those decisions must be made by another process. The Patient Self Determination Act (1990) gives people the right to determine their own healthcare and make an advance directive to define their healthcare decisions. It also required healthcare institutions that receive federal funding to inform patients of their rights on admission, document their advance directives and comply with state laws
related to advance directives. Most states have enacted statutes that identify the default authority for healthcare decision-making for incapacitated persons, usually by kinship priority. In the absence of an advance directive, most states require that the surrogate make decisions by using the substituted judgment and best interest standards as described in the next section (Wynn, 2014). Pennsylvania law defines advance directives (both living wills and health care power of attorney). If a health care representative has not been identified by a person, the order of priority in Pennsylvania is: (a) the spouse unless an action for divorce is pending and the adult children of the person who are not children of the spouse, (b) an adult child, (c) a parent, (d) an adult brother or sister, (e) an adult grandchild, and (f) an adult who has knowledge of the person’s preferences and values, including, but not limited to, religious and moral beliefs (Pennsylvania [PA] Code, Title 20, Chapter 54, 2006).

Discussion of the moral justification for family surrogate decision-making often relies on the same standards of substituted judgment and best interest as the legal justification (Arnold & Kellum, 2003). Potential conflicts in the surrogate’s moral authority have been identified (Arnold & Kellum, 2003; Eliott & Olver, 2007a; Eliott & Olver, 2007b; Hyun, 2003; Nelson & Lindemann, 2007). These conflicts can be categorized as the surrogate making decisions based on their own values and best interests, rather than the patient’s values and best interests; the surrogate being incapacitated by emotional involvement with the patient; and the surrogate lacking the requisite medical knowledge to make appropriate decisions. A qualitative study of physicians about the ethical framework for surrogate decision-making indicates that physicians consider surrogates’ wishes and interests and their own clinical judgment as well as the patients’ wishes and interests (Torke, Simmerling, Siegler, Kaya, & Alexander, 2008), supporting a model of shared decision-making authority.
Patients lacking capacity without an identifiable surrogate present an additional problem. The issue is beginning to be addressed legislatively but there is not legal guidance in most jurisdictions (Pope & Sellers, 2012). Some have recommended an intensive search for a person capable as acting as surrogate decision-maker (Smith & Luck, 2014). Pennsylvania law is beneficial in this regard, as the definition of health care representative includes “an adult who has knowledge of the person’s preferences and values, including, but not limited to, religious and moral beliefs” (PA Code, Title 20, Chapter 54, 2006). Some have recommended involvement of social services, ethics committees, and hospital administration (Hyun et al., 2006). Most often, decisions for patients without a surrogate decision-maker are made by the physicians providing their care without institutional or judicial review (D. B. White, Curtis, Lo, & Luce, 2006; D. B. White, Curtis, et al., 2007).

**Ethics Guidance Principles for Surrogate Decision-Making**

Buchanan and Brock (1986) describe three guidance principles (advance directive, substituted judgment, and best interest) for surrogate decision-making along with conflicts that may occur among them. Conflicts among the principles arise when a different decision can be reached depending on which principle is used to make the decision. Though written 28 years ago, these decision-making principles and their related conflicts remain pertinent to current clinical practice. The three hierarchical principles are expected to be a guide for the surrogate decision-maker (Beauchamp & Childress, 2013). These principles are intended to be used when a person cannot make their own healthcare decisions. An important point is that they are intended to be used in the specified order as will be explained below: advance directive, substituted judgment, best interest (Buchanan & Brock, 1986).
The construct of individual autonomy developed from Western democracy’s respect for personal liberty (Beauchamp & Childress, 2013). The decisional hierarchy is based on autonomy and the notion that the role of the surrogate decision-maker is to preserve the patient’s autonomy. Therefore, the first principle to apply is the advance directive. The advance directive principle states that when an advance directive exists, it is to be followed (Buchanan & Brock, 1986, 1990). This is a formal written document previously completed by a competent patient to direct decisions about their medical care should they become incapacitated. It is sometimes referred to as a living will. Designation of a medical power of attorney to make decisions may be part of the written document; it identifies the surrogate decision-maker and whether they have the authority to override the decisions in the advance directive. In the absence of an advance directive, the surrogate is required to make a decision and either substituted judgment or best interest will apply.

The second principle to apply is substituted judgment. The substituted judgment principle states that the surrogate should make the decision that the patient would choose given the current circumstances (Buchanan & Brock, 1986, 1990). Braun, Naik, and McCullough (2009) posit that substituted judgment actually calls for the surrogate to provide a report rather than make a decision since the decision is based on what was previously expressed by the patient. The decision is made on the basis of what the patient has indicated in the past or what the surrogate believes the patient would decide if able based on prior discussion with and knowledge of the patient and their values. Substituted judgment aligns with System 1 of the dual process model in which decisions are made intuitively or from prior knowledge and experience. Decisions are made quickly and do not require extensive consideration.
When the surrogate decision-maker is not certain of the patient’s wishes (either expressed or able to be determined by consideration of their known values), the best interest principle is applied. The best interest principle states that the surrogate should make the decision by considering all aspects of the patient’s interests to determine the greatest benefit (Buchanan & Brock, 1986, 1990). In health care decision-making, this may involve seeking out information about the disease process, treatment options, and prognosis. Best interest standard aligns with System 2 of the dual process model in which decisions are made by rational consideration of all aspects of the situation. Table 1.1 compares the decision-makers and basis for making decisions using each of the guidance principles.

<table>
<thead>
<tr>
<th>Decision-Making Principle</th>
<th>Decision-Maker</th>
<th>Basis for Decision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substituted Judgment</td>
<td>Surrogate</td>
<td>Belief of what patient would choose based on prior conversation or knowledge of patient values</td>
</tr>
<tr>
<td>Best Interest</td>
<td>Surrogate</td>
<td>Balance of prognosis, risk/benefit to achieve maximum benefit to the patient</td>
</tr>
</tbody>
</table>

The conflicts among the three guidance principles become apparent in practice. A decision based on an advance directive may be different from the surrogate’s substituted judgment because current conditions may not have been anticipated in the patient’s advance directive document. The advance directive and substituted judgment principles may both conflict with the patient’s best interest at that point in time. The best interest principle considers
only the patient’s status at the time of the decision, while advance directive and substituted judgment principles consider the patient’s prior expressed wishes and values in arriving at a decision. The fact that the conflicts described by Buchanan and Brock (1986, 1990) have not yet been resolved to achieve an agreed upon mode of surrogate decision-making indicates the complexity of the issue.

Others have made similar arguments about the conflicts and limitations of substituted judgment and best interest standards (Arnold & Kellum, 2003; Torke, Alexander & Lantos, 2008). Substituted judgment is justified as the equivalent of the patient’s right to autonomy carried out by the surrogate who understands what that autonomous decision would be based on previous discussion with and knowledge of the patient. The principle is not complete; a competent person can change their mind. In addition, the specific health care situation with all of the current variables is unlikely to have been discussed by the patient in the past. As previously discussed, the surrogate may be influenced by their own values and best interests (Arnold & Kellum, 2003; Eliott & Olver, 2007a; Eliott & Olver, 2007b; Hyun, 2003; Nelson & Lindemann, 2007). They may hesitate to make a decision by which they feel responsible for the patient’s death (Schenker et al., 2012). Advance directive principle has similar justification and limitations to substituted judgment. Best interest is justified as decided by the surrogate, who best understands the patient’s values and interests. The principle is also not complete because best interest standards consider what is ‘best’ based on populations of averages, not necessarily the individual.

Buchanan and Brock (1986, 1990) suggest that advance directive should be used when possible, followed by substituted judgment, and finally best interest when the patient’s wishes are not known. A survey of 1156 physicians demonstrated that the majority believed that the
surrogate decision-maker should prioritize what the patient would have wanted (substituted judgment) over what they believe is their best interest (M. P. Comb, Rasinski, Yoon, & Curlin, 2013). This perspective honors patient beliefs and values when the patient is not capable of expressing them independently. However, when presented with a vignette in this same study, most physicians believed it was not appropriate for a surrogate to refuse lifesaving treatment based on substituted judgment. Since there was not a qualitative component to the study, the question of why this contradiction appears is not answered. Despite the expressed beliefs, it is difficult to determine what actually happens in practice since this has not specifically been studied.

Torke, Alexander, and Lantos (2008) proposed that the ethical principle of respect for persons resolves the conflicts among the three ethical principles as described above. Respect for persons involves consideration of the patient’s life story. The authors posit that in doing so, it is a broader principle than autonomy. In the context of surrogate decision-making, the principle of autonomy can only include decisions in which the patient’s wishes were explicitly expressed in the past. Basing decisions on the principle of respect for persons, however, includes consideration of the patient’s values and interests within the current situation. Beauchamp and Childress use the term respect for persons with a different meaning (Beauchamp & Childress, 2012; Lysaught, 2004). In their view, respect for persons describes an aspect of autonomy, referring to the right of a person to their own judgments. In that context, respect for persons applies only to the autonomous individual and would not be relevant in the context of surrogate decision-making.

Others describe essentially the same concept as Torke, Alexander, and Lantos’s (2008) respect for persons using the term authenticity. Brudney (2009) describes authenticity as the
ability to be a distinctive individual with beliefs and values and to make decisions (or have the surrogate make decisions) based on those beliefs and values. Scheunemann, Arnold, and White (2012) state that an authentic decision is a decision informed by knowledge of the patient’s values and motivated by an intention to deliver care that respects the patient as a person. Both respect for persons and authenticity could be used within the context of the three guidance principles. They place the considerations of the surrogate in the context of the patient when making either a substituted judgment or a best interest based decision, allowing for a decision based on the patient’s values and needs.

Berger, DeRenzo and Schwartz (2008) discuss the difficulty in applying the ethical principles to clinical practice. They discuss substituted judgment and best interest at opposite ends of a continuum with recommendations for clinical practice falling in the middle. The implication is that both the patient values and medical condition and prognosis must be considered in making an optimal decision. Sulmasy and Snyder (2010) propose an integrated model of surrogate decision-making – substituted interests. Their intent is to reframe surrogate decision-making to apply the patient’s authentic values, wishes, and real interests, as best they can be known. Wendler and Phillips (2015) point out that substituted judgment cannot replicate a person’s autonomous decision and propose the endorsed life approach to surrogate decision-making. This involves making decisions consistent with promoting the course of life the patient valued (Phillips & Wendler, 2015). Dresser (2015) argues that the endorsed life approach is not superior to the original concept of substituted judgment, acknowledging that application of any of these principles in real life is “messy”. Ultimately, each of these approaches is an attempt to make decisions consistent with patient values that are likely to have a result also consistent with
those values. Clinical situations requiring surrogate decision-making are complex and may require multiple considerations and approaches.

**Advance Directives.** Despite a great deal of theoretical literature, there is a paucity of empirical literature on use and choice of guidance principles in surrogate decision-making. The majority of work has been done on advance directives. In order for an advance directive to direct medical decisions or to guide the surrogate decision-maker, it must have been completed when the patient was competent. Among patients who require hospitalization, completion rates are not high, limiting general usefulness of advance directives. Further complicating the situation, completed advance directives are often not available in the medical record (House & Lach, 2014). A retrospective review of patients who died in a single hospital indicated that 22.2% had advance directives, 25% of which did not have a do not resuscitate (DNR) order at time of death (Morrell, Brown, Qi, Drabiak, & Helft, 2008). Similarly, a study of 44,768 admissions over a 5-year period demonstrated that 12.7% of heart failure patients had an advance directive (Butler et al., 2015). The factors associated with a higher chance of having an advance directive were older age, female, white, higher socioeconomic status, higher risk for adverse outcomes, length of stay $\geq$ 5 days, hospice discharge, palliative care consult, and a do not resuscitate order. In a cardiac intensive care unit, 64.4% of patients did not have an advance directive prior to admission; only 9% completed an advance directive during the hospitalization with slightly higher rates in those with more comorbidities and those who died in the ICU. Of those who declined to complete an AD, 33.8% later said they did not understand the question (Johnson, R. W., Zhao, Newby, Granger, & Granger, 2012). Even among the chronically critically ill, only 82% in one study and 57% in another had completed an advance directive (C. G. Kelley, Lipson, Daly, & Douglas, 2006). Abbo and Volandes (2008) argue for requiring advance directives of
all patients. The findings of these studies raise important ethical questions regarding availability of advance directive as an option for making decisions.

One of the most important factors affecting the ability to achieve the goals of the advance directive may be the time frame relative to end of life in which it is completed. Bischoff, Sudore, Miao, Boscardin, and Smith (2013) found that the mean duration between completing the advance directive and death in a nationally representative sample of elderly patients was 61 months. Similarly, Silveira et al. (2010) found that ADs were completed a mean of 43.5 months before death. Changes in health (e.g., new diagnoses or downward trajectories) and major life changes (e.g., death of a loved one) could reasonably be expected to affect a person’s choices for care. If the advance directive is completed prior to one of these changes, it may not reflect the person’s current values and preferences. In the United States, there is not a time limit on advance directives, though other countries have addressed this issue. France, for example, requires an advance directive to be renewed every three years (Andorno, Biller-Andorno, & Brauer, 2009; Horn, 2014). Though the implications are logical, the effect of advance directive timing on congruence with the person’s current values has not been studied.

Billings and Bernacki (2014) discuss this problem with timing, calling for prognostic models. The capability of prognosticating, even in terminal illness, is limited. This issue of timing might be better addressed by more frequent completion or updates of the advance directive decisions. When decisions are guided by an advance directive, family members and health care providers presume that they are following the patient’s wishes. If the patient’s values and preferences have changed since the advance directive document was signed, reliance on the advance directive actually results in choices that the patient would not have autonomously made. In addition, the advance directive may not address the specific treatments under consideration
As discussed previously, there is frequently poor congruence between patient and surrogate decisions (Corke et al., 2005; Seckler et al. 1991; Shalowitz et al., 2006; Suhl et al., 1994). Since these studies were not conducted during real clinical situations impacting the patient, it is difficult to determine the implications of this lack of congruence. It may be due to the hypothetical nature of the research question. Since the surrogates are more aggressive in treatment decisions, it may be due to the surrogate’s reluctance to feel responsible for the patient’s death. When comparing surrogate decisions to the advance directive, it may be reflective of a process in which the surrogate is able to consider all aspects of the clinical situations – information that was not available to the patient when they completed the advance directive.

An accurate, current advance directive can provide guidance to both family and health care provider in their roles as decision-makers. In a qualitative study of surrogate decision-makers of hospitalized older adults, patient preferences, including those defined in advance directives, were one of the major considerations of the surrogates. The surrogates “often expressed the need for more information about what the patient would have wanted in cases where the patient’s wishes were not known” (Fritsch, Petronio, Helft, & Torke, 2013, p 7). In the absence of that information, surrogates are obliged to make decisions based on other factors, such as their own preferences or risks and benefits as described by the healthcare clinicians. Hickman and Pinto (2014), in a study of 489 surrogate decision-makers of chronically critically ill patients, found that the presence of an advance directive decreased decisional burden by decreasing the surrogate decision-maker’s role stress and severity of symptoms of depression.

In summary, the literature on advance directives leads to the conclusion that they may be helpful to the surrogate decision-maker, but may also be misleading. The majority of patients
who require a surrogate to make decisions about their healthcare will not have an advance directive in place. Many who have an advance directive will not have updated it in several years, increasing the possibility that it no longer reflects their current preferences. Use of an advance directive decreases decisional burden of the surrogate decision-maker but it is unclear whether it improves congruence with the decision the patient would have made independently.

**Bioethical Theoretical Scholarship in Surrogate Decision-Making**

Most of the empirical literature on surrogate decision-making does not cite a theoretical basis for the paper, particularly in discussion of ethics. The empirical work is largely found in the medical literature (which does not commonly use a theoretical framework) and the nursing literature (which may have a theoretical framework that is not explicitly included in the publication). A qualitative systematic review of the literature addressing surrogates’ experiences in end-of-life planning for incapacitated adults identified only 7 research papers with explicitly stated ethical theories, principles, or concepts (Kim, Deatrick, & Ulrich, 2016). Only one used a specific ethical theory (casuistry); the remainder focused on some combination of autonomy, substituted judgment, and best interest. There is, however, a significant body of theoretical scholarship on surrogate decision-making that analyzes the issue by application of ethics theory.

**Bioethics Theories.** There is such variation in the theoretical frameworks used in the field of bioethics that some have questioned as to whether bioethics exists as a discipline (Turner, 2009). The multiple theoretical frameworks, however, provide a variety of viewpoints rather than a single dogmatic approach. The pattern of multiple theoretical approaches is true of many disciplines, and not unusual within health care fields where heterogeneity of people and situations demands a more flexible approach.
Descriptions of the common ethical theories are readily available (Beauchamp & Childress, 2013; Steinbock, 2007; Sugarman & Sulmasy, 2010; Taylor, 2013). Theoretical scholarship evaluates the application of the theories to the practice of bioethics.

Review of the theoretical literature in bioethics does allow an interpretation of how each of the frameworks could be applied to the situation of surrogate decision-making. Virtue ethics, consequentialism, deontology, and ethics of care are the most commonly cited abstract theories applied in bioethics. Casuistry and principlism are applied ethical frameworks rather than abstract theories. Casuistry relies on case-based reasoning is used in clinical healthcare ethics. Principlism is the most commonly used framework in clinical healthcare ethics. In the section that follows, each framework is discussed including relevant theoretical scholarship and potential application to surrogate decision-making.

**Virtue ethics.** Virtue ethics is the oldest of the ethical theories, based in the writings of Plato and Aristotle. Virtue refers to the ‘highest good’ or well-being, which is the ultimate goal of human action for the reasonable person. It is a combination of the intellectual, which is taught, and the moral, which becomes a habit. Virtue requires balance. It can be thought of as the mean between two extremes for a particular person, e.g., foolhardiness and weakness are the extremes and courage is the virtuous mean. It is important to understand that virtue encompasses an entire lifetime, not a single action (Beauchamp & Childress, 2013; Pellegrino, 1995).

Virtue ethics is often discussed as a basis for healthcare ethics (Begley, 2005; Giblin, 2002; Pellegrino, 1995). It is reasonable to desire clinicians who are morally good with the highest motives for choosing and carrying out decisions. It has been suggested by some that the clinician operating based on virtue ethics should make all decisions based on the highest good for the patient (Pellegrino, 1995; Rothman, 2000; Wynia, Lathman, Kao, Berg, & Emanuel,
If these decisions are contrary to the well-being of others, including the clinician, it must be considered whether the virtue being expressed is in balance to the mean. A clinician may choose to treat patients 16 hours every day for their well-being; but when the results include destruction of his family and his own physical health, the action cannot be considered virtuous.

Three papers use virtue ethics as the theoretical basis for qualitative investigation: a patient case study on honesty about diagnosis (Begley, 2008), narratives from patient living with end stage renal disease (Dekkers, Uerz, & Wils, 2005), and examination of virtuous acts among medical practitioners (Little, Gordon, Markham, Rychetnik, & Kerridge, 2011). There is support in the theoretical scholarship of bioethics for use of virtue ethics, if not solely, then in conjunction with deontology (Saunders, 2011) and principlism (Campbell, 2003; Saunders, 2011). Bock (2014) proposes the use of a virtue-based approach in evaluating the legitimacy of decisions made by the surrogate.

Using virtue ethics in the scenario of surrogate decision-making, the surrogate would make decisions based on the goal of achieving the highest level of well-being for the patient (not exclusively physical well-being). The fact that the surrogate would also be obligated to consider his or her own well-being is a potential conflict. However, the standard for virtue ethics is based on ‘the reasonable person’, one could expect that the surrogate could arrive at the same decision as the patient (if the patient were able to function independently). The surrogate might describe the motivation for his decision as “doing the right thing” or “doing the best thing” for the patient.

Consequentialism. Consequentialism refers to a group of ethical theories that hold that actions are judged as right or wrong based on the balance of good and bad consequences. Utilitarianism is the most prominent of these approaches. It is often summarized as doing the greatest good for the greatest number. Actions are right in proportion to the degree they tend to
promote happiness and wrong as they tend to promote the reverse of happiness. The judgment of consequences and utility is based on an impartial person giving equal weight to all affected parties (Beauchamp & Childress, 2013; Mill, 1879).

Consequentialism and utilitarianism are rarely discussed overtly in the healthcare literature. These may be a reasonable approach to ethical decisions, particularly in the area of population health and situations in which there is a shortage of resources. The terminology related to these ethical approaches could be avoided because of the belief of the general public in the United States that all things in health care should be available to all people at all times. In regard to surrogate decision-making in particular, the surrogate is expected to make a decision for another individual. Consideration of others is likely not relevant.

The utilitarian approach to surrogate decision-making requires the surrogate to consider all involved parties when making decisions for the patient. Affected parties include the patient, surrogate, and family. These parties may be a natural consideration for the surrogate. Controversy may ensue in consideration of other possible affected parties – physicians, nurses, the hospital, and/or society. The surrogate might describe the motivation for his decision as “it’s the best thing for everyone involved” or “someone else would be helped more by it.”

Deontology. Deontology is a theoretical approach to ethics grounded in reason and duty. The value of a person’s actions is based on the acceptability of their motivation for action. The optimal moral action only exists when the person is motivated by a desire to do what is morally required. Even the most positive of actions is not moral if it is driven by ulterior motivation. There are several versions of the categorical imperative, a criterion for judging actions. The most widely used categorical imperative is: one must act to treat every person as an end and never as a means only (Beauchamp & Childress, 2013; Kant 1785).
As an ethical approach, deontology is rarely mentioned in the healthcare literature. Surrogates’ responses in qualitative studies may reflect a sense of duty but the motivation for their decisions is not clear (Jeffers, 1998; Kirchoff et al., 2002; Schenker et al., 2012). However, the duty of clinicians to patients is often discussed. It is a clear expectation that clinicians have a duty to take actions that are in the best interest of their patients. According to deontology, the clinician’s actions are only moral if the motivation is to perform a moral action. In the case of a patient in need of emergent surgery, the surgeon who performs the operation because he has a moral duty to the patient acts morally; the surgeon who performs the operation because there is no one else available and he will be sued if he refuses does not act morally even though he performs the same action.

From the perspective of deontology, or Kantian ethics, surrogate decision-making should be grounded in doing that which is morally required. Since the surrogate is making decisions for the patient, the patient must be treated as an end in himself, not as a means to the surrogate’s end. Therefore, only considerations related to the patient alone would apply. The surrogate might describe the motivation for his decision as “it’s the right thing to do for her” or “I need to make the decisions that she would want.”

*Ethics of Care.* Ethics of care is an ethical theory related to feminist ethics. Both focus on social ideals, caring and compassion (Baier, 1987; Gilligan, 1982). The terminology of feminist ethics may be used more often related to ethics in general (Held, 1990). Ethics of care is perhaps the terminology used more often related to healthcare ethics. The prominence of ethics of care, as opposed to other ethical theories, has increased as technology has advanced and health care has become increasingly depersonalized (Sprengel and Kelley, 1992). Caring has also been considered a virtue, creating a relationship between the ethics of care and virtue ethics.
(Benner, 1997). Ethics of care is not commonly used in discussions of surrogate decision-making and the surrogate-patient relationship but it is often used in relation to nursing and the nurse-patient relationship. Because of this, it may be a particularly salient theory for consideration by nurses. Stonestreet (2014) argues for a “best judgment” model of surrogate decision-making grounded in the idea of love. Though not using the terminology of ethics of care, the model is based in the same values.

Surrogate decision-making based on the ethics of care would require the surrogate to make decisions reflecting care and compassion for the patient. The only important factor is to choose what is best for the patient from a position of genuine caring. The surrogate might describe the motivation for his decision as “this is what I feel is best for her” or “I did just what she always said she wanted.”

_Casuistry._ Casuistry involves the use of case comparison and analogy to reach a conclusion (Beauchamp & Childress, 2013). Casuists are skeptical of rules and principles but do use both when they are consistent with analysis of the case. New cases are decided by comparison to precedent paradigm cases.

The healthcare literature includes countless numbers of case reports on any imaginable topic. Whether these cases rise to the level of paradigm cases, however, is left to the judgment of the individual reader. Each practitioner uses paradigm cases and their own moral history to draw analogies to the current case and make a judgment (Cudney, 2014). Medical practice is often taught by case examples. In keeping with the practice, casuistry may be an effective perspective for physicians considering surrogate decision-making. Casuistry is not cited specifically in the surrogate decision-making literature. Review of qualitative work on surrogate decision-making does demonstrate that surrogates rely on their previous experiences (Jeffers,
1998; Kirchoff et al., 2002; Schenker et al., 2012), perhaps using those as their personal paradigm cases.

Surrogate decision-making based on casuistry requires the surrogate to consider similar cases to the current patient situation. These may come from personal prior experience, narratives from family and friends, or stories heard from news reports. The most valid cases are those most similar to the current case. The surrogate might describe the motivation for his decision as “we took dad off the ventilator and it was the best thing” or “look at Jahi McMath – they said she was brain dead, but now she’s alive.”

Principlism. Principlism is an ethical framework based on principles derived from the norms of common morality. The four principles are autonomy, nonmaleficence, beneficence, and justice. Autonomy represents a norm of respecting and supporting autonomous decisions. Nonmaleficence represents a norm of avoiding the causation of harm. Beneficence represents a norm of relieving, lessening, or preventing harm, or of providing benefits. Justice represents a norm of fairly distributing benefits, risks, and costs. None of these principles has primacy over the others but all must be considered, weighed, and balanced against the others (Beauchamp & Childress, 2013). Health care providers’ education in ethics is based on this framework (Goldberg, 2009). The terminology of principlism is commonly heard and used by the general public, particularly the concept of autonomy – in written and electronic publications, audiovisual media, and conversation focused on the rights of the individual. Though autonomy is discussed frequently in the medical and surrogate decision-making literature, principlism as a whole is not discussed outside of the bioethics literature.

Surrogate decision-making based on principlism must involve consideration of the norms represented by each of the four principles. Depending on the specifics of the decision, some
principles may be weighed more heavily than others. The surrogate might describe the motivation for his decision as “this is how she wanted things” or “I don’t want to do her any harm” or “I know it will help” or “it’s fair.” Though autonomy is most often considered, a decision based on principlism should reflect all of the principles.

Other theories. The theoretical literature in bioethics includes multiple other proposed theories for clinical decision-making and surrogate decision-making. Baeroe (2008) recommends a framework of reasonableness in deciding for others that incorporates personal autonomy with regulation by morality. Rhodes and Holzman (2004) describe a model for accepting surrogates’ decisions based on the standard that the decision is not unreasonable. Padela, Malik, Curlin, and de Vries (2014) argue that the principle of respect for persons best informs clinical decision-making from an ethical perspective. The proposed theories found in the literature are often variations on and attempts to improve one of the standard theories (most often principlism). This search to develop the optimal bioethical theory for use in clinical practice is not limited to bioethicists. Drolet and Hudon (2014) describe a theoretical framework for ethical issues in physiotherapy practice that combines consequentialism, deontology, virtue ethics, and professional values.

J. W. Glaser’s theoretical model of Three Realms of Ethics has been used in the context of the American Nurses Association’s Code of Ethics for Nurses (Haddad, 2015). J. W. Glaser (1994) focuses on beneficence. The model identifies three spheres of beneficence: individual, institutional, and societal. Ethical issues can be viewed from all three perspectives, but in any specific situation, one sphere may take precedence. In the case of surrogate decision-making, the surrogate’s priority would be expected to be the realm of the individual with secondary consideration to the institutional and societal realms.
Bioethical Conceptual Framework - Principlism

The empirical literature related to bioethics and surrogate decision-making does not include evidence for or even evaluation of any of the bioethical theoretical frameworks to be used in practice. No study on surrogate decision-making defines the bioethical theoretical basis for the study design or analysis. The most common bioethical concept cited is autonomy, in reference to the surrogate representing the autonomy of the patient. Even in those cases, principlism as a whole is not cited.

Despite their absence in the literature, the concepts inherent in principlism are rooted in health care. It was developed as a method to evaluate decisions in medical ethics (Beauchamp & Childress, 2013). Since the health care providers who interact with surrogate decision-makers have been educated in ethics based on principlism and that terminology is used in the lay literature, it can reasonably be expected that the surrogate decision-makers will be most familiar with at least some concepts of principlism. In addition, since it is the primary ethical framework familiar to critical care clinicians (Goldberg, 2009), it could be expected that findings framed by principlism would be well positioned to apply to clinical practice. Therefore, the chosen bioethical conceptual framework for this study is principlism.

Principlism is an applied theoretical framework commonly used in clinical healthcare ethics. Despite this, my informal survey of 20 nurses and physicians in academia and critical care revealed none who had ever heard the term principlism. All were aware of the four principles of autonomy, nonmaleficence, beneficence, and justice and could define them. Of the four principles, the empirical literature on surrogate decision-making primarily refers to autonomy. It seems that with the focus on autonomy, it has been forgotten that the four principles are to be used together as a bioethical framework. American bioethics and medical
ethics developed in a diverse society with an emphasis on individualism during a period in which society was moving away from paternalism in medicine and laws to protect individual rights were being implemented (Brazier, 2006; Coggon & Miola, 2011; Dunn & Foster, 2010; Moreno, 2007, Tauber, 2001). This likely accounts for the continuing emphasis on autonomy despite a set of principles that are meant to hold equal weight.

Autonomy requires that a person act intentionally, with understanding, and without controlling influences that determine their choice. Nonmaleficence prohibits infliction of evil or harm. Beneficence requires taking action to prevent or remove harm and to promote good. Justice can be defined as fairness and equality, not only among equals. These condensed definitions describe the major ideas to be considered when applying principlism to any health care decision, including those made by a surrogate decision-maker. They are intended to be used together with none more important than the others (Beauchamp & Childress, 2013). It has been questioned whether principlism can promote population health with its emphasis on autonomy (Azetsop & Rennie, 2010). It can, when the entire framework is considered.

Principlism has been compared to traditional moral and ethical theories, most commonly virtue ethics and casuistry (Beauchamp, 1995; Campbell, 2003; Cudney, 2014; Pellegrino, 1995). Casuistry involves paradigm cases to guide decisions. These cases are defined by facts and values that are essentially not different than those that would be defined by the four principles. Virtue ethics guides decisions based on virtues which, when examined, are consistent with values defined by the four principles. Both casuistry and virtue ethics are compatible with and complement principlism. The criticisms occur when individual principles are cited without using the complete framework (Beauchamp, 1995).
Bioethical Issues in Surrogate Decision-Making

Examining surrogate decision-making from a bioethical perspective is not as simple as applying the guidance principles of advance directive, substituted judgment, and best interest and determining an answer. It is not as simple as choosing a bioethics theory to follow to the correct answer. Multiple issues can complicate the course of action in any given situation. These issues may relate to the patient, the surrogate, or the healthcare provider.

We expect patients to make independent decisions about their healthcare based on their own values. The expectation of the surrogate decision-maker is that those values will be honored. There are times when the patient’s choice may be influenced by concern for being a burden on the family (Berger, 2009; DeRenzo, 2009; Derse, 2009; Levine, 2009; Nelson, 2009). Though valid from the patient’s perspective, this is difficult for most surrogates who may not consider the patient’s care to be a burden. Patient preferences may change near the end of life, constructed from rational, nonrational, and contextual influences (M. T. White, 2014). The surrogate must decide whether to follow previously expressed wishes or wishes expressed now when the patient does not have capacity to decide independently.

Surrogate decisions are expected to be based on the patient’s previously expressed wishes and values. In addition to those considerations, surrogates make decisions based on their own wishes, beliefs, and values or by family consensus (Fritsch et al., 2013). There is a presumption that the family surrogate shares religious beliefs with the patient but this may not be accurate (Berger, 2007; Eskew & Meyers, 2009).

Healthcare providers also contribute to the difficulty of surrogate decision-making. In a study reviewing 71 conferences between providers and surrogates for critically ill patients, the patient’s values regarding cognition, physical function, and end-of-life care were rarely
discussed (Scheunemann, Cunningham, Arnold, Buddadhumaruk, & White, 2015). There is also some evidence that clinicians’ interpretation of both patient and surrogate expressed goals of care is not consistently correct (Brandt, Shinkunas, Gehibach, & Kaldjian, 2012). Review of the literature on surrogate preferences for decision-making indicates a preference for shared decision-making that includes a physician recommendation (Prochaska & Sulmasy, 2015). However, even when surrogates describe good communication regarding prognosis, inaccurate expectations are common (Chiarchiaro, Buddadhumaruk, Arnold, & White, 2015).

**Summary**

Countless other bioethical issues could be identified in a close examination of surrogate decision-making. Many of these have not been studied, either empirically or theoretically. Knowledge about advance directives is incomplete, yet far more comprehensive than knowledge of how surrogates use substituted judgment or best interest standards. Knowledge about bioethical theories remains theoretical and untested from an empirical perspective. The bioethical aspects of surrogate decision-making are vital to understanding and improving the process for all involved.

**Chapter Summary**

The science in surrogate decision-making is not young, but it is immature. The background literature on bioethical theory and dual-process models of decision-making is strong but there are not studies to tie either to surrogate medical decision-making. The studies on patient preferences for decision-making and on all aspects of surrogate decision-making are observational. Many are retrospective as well. There are few intervention studies and those few are lacking a theoretical justification. Evaluating the literature using the GRADE system (Appendix A), the Quality of Evidence is C (low) primarily because the related studies are
observational. Though well done, small sample size and limited numbers of studies do not support upgrading the Quality of Evidence grade. The Level of Evidence is weak in most areas based on small sample sizes with limited generalizability.

Is shared decision-making the ideal? The policy statement by the American Thoracic Society and the American College of Critical Care Medicine states that ICU clinicians’ default approach should be shared decision-making, including information exchange, deliberation, and making a treatment decision (Kon et al., 2016). The recommendations do acknowledge that some surrogates prefer either significantly more control over decisions or to cede control to physicians. Within that continuum of shared decision-making, everything from independent to reliant decision-making would be included. The recommendations seem to suggest that, in the scenario of critical illness, discussion with the surrogate decision-maker and supporting their choice for degree of involvement in decision-making is optimal. But some studies have shown that asking patients and surrogates their preference for decision-making does not accurately reflect their actual preferences (Haward, Murphy, & Lorenz, 2012; Curtis & Tonelli, 2011).

The bioethical principles involved with decision-making are clear, but the relationship to choice of type of decision-making and how the surrogate decides has not been defined. The relationship of bioethical theory to surrogate decision-making has been studied only superficially. Dual process models fit well with surrogate decision-making based on factors affecting decisions, but a model has not been adapted for this use in the clinical area.

What theoretical model can we use to explain the surrogate decision-making process? Surrogate decision-makers are expected to make decisions according to ethical standards that require their decisions approximate the choices the patient would have made if able (Beauchamp
& Childress, 2013; Buchanan & Brock, 1986). However, evidence suggests that making decisions based on the concordance between surrogate and patient is not realistic.

Based on the current state of the science, a dual theoretical foundation for this study was employed. The framework for surrogate decision-making is the basic dual process model. The framework for the bioethical perspective is principlism since this is currently the most common framework used in clinical practice. There is not strong enough evidence to establish that either theory is best. As stated by anthropologist Paul Farmer (2014), “to be wed to a concept or an academic theory is dangerous. That’s a 19th century trap. I wouldn’t recommend it to you as a student … It’s a theory! It’s an idea! And it’s important to have ideas.” This is consistent with the grounded theory methodology of the work.

There are significant gaps in the literature. The importance of this study lies in those gaps. There is a professional ethical responsibility to investigate how best to support patients and families in healthcare decision-making consistent with the patient’s values, goals, and preferences (National Institute of Nursing Research [NINR], 2011). This study aims to investigate the gaps in knowledge about the process of surrogate decision-making in the context of critical illness, surrogates’ decision-making methods, and ethical bases of decisions. The results and analysis of this study are discussed in relation to both theoretical frameworks in Chapter 5. Ultimately, the theory supported or developed in this study can inform future intervention studies to improve the process of surrogate decision-making in critical care to the benefit of all involved.
Chapter 3

Research Design and Methods

The purpose of this study was to explore the process of surrogate decision-making during critical illness. The specific aims of the study were to describe the process of surrogate decision-making for critically ill adult patients during the acute phase of critical illness, including participants’ cognitive and moral decision-making processes and to develop a model explaining the process. Current cognitive decision-making theories and bioethical theories have not been studied in relation to surrogate decision-making. Critical illness adds an additional layer of complexity to the process, as rapid decisions in life-threatening situations are often necessary. Through in-depth description of the surrogate decision-making process, this study generated a model of surrogate decision-making in the context of critical illness.

Design of the Study

A prospective, longitudinal qualitative approach using a grounded theory design was used to examine the process of surrogate decision-making in the context of critical illness. A prospective design was chosen to study the process as it was occurring. Prior studies have been retrospective, adversely affecting trustworthiness of the data and analysis since recall of the participants is affected by the time lapse and the outcome of the decision is known. A prospective design was chosen because the phenomenon of interest (surrogate decision-making during critical illness) can involve multiple decision points or decisions that must be considered over time. This design allows capture of data from those multiple points. A qualitative approach was chosen to obtain a detailed view of this complex issue. The quantitative studies completed in this area are observational, resulting in an inability to determine with certainty the direction of
the relationship between variables. The qualitative approach allows the researcher to raise the question of “Why?” when relationships and directionality are unclear.

Since there is not an accepted decision-making or bioethical theory for the process of surrogate decision-making in critical illness, grounded theory was the specific qualitative method of choice. Grounded theory is appropriate when a theory does not exist to adequately explain the phenomenon of interest. Use of theoretical frameworks to support grounded theory studies is not recommended (Corbin & Strauss, 2015) but has been discussed in Chapter 2 to provide an overview of established decision-making and bioethical theories that may be applicable to surrogate decision-making during critical illness. The surrogate decision-making model and bioethical analysis were developed grounded in data obtained from participants experiencing the process (Corbin & Strauss, 2015).

**Protection of Human Subjects**

This study was reviewed and approved by the Pennsylvania State University Office for Research Protection (Appendix B). All members of the research team (Birriel, PI; Kitko; Hupcey) had current human subjects training (CITI). As described above, all data with identifiers was encrypted and stored on password-protected computers or locked files.

All participants were given the following information, prior to consent: (a) the purpose of the study, (b) procedures to be followed, (c) discomforts/risks, (d) benefits to themselves and others, (e) time commitment, (f) assurance of confidentiality, (g) their right to ask questions, (h) that their participation is totally voluntary, and they may refuse to answer any questions or drop out of the study at any time. There were minimal risks to participants in this study. If any participant became upset during the interview, it could be terminated at their request. If they remain upset, pastoral services would be contacted and a referral made with the participant’s
permission. There was no direct benefit to the participants other than the opportunity to talk with the researcher about their experiences and the knowledge that the results of the study will be used to aid future patients and surrogate decision-makers.

**Sample and Setting**

**Participants**

Screening and enrollment flow is illustrated in Figure 3.1. A total of 522 electronic patient records were screened to identify potential participants for this study over a period of 6 months. Those who did not meet the patient-based inclusion criteria of ICU status (257) were eliminated. Following chart review and discussion with the patient’s attending providers, those who did not meet the patient-based inclusion criteria of inability to make independent health care decisions due to critical illness (196) were eliminated. Surrogate decision-makers of the remaining 69 patients were identified as potential participants. Of those, 47 potential participants were not present in the ICU during times that the investigator was available; 22 potential participants were available to the investigator during their ICU visits. Nineteen surrogate decision-makers of critically ill patients were enrolled in the study. Three declined to participate. In two cases in which the surrogate declined, the patient was actively dying and the family was visibly upset. In one case in which the surrogate declined, the family felt they had nothing to contribute to the study, explaining that they were happy with everything. Recruitment continued until data saturation was reached. This sample size provides sufficient data to fully describe the phenomenon of interest (Creswell, 2007, p.126; Morse, 1995; Morse, 2000; Sandelowski, 1995).
Inclusion criteria for patients required that they were adults (over age 18), designated as ICU status in the medical record, and unable to make independent health care decisions as determined by their health care team. Patient participation was solely for access of the medical record (current status, diagnoses, plan of care, and prognosis; and for any documentation of interaction with family). The surrogate decision-maker provided written informed consent on behalf of the patient.

Inclusion criteria for surrogate decision-maker participants required that they were the person identified as the primary decision-maker on the patient chart (by patient, family) and consistent with Pennsylvania law (PA Code, Title 20, Chapter 54, 2006) and IRB policy (HRP-013). It is acknowledged that the surrogate decision-maker may consider decisions within the context of the larger family but the study aimed to determine the decision-making process of the individual who is responsible for the final decision. The surrogate decision-maker was required
to provide written consent for both themselves and the patient for whom they were making decisions.

Exclusion criteria for surrogate decision-maker participants included age under 18 years and impaired communication. Although family members under age 18 may be involved in conversations about healthcare decisions, they are not the legally recognized decision-makers (PA Code, Title 20, Chapter 54, 2006). In addition, for research conducted in Pennsylvania, persons under the age of 18 are considered children and could not independently consent to participate (Code of Federal Regulations, Title 45, Part 46.402, 2009). Persons with language or sensory barriers to communication are likely to have different or additional experiences as a surrogate decision-maker than those without those barriers. Investigation of their decision-making could be undertaken as a separate or subsequent study.

Setting

The Penn State Milton S. Hershey Medical Center (HMC), Dauphin County, PA: HMC is a tertiary and quaternary care, 551-bed, Level 3 trauma center, located in a rural area of central Pennsylvania. As a regional referral center, HMC draws patients from both rural and urban areas throughout central Pennsylvania resulting in a diverse patient population. There are four intensive care units (ICUs) with patient distribution based on primary diagnosis: cardiovascular, medical, neuroscience, and surgical. The combined ICUs total 117 critical care beds. Based on the size and volume of the ICUs, recruitment of an adequate sample for this study was successful. The setting for the individual interviews of participants was in a private room near each of the ICUs.
Sampling Technique

Purposive sampling was used initially to choose participants in all four of the ICUs as potential participants were identified. In this study, this refers to individuals who were experiencing the process of surrogate decision-making during critical illness and can describe the decision-making process.

Following enrollment of participant 8, focused strategies for recruitment were used to obtain as a diverse sample as possible. In a grounded theory study, it is concepts and not people that are sampled. Theoretical sampling was used to obtain participants that could maximize opportunities to identify and develop themes, including variations and relationships between themes, concerning the phenomenon of interest (Corbin & Strauss, 2015). For example, gender, relationship to the patient, and medical conditions were taken into account for subsequent recruitment. Recruitment of this diverse sample maximized the opportunity to confirm the identified themes and developing model under multiple conditions. The investigator was employed as an Acute Care Nurse Practitioner in the cardiovascular ICU but did not work or care for any participant during their enrollment in the study.

Participant Recruitment

The investigator coordinated all recruitment efforts. The investigator worked closely with the charge nurses and attending medical services in the four intensive care units. The charge nurses and representatives of each attending medical service were educated on the study goals and protocols in person by the investigator. Potential participants were identified, based on the above criteria, by the ICU nurse practitioner, ICU nurse, or the investigator based on chart review. Once identified as meeting inclusion criteria, a member of the health care team approached the potential participant to discuss the project briefly and to solicit potential
participation. If they agreed to consider participation, the investigator met with them to explain
the study and obtain written informed consent. Historically, recruitment of adequate numbers of
participants within the population of this institution had been not been problematic. The
investigator and doctoral advisors have successfully recruited participants for funded qualitative
studies from this institution in the past. Participants have also been successfully recruited within
the individual ICUs by other investigators for IRB approved studies. The investigator
coordinated recruitment efforts with investigators of all studies that were actively recruiting at
the same time as this study to eliminate conflict in the recruitment process. Recruitment efforts
progressed smoothly with this process, though more slowly than anticipated. This was primarily
related to the inclusion requirement that patients be unable to make independent health care
decisions and the irregular presence of the family surrogate decision-makers in the ICU.

**Informed Consent**

Informed consent was documented in writing with the IRB approved forms (Appendix C). The investigator obtained all consents. Both the participant and the investigator printed and
personally signed their names, dated and timed the consent forms. Copies of signed consent
forms were provided to each participant.

The consent forms include two separate signature lines for the participant. The first
consent line applies to their personal consent to be interviewed for the study. The second
consent line applies to their consent on behalf of the patient (for whom they were the legally
authorized representative) only for review of the medical record.

**Participant Retention**

Issues with retention were not anticipated since data collection occurred only during the
intensive care unit stay and at the convenience of the surrogate decision-maker participant. It
was made clear that participation was strictly voluntary and the participant could stop engaging in the study at any time. No participants withdrew from the study after providing informed consent.

**Data Collection**

**Interviews**

The investigator conducted all interviews to develop a relationship with participants that encouraged open sharing and responses to questions. The investigator had previously been trained in qualitative interview technique by the doctoral advisors and had participated in qualitative data collection on the doctoral advisors’ funded studies as a research assistant. The initial interviews, using traditional qualitative techniques, were conducted on enrollment. The second interview was conducted 14 days after the initial interview, or at discharge from the ICU or when the patient regained decision-making capacity. Multiple interviews were conducted to allow the participants to become comfortable talking with the investigator and encourage sharing. Although there were only two interviews, the participants were subjectively more comfortable talking during the second interview. The research design allowed for collection of data at multiple time points, to evaluate for any changes in surrogate decision-making over time, and about multiple decisions that were required of the participants. Interviews during the time that the patient was critically ill and unable to make independent health care decisions ensured true prospective data collection as the participants discussed their decision-making process during the time that it was happening without knowledge of the outcome. Interviews were conducted in person, in a private room within the hospital. Interviews were audio-recorded, transcribed verbatim, and verified line by line by the investigator. At the time of each interview,
the medical record was reviewed for demographic information, current status, diagnoses, plan of care, and prognosis; and for any documentation of interaction with family.

The investigator interviewed each participant using the established interview guide. The semi-structured interview guide (Appendix D) was developed based on the surrogate decision-making literature with input from the doctoral advisors (Kitko, Hupcey), experts in qualitative research. The interview guide served as a reference to maintain consistency in topics that the participants were encouraged to describe. It did not dictate the structure and order of the interview or limit participant voice in any way. Participants were encouraged to talk about their decision-making experiences freely. All interviews ended with the question:

- Is there anything else that you would like to share?

If any participant became upset during the interview, it would have been terminated at their request. If they remained upset, pastoral services would be contacted and a referral made with the participant’s permission. Within Hershey Medical Center, this supportive role is typically filled by pastoral services. Social services could be consulted if necessary. This was not necessary during any study interview.

*Initial interviews* lasted approximately 40 minutes. All initial interviews included descriptive information that was collected on the Demographic Sheet (Appendix E). The initial interviews began unstructured (Corbin & Morse, 2003), with an open-ended question to explore participants’ decision-making processes:

- Tell me about your experience as the person making decisions for (patient). I have some questions for you later, but first just talk freely.

Unstructured interviews provide the richest source of data for theory building (Corbin & Strauss, 2015). The participants’ responses provided a rich, broad description of themes
involved in the surrogate decision-making process. As the interviews progressed, a semi-structured interview technique was used. Specific probes were used to explore participants’ decision-making thought processes, as well as to identify potential needs of the surrogate throughout the process. For example:

- When you are making health care decisions for (patient’s name), do you feel more comfortable deciding on your own, letting the doctor decide, or deciding jointly with the doctor?
- What do you know about (patient’s name)’s preferences for care?
- What kinds of things did you consider in making that decision?

Second interviews lasted approximately 20 minutes. It was expected some patients for whom the participants were making decisions would be discharged from the ICU prior to the second interview at 14 days based on the Society of Critical Care Medicine’s reported average ICU length of stay of 6.1 days in intensivist-led ICUs and 9.3 days in ICUs managed by attending physicians (Society of Critical Care Medicine, 2015; Combs & Rainey, 2003; Lee, Rogers, & Horst, 2010; Mains et al., 2009). The ICUs at Hershey Medical Center use a mix of both medical management models. The decision to set a time frame of 14 days was based on the transition from acute critical illness to chronic critical illness. Critical illness describes an acute condition of physiologic instability requiring constant monitoring and intervention. Due to advances in treatment and technology, some patients survive the acute phase of critical illness but transition to a phase of chronic critical illness marked by ongoing physiologic abnormalities and dependence on technology (Girard & Raffin, 1985; Wienczek & Winkelman, 2010). The time of the transition to chronic critical illness is not agreed upon but most definitions describe a period of several weeks (Wienczek & Winkelman, 2010). The types of decisions required and the
decision-making process may differ in acute and chronic critical illness. The time frame covering 14 days focused this study on the acute phase of critical illness.

In 10 cases, the second interview was conducted when the patient for whom the participant was making decisions was discharged from the ICU. The patients remained unable to make independent health care decisions but no longer met the inclusion criteria of “ICU status”. In 9 cases, the second interview was conducted 14 days after the initial interview as the patient remained critically ill and unable to make independent health care decisions. Follow-up interviews followed the same pattern from unstructured to semi-structured as the initial interviews. They began with the question:

- How have things been going since we last talked?

Probes focused on current decisions and the decision-making process. For example:

- What kind of decisions have you had to make about (patient’s name)’s care?
- What decisions do you think are coming up?

Additional focused questions were added to the follow-up interviews as themes that required further exploration were identified through ongoing analysis. For example:

- What do you think will be different about making decisions in the next few weeks?
- Can you tell me how you feel that you know what (patient’s name) would want when you said that you haven’t talked about it?

Field Notes and Memos

Field notes were written immediately following each interview to describe the event and the investigator’s observations during the interview. These contained some conceptualization, but were primarily observational. Memos were written after each interview as written records of
analysis. As memos grew in complexity with additional interviews, diagrams of the developing model were included (Corbin & Strauss, 2015)

**Data Management**

On enrollment, each participant was assigned a unique identifier. The first participant enrolled was assigned S1 (surrogate 1). The initial interview was labeled S1.1 and the second interview S1.2. Digitally recorded interviews and field notes were uploaded to a password protected computer. The recorded interviews were transcribed by the investigator, reviewed for accuracy, and immediately cleaned to remove potentially identifying data, such as names of participants or patients and names of clinicians. De-identified data was stored on a password-protected computer.

Written field notes and memos were de-identified at origination, identified only with the participant unique identifier. Field notes and memos were maintained in a locked file cabinet and office in the College of Nursing at the Pennsylvania State University Hershey campus when not in use.

De-identified data from the Demographic Sheet (Appendix E) was entered into a spreadsheet on a password-protected computer. All potentially identifying hard copy information (consent forms, demographic forms) was stored in a locked file cabinet and office in the College of Nursing at the Pennsylvania State University Hershey campus. Electronic interview recordings were destroyed immediately after the transcript was verified to the recording. Consent forms and demographic forms with identifying data will be destroyed at study completion. To maintain confidentiality, data analysis sessions were conducted in a private office or meeting room at The Pennsylvania State University, College of Nursing.
Data Analysis

The process of data analysis was based on the grounded theory work of Corbin and Strauss (2015). Data analysis is an iterative process in which data are collected and analyzed simultaneously. Analysis began with the first interview of the first participant. Initial analytic thoughts were written in the field notes immediately following each interview. Memos, which reflect the researcher’s interaction with the data and the thought process of the analysis (Corbin & Strauss, 2015), were completed after each individual and group analysis session. Per the tenets of grounded theory (Corbin & Strauss, 2015), each interview transcript was read to understand the perspective of the participant and the content of the responses. Each interview was then re-read and thematically analyzed to generate or elaborate on themes. Then the interviews were analyzed based on specific interview questions. For example, does the surrogate believe they know the patient’s preferences for care and what are they? Are they following these preferences, why or why not? What model of decision-making is being used? What ethical principles are being considered? What resources have they used to aid in their decision-making? What resources/services do they want that they have not received?

The investigator met regularly with her doctoral advisors, who are experts in qualitative research. The advisors critiqued the investigator’s interviews, provided suggestions for follow-up questions, discussed emerging categories and themes. Themes derived during analysis became the basis for further data collection in subsequent interviews. Following a cyclical pattern, the data from those interviews were analyzed. The cycle of data collection and analysis continued until saturation was reached: the point at which no new themes were emerging and the properties, dimensions, and variation of identified themes was not expanding (Corbin & Strauss, 2015). Following all data collection, a team analysis session was conducted with the advisors’
research team (the 2 advisors, 5 PhD students, research assistant) to further confirm and clarify the identified themes. Ultimately, data analysis moved toward generation of a model of the surrogate decision-making process in the context of critical illness.

Corbin and Strauss (2015) state:

The actual procedures used by any analyst are not as important as the task of identifying the essence or meaning of the data…The greatest tools researchers have to work with are their minds and intuition. (p. 219)

The major analytic procedures described by Strauss and Corbin (1990) and later refined (Corbin and Strauss, 2015) that were used in this study to describe and derive a model of surrogate decision-making in the context of critical care follow.

- Coding – thinking abstractly and denoting concepts from the data
  - Open coding – denoting concepts (themes) to stand for your interpreted meaning of the data
    - Concepts range from lower-level concepts to higher-level concepts.
      Higher-level concepts are categories, main themes of the research that are found in some form in all of the data. Lower-level concepts are sub-categories; they define and provide explanations of the categories.
  - Axial coding – interconnecting the concepts (themes)
  - Selective coding – explaining the connections between the concepts (themes)

- Analytic strategies
  - Constant comparison – comparing incidents within the data for conceptual similarities and differences
  - Asking questions of the data
• Considerations in developing theory
  
  o Context – the set of condition affecting persons or phenomenon of interest that facilitate or constrain the ability to take action
  
  o Process – changes in conditions and action-interaction over time
  
  o Integration – weaving of categories around the core concept (main theme of the research)

The design of the study influenced the analysis. Analysis included each participant individually and the sample as a whole. Each participant completed 2 interviews, the first on enrollment and the second up to 2 weeks later. Consequently, analysis included within person analysis over time and group analysis over time.

Data analysis included interpretation of the participants’ thought processes and motivations. Psychological research has demonstrated that the accounts people provide of their own behavior are not reliable. Factors below their threshold of awareness frame their interpretations of and reactions to situations that require ethical decisions. (Appiah, 2008).

Underlying the procedures of grounded theory analysis is a set of assumptions derived from pragmatist and interactionist philosophies (Corbin & Strauss, 2015, pp. 23-24). These assumptions are primarily based in symbolic interactionism and its antecedents. The core of symbolic interactionism consists of three premises. First, people act toward things based on the personal meaning of those things. Second, the meaning of things is a result of the social interaction a person has with others. Finally, the person uses an interpretive process to use and modify the derived meanings in determining actions toward things that are encountered (Blumer, 1969). Because symbolic interactionism forms the theoretical basis for the grounded theory methodology, these premises guided the analysis and development of the model.
Scientific Rigor

Validity and reliability have traditionally been used as criteria for scientific rigor in quantitative studies. There are multiple approaches to translating validity and reliability criteria for application to qualitative studies (Corbin & Strauss, 2015; Creswell, 2007). Corbin and Strauss (2015) express discomfort with the terms ‘validity’, ‘reliability’, or even ‘truth’ in discussion of qualitative research, particularly grounded theory, preferring the term ‘credibility’ as used by B. G. Glaser and Strauss (1967) and Lincoln and Guba (1985). Credibility encompasses the idea of both reliability and validity, indicating that “findings are trustworthy and believable in that they reflect participants’, researchers’, and readers’ experiences with phenomena, but at the same time, the explanation the theory provides is only one of many possible ‘plausible’ interpretations from data” (Corbin & Strauss, 2015, p. 346). Credible findings, therefore, support rigor and truth in the research process.

B. G. Glaser and Strauss (1967) defined criteria for judging a study’s credibility and applicability as measures of scientific rigor. The criteria for credibility are 1) sufficient detail and description to allow readers to feel they were in the field and could judge for themselves, 2) sufficient evidence on data collection and analysis for the reader to assess how the conclusions were reached, 3) multiple comparison groups, and 4) explanation of the kinds of data used to reach the final interpretation (B. G. Glaser & Strauss, 1967, pp. 223-235). The criteria for applicability are that the theory should 1) fit the area from which it is derived and where it will be used, 2) be readily understandable by both laypersons and professionals, 3) be sufficiently general to be applied to diverse situations and populations, and 4) provide the user with sufficient control to bring about change in situations (B. G. Glaser & Strauss, 1967, pp. 237-250). These criteria for credibility and applicability are used to judge the present study.
Credibility

1) Sufficient detail and description to allow readers to feel they were in the field and could judge for themselves. The study findings and analysis do provide depth of detail and description of the themes included in the surrogate decision-making model, the connections between the themes, and the relevance of the overarching theme.

2) Sufficient evidence on data collection and analysis for the reader to assess how the conclusions were reached. The methodology used in this study provides evidence of effective data collection through multiple interviews and analysis techniques consistent with grounded theory to reach the study’s stated conclusions. Interviews were critiqued by expert qualitative researchers and independently analyzed by members of the research team.

3) Multiple comparison groups. The study included multiple groups for comparison: multiple ICUs and diagnoses, participants with experience or no experience in surrogate decision-making, participants with various relationships to their family member patient.

4) Explanation of the kinds of data used to reach the final interpretation. The study findings clearly explain the data used to reach the final interpretation and the model developed from the data. Strictly following the grounded theory methodology through the course of the study assured that the results would be credible.

Applicability

1) Fit the area from which it is derived and where it will be used. The model developed from the study findings does fit surrogate decision-makers for critically ill family members in the acute phase of critical illness. It may also be applicable to other scenarios but has yet to be tested in those contexts.
2) Be readily understandable by both laypersons and professionals. The model developed from the study findings is understandable to all. Terminology was chosen to avoid healthcare or professional jargon. Partial findings presented both informally and formally have been understandable to lay and professional audiences. Findings related to bioethics theory were presented at the Eastern Nursing Research Society conference with positive comments and questions from those attending. The overall study was presented are the Pennsylvania State University Graduate Exhibition, receiving positive comments from those attending the poster session.

3) Be sufficiently general to be applied to diverse situations and populations. By focusing on integration of the identified themes, the model may be applicable to diverse situations and populations in addition to the scenario in which it was developed.

4) Provide the user with sufficient control to bring about change in situations. The model developed from the study findings does inform opportunities to design interventions to bring about change or assistance to surrogate decision-makers. Focusing on any of the individual themes within the model has the potential to introduce change.

Chapter Summary

This prospective qualitative study investigating the process of surrogate decision-making in the context of critical illness generates new knowledge and contributes to the current body of evidence. Corbin and Strauss’s (2015) grounded theory methodology forms the basis of the design for data collection and analysis. The results of this study describe the process of surrogate decision-making during critical illness and produce a substantive model of surrogate decision-making in the context of critical illness including both cognitive and ethical perspectives.
Chapter 4

Results

The purpose of this study was to explore the process of surrogate decision-making during critical illness. Family surrogate decision-makers for critically ill adults who were unable to make independent health care decisions were interviewed near the time of admission and 2 weeks later or when the patient for whom they were making decisions was discharged from the ICU if that occurred prior to 2 weeks. The time frame of the interviews covered the acute phase of critical illness as defined by the physiologic changes related to critical illness (Girard & Raffin, 1985; Wiencek & Winkelman, 2010). The specific aims of the study were to describe the process of surrogate decision-making for critically ill adult patients, including participants’ cognitive and moral decision-making processes and to develop a model grounded in the data to explain the process.

Analysis and interpretation of the results of the study are presented in this chapter, supported by participants’ discussion of their surrogate decision-making processes. As previously described, analysis was an ongoing process throughout the study, consistent with the methods of grounded theory. The decision-making theoretical framework of dual-process theory informed the early stages of this investigation. Four major themes were identified: Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values. As data collection and analysis progressed, the overarching theme of Integration emerged and a model of the Process of Surrogate Decision-Making in Critical Illness was developed.
Participant Demographics

The demographic data verifies the initial use of purposive sampling, transitioning to theoretical sampling methods consistent with grounded theory methodology. The sample included family surrogate decision-makers for patients from the cardiovascular, neuroscience, medical, and surgical ICUs and generally reflected the proportion of those demographic characteristics in the hospital population. The findings in a grounded theory study are not expected to be generalizable (Corbin & Strauss, 2015; Creswell, 2007). Description of the sample does provide context to the interpretation of the findings, allow clinicians and researchers to interpret the applicability of the findings to their own populations, and identify potential gaps in sampling deserving of future study.

The patients for whom the participants served as surrogate decision-maker were critically ill family members in the acute phase of critical illness, defined as 14 ICU days (Girard & Raffin, 1985; Wiencek & Winkelman, 2010). Nineteen patients were included in the study. They were primarily male (4 female, 15 male). All were Caucasian. There was a wide age range of 43 to 85 years of age, with a mean age of 63 years of age. Only four of the 19 patients had an advance directive; those four were among the oldest in the group. All four had living wills and one also had a healthcare power of attorney. Demographic data also demonstrated a distribution of primary diagnoses, including acute leukemia, cerebrovascular accident, gastrointestinal bleeding, heart failure, myocardial infarction, sepsis, suicide attempt, and trauma. The acuity of onset of those conditions varied. In eight cases, the patient was admitted due to acute conditions with no previous illness; nine were admitted with acute conditions but known risk factors and comorbidities; two were admitted with exacerbations of chronic illnesses. Common comorbidities included atrial fibrillation, chronic kidney disease, coronary artery disease,
diabetes mellitus, and hypertension. None of the patients died during the time they were enrolled in the study.

The sample consisted of 19 persons identified as surrogate decision-makers for a critically ill family member during the acute phase of critical illness, defined as 14 ICU days (Girard & Raffin, 1985; Wiencek & Winkelman, 2010). The majority of participants were female (16 female, 3 male). One participant was Pacific Islander and all others were Caucasian. They ranged in age from 31 to 83 years, with a mean age of 57 years, slightly younger than the patients for whom they were making decisions. Fourteen of the surrogate decision-maker participants were the spouse of the patient, four were adult children of the patient, and one was a sibling of the patient. All were the designated surrogate decision-maker on the medical record and by Pennsylvania law (PA Code, Title 20, Chapter 54, 2006). Ten participants had prior experience acting as a surrogate decision-maker for healthcare decisions; five for the current critically ill family member and five only for other family members.

Demographics related to trajectory of patient illness were evenly distributed. In 9 of the 19 cases, the family member remained critically ill in the ICU at the time of the second interview. In 10 of the 19 cases, the family member no longer required ICU care but remained unable to make independent healthcare decisions due to the effects of their illness and treatment. The sample, therefore, reflected surrogates whose family members recovered during the acute phase of critical illness and those whose family members were transitioning to chronic critical illness.

All of the patients required either a ventilator for pulmonary support and/or vasoactive infusions for cardiovascular support at some point during the study. The surrogate decision-maker participants were involved in making the decision to initiate or continue those life-
sustaining treatments. By virtue of being designated as the patient’s surrogate decision-maker, they also gave approval for the “routine” care and treatment, though none identified those measures as decisions that they needed to make. No patients died during the study; no participants made a decision about withdrawal of treatments.

Demographic characteristics were considered throughout analysis and interpretation of the data. The themes that emerged from the data are consistent across age and gender of both the surrogate decision-maker participants and their family member patients. The themes that emerged were also consistent whether the patient recovered during the acute phase of critical illness (discharged from the ICU during the study period) or was transitioning to chronic critical illness (remained in the ICU at the end of the 14 day study period). The specific diagnosis and the acuity of onset of the condition did not alter the findings. Two demographic factors were identified that affected the surrogate’s decision-making process: the relationship to the patient and whether the surrogate had prior experience making health care decisions for others. The surrogate decision-maker’s relationship to the patient influenced the decision-making process. This will be elaborated on when discussing the Considering Family Perspectives theme. The surrogate’s past experience making health care decisions for others also influenced the decision-making process. This will be elaborated on when discussing the themes Understanding the Patient’s Values and Preferences, and Acquiring Health Care Knowledge.

Themes

Participants provided a rich description of their decision-making processes and experiences as surrogate decision-makers for critically ill family members. Descriptions were comparable between responses to direct questions and open ended questions in which they spoke freely about what was important to them at the time. Through the process of constant comparison
within and across participants, four themes emerged connected by one overarching theme. Each theme was verified and expanded on by questioning subsequent participants until data saturation occurred.

The four major themes that emerged from the data were Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values. The overarching theme that explains the connections between the major themes is Integration. The model of the Process of Surrogate Decision-Making in Critical Illness was developed, grounded in the data. The four major themes are discussed first, followed by the overarching theme, and finally, explication of the model.

**Understanding the Patient’s Values and Preferences**

*Understanding the Patient’s Values and Preferences* includes multiple lower level concepts. The participants expressed their understanding of their critically ill family member’s values and preferences through knowing about their advance directive, having prior conversation about health care wishes, and/or through their overall relationships.

A person’s preferences regarding healthcare decisions can be recorded in an advance directive, which may be either a living will or a healthcare power of attorney. Only 4 of 19 participants responded that their critically ill family member had an advance directive. All four had living wills and one also had a healthcare power of attorney. Each of these patients had chronic illnesses. However, 7 other patients with a similar history of chronic illnesses did not have advance directives. Of those with an advance directive, 3 of 4 surrogate decision makers had not made health care decisions for their family member patient in the past. Neither diagnosis, chronicity of illness, or prior need for a surrogate decision-maker appeared to be
related to completing an advance directive. The ages of the patients with an advance directive ranged from 77-85 years, among the oldest in the study.

Of the participants who had an advance directive available, the adult child of a 77-year-old man with heart failure and shock expressed “I’m glad we had that living will done.” The others, who had not made health care decisions for their family member in the past, were less sure about the helpfulness of the living will. When asked if the living will helped them to make decisions, the wife of an 80-year-old man with a stroke responded with an unenthusiastic “I guess so”. The wife of an 85-year-old man with a ruptured abdominal aortic aneurysm just shrugged her shoulders in response. One patient had both a living will and healthcare power of attorney. His adult daughter said “He does have a living will and I am his power of attorney which I know superseded that”, clearly feeling that she was responsible for any healthcare decisions regardless of the content of the living will.

Many participants who did not have an advance directive available said that they wished they had. Several had begun the process.

• “You won’t believe this but…. we were at the lawyers last week to draw up the papers.”
• “We have papers, didn't fill them out.”

These were surrogate decision-makers for patients with a history of chronic illnesses. Others acknowledged that they felt they should have completed an advance directive prior to this event but did not express strong feelings about the usefulness. These were surrogate decision-makers for patients without any significant medical history prior to the current episode. Field notes from those interviews indicate that they responded “yes” only because they were asked and felt it was the appropriate response.
Some participants developed understanding of their critically ill family member’s values and health care preferences through conversations they have had with the person. Participants described prior discussions (or absence thereof) and their beliefs about how well they knew their family member’s wishes about healthcare decisions. Seven participants had at least some prior conversations with their family members about their healthcare wishes. These were all surrogate decision-makers for a family member patient with chronic illnesses but most had not made decisions for that person in the past. In describing the content of those conversations, the majority of ideas expressed were related to the initiation or continuation of life support.

- “I know that it’s not his wish to have life support.”
- “He wouldn't want life support… he definitely wouldn't. Even if something catastrophic would happen, we are not going to pursue heroic measures. When we drive past the nursing home, he says "don't ever let me…”
- “He’s ok with things like the breathing tube as long as it will be temporary.”

Twelve participants had no prior conversations with their family member about their healthcare wishes. The critically ill family members of those participants were among the youngest in the sample, with an age range of 43-63 years. Seven of those family members had no previous health problems. These participants expressed that they had not thought this was a necessary topic, but many expressed regret that they had not discussed it.

- “We talked on and off, especially dealing with elderly relatives, but we're also younger. What could we put in place for when we're not able to take care of ourselves? Yes. But not really like this…”
• “You don't think you need to talk about this either when you’re young. Now I think that's the most important time to talk about it.”
• “We haven’t talked about it but we should have.”
• “He doesn't really talk about it, he thinks everything is fine and it’s not necessary.”

Despite the absence of prior conversation, all of the participants felt that they knew what their family member would want them to decide based on their overall relationship with them. This was the case regardless of age, acuteness of diagnosis, relationship to the patient, or any other factor. They expressed that they felt they were making decisions in accordance with the patient’s wishes.

• “I think I know what he would want - to take whatever chances he needs to live… he has too much to live for to not try.”
• “I think we’re both of the mindset that if anything can be done, that’s what we’re doing for each other, that we’re committed to making sure that whatever can be done will be done to save each other.”
• “I think I know his feelings about things.”
• “…make decisions she would make? - ummmm, yes.”
• “Yes, probably.”
• “I think if he had to, he would have decided to have it done.”

Those participants who had prior experience with making decisions for others relied on those experiences. Ten of the 19 participants had some type of past experience as a surrogate decision-maker and 8 of those had experience with the family member for whom they were currently making decisions. When asked directly if their previous experience helped their ability
to make decisions, all 10 participants said yes but rarely elaborated. One participant said “just because you’ve done it before”.

In summary, the theme of *Understanding the Patient’s Values and Preferences* was considered by all participants. Those who had an advance directive available did not express strong feelings about the helpfulness of the document. Those without an advance directive expressed a desire to have it available. The majority of participant did not have a prior conversation about healthcare wishes with their currently critically ill family member. The presence or absence of chronic illnesses appeared to affect the likelihood of conversation about healthcare wishes. Of the participants whose family member had no history of chronic illnesses, only one had discussed healthcare wishes. In that case, the diagnosis prompting ICU admission was acute leukemia and the husband said “yes, we’ve talked about it since the cancer.” Those participants who had conversations about health care wishes focused only on the question of life support. Those who did not have a prior conversation expressed regret. Regardless of prior conversation, all participants felt that they understood what their family members would want and that they were making decisions in accordance with their wishes.

**Acquiring Health Care Knowledge**

Healthcare knowledge includes the surrogate decision-maker’s previous knowledge, knowledge obtained from the current healthcare providers, and knowledge sought from other sources. It involves more than just information gathering; it includes processing the information from multiple sources. All participants expressed the strongest reliance on information provided by the current healthcare providers.

- “I feel very focused, trying to get all the information, ask questions, so I feel very hyperaware of what's going on. What should I ask? What's going on? Do I
understand?” . . . “I feel like I get all the information I need eventually, sometimes it changes.” . . . “I think many of them (decisions) have been the doctors. They've always made sure I was ok with everything. I really do look to them and say this is a serious situation; this is life and death. I am trying to be an informed consenter. And when you can pick this or this, that was obviously combined and then ultimately my decision. I guess I could have told them not to put in the breathing tube because they were saying ‘this is why we want to do this, are you ok?’ But I said absolutely yes because we have to protect him. I don’t think they’re acting in a way that tells me I have no choice. But it’s definitely more like we want to do this and why would I say no?”

• “I rely on the doctors and their expertise.”

• “I had to go by what the doctors said – they’re the experts. This isn’t something that it’s easy to look up.”

• “The doctors here are the experts, the trauma doctors.”

• “Mostly though I look to the doctors as far as what’s happening with him . . . the specifics right now.”

• “The doctors answer everything and then ask if I understand . . . it's a lot of information.”

• “The doctors are great about letting us know what’s happening, what is the plan, what comes next. This is more than what we know so they are our source of information.”

• “I rely on the doctors for information both about the medical problems and the specifics of how he is doing with all of it. And for what to expect for him recovering.”
They emphasized the importance of good communication, both the need for it and the problems created when it was absent.

- “Every person that explained something to me explained it that I could understand it and were consistent with what they were saying to me. Everybody was taking their time, telling me who they are. To have that time, have it repeated, have an opportunity to write it down - I think that’s helpful for people who are trying to make decisions.”

- “It’s been missing – talking to the doctors to see what’s next. We don't know anything, what they expect, how much damage.”

Several participants sought additional information from other sources. Written information available in the waiting areas was used by a few. Several participants or their family members used internet searches to obtain additional information.

- “I did then go into the rehab website and did my own looking around and I could find outcomes and numbers and things like that.”

- “My son would look it up afterwards but he said everything was right.”

- “I rely on the internet a lot when I do searches. I don't know if that's a good thing or a bad thing for doctors but I research the drugs that she’s on, I definitely do.”

Those who did not use the internet voiced a variety to reasons:

- “There wasn't time to look for information anywhere else.”

- “I haven’t looked up anything . . . not a big internet person and I don't think there would be much about getting run down by a cow anyway!”

- “You have to be careful - everything on the internet's not true.”
Eight of the participants had acted as surrogate decision-maker for the same family member who was currently critically ill, acquiring knowledge in the past that was used during their current decision-making process. When asked directly if their previous experience helped their ability to make decisions, all said yes but rarely elaborated. The wife of a 49-year-old man with chronic obstructive pulmonary disease and multiple previous admissions said, “He’s had this for awhile so you get to know what to expect to a degree.”

In summary, the theme of Acquiring Health Care Knowledge was identified as important to decision-making by all participants. Their primary trusted source of information was the physicians involved in their family member’s care. The internet was a secondary source of information for some. This was limited by the rapid time frame required for some decision-making, lack of information specific enough to the patient, and their general comfort with internet use. For those who had acted as surrogate decision-maker in the past for the same family member, prior knowledge formed a basis for decision-making in the current circumstance.

**Considering Family Perspectives**

*Considering Family Perspectives* refers to any effect on the surrogate decision-making process due to interaction with other family members. Family is defined in an extended sense of the term, including blood related, adoptive, or intentional family members. All participants referred to family as a support system. Multiple participants said “They’re here for me.” The wife of a 43-year-old man who had an acute myocardial infarction requiring advanced life support talked about “a lot of family around and helping with the kids at home.” The 14 participants who were the surrogate decision-maker for their spouse clearly assumed sole responsibility for decisions:

- “The final decisions are from me.”
• “They (other family members) aren’t making decisions for him.”

• “It was what I wanted to do and then they (adult children) were all in agreement. No one else voiced an opinion.”

• “Lot of family but they are here for support. If there’s a decision to be made, I am the one to do it…but I can count on them to be with me.”

• “I’m the one responsible to decide but have lots of people to talk to.”

The 5 participants who were the surrogate decision-maker for their parent or sibling described a different experience. Although the participant was identified in the medical record and legally as the surrogate, they consistently aimed to make joint decisions with the other members of the family:

• “It’s a joint effort - my father, my other sister and I.”

• “I talk with my brother and sister and we decide together.”

• “Myself and brother and sister...we talk things out together to make decisions. If only one of us were here and it was an emergency, we’d be ok with whatever was decided. We’ve talked out things enough.”

• “I’m the oldest but I am making decisions along with my sister. We generally agree about what we are doing.”

One participant described difficult interactions in making those joint decisions. The participant lived with her father (the patient) and had a close relationship. Her sister, who did not live in the immediate area, had come home due to their father’s critical illness. “I have a sister who isn’t quite as close to my dad and now has wanted to become active and that's very difficult to stomach. It’s hard to recognize as a genuine concern and you try to keep your cool.” Despite the
fact that the participant was the health care power of attorney, she sought to reach agreement
with her sister.

In summary, the theme of Considering Family Perspectives was discussed by every
participant. The effect of the theme on the surrogate decision-making process varied based on
the participant’s relationship to the patient. Spouses took full responsibility for decisions, while
adult children and siblings sought consensus among family members.

Recognizing Personal Values

Recognizing Personal Values refers to those things that are important to the surrogate’s
ethical and spiritual belief systems. The traditional goal of surrogate decision-making is to make
decisions consistent with the patient’s values. Therefore, in the context of surrogate decision-
making, the surrogate’s values are considered separately from the patient’s values.

When asked directly about their values in comparison to their critically ill family
member’s values, participants consistently replied that they were “the same” and were unable to
elaborate. Every participant expressed the desire to make choices that would prolong their
family member’s life and return them to health. This was unchanged regardless of age,
diagnosis, previous health, surrogate relationship to the patient, or any other identifiable factor.
Participant expressions related to the value of preserving life were so consistent that the content
could easily have fit into any other participant’s interviews.

• “Do everything to save his life that we can.”

• “I don't want to lose him. I just want to do everything I can to get him through this if
  we can. I know he has some big hurdles. One thing at a time.”

• “We do want her to live.”
• “I just want to do whatever it takes for him to recover, treat everything that can be treated. They tell me this will be a long time but he will get better.”

Participants were also clear that valuing life meant more than just keeping the person alive. Though they wanted their family member to live, all were cognizant of the quality of life. They acknowledged that if there were not hope of meaningful recovery, they would make decisions that stopped ineffective treatments. Every participant at least mentioned the idea at some point in their interviews though they were not presented with the question directly:

• “I want to do what will help him live . . . if it will help him live.”

• “I want her to live as long as she can, keep treating this as long as there is something to help. If they tell me there’s nothing else to do, then I’ll have to make that decision when the time comes.”

• “As far as his health now, I'll do everything we can for him to get through this. He wouldn't want to be living but unconscious forever and I wouldn't want him to be.”

• “We want to do everything we can for her to live. We have to see how she recovers and give the time to see. If she’s not getting better, we may have to rethink but it’s not time for that yet.”

• “We want to do everything we can as long as there’s the chance that he gets better. At some point, these things won’t help but until then, we want to do what there is.”

In summary, the theme of Recognizing Personal Values emerged through interpretation of the participants’ description of their reasoning in making decisions. The participants had a strong belief that their values matched the patient values. They expressed a strong personal value for the preservation of life, though noting the potential to make a different decision in the future if the clinical circumstances changed. They did not express specific circumstances under
which they would withdraw life-sustaining treatment, but described this as a decision to be made if there was no hope of meaningful recovery.

**Overarching Theme: Integration**

The four individual themes of *Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values* emerged from analysis of the data. All participants used some aspect of each of the themes in their decision-making process. Participants described competing influences on their decision-making at times, as influences from one theme conflicted with influences from another theme. Ultimately, the participants made decisions by considering all of the themes together, integrating the information to achieve an answer. The overarching theme of *Integration* ties together the other four themes. Merriam-Webster (2003) defines integration as “incorporation as equals into society or an organization of individuals of different groups”. As the overarching theme *Integration* applies in this study, it refers to the incorporation of the four underlying themes as contributors to decision-making. The surrogate decision-making process involves all four areas simultaneously. It is illustrated by the following exemplars.

The adult child of an 83-year-old man with subarachnoid hemorrhage and acute respiratory failure was considering a decision for tracheostomy and gastrostomy feeding tube as her father’s condition improved but he was unable to be weaned from the ventilator. She said:

- “In his living will he doesn’t want a feeding tube, but I think his opinion is – I don’t want to lay in a bed in a home for 5 years being fed by a tube. So I, as a daughter and power of attorney, have to understand that and make the decisions for him which I think is the best . . . that this is a temporary situation and then, if I were to see that it
was leading to long term and it would be against his wishes, then I would have to make that decision. It’s difficult.”

And later, she continued:

- “It’s hard because I do know at some point I’m going against his wishes but I don’t know that he thoroughly understands there’s a difference in a temporary feeding tube and a permanent feeding tube. Especially when he’s looking at me and he’s intubated and he’s rolling his eyes and I’m having to say I know what your wishes are dad, but you have to trust me.”

She is *Understanding the Patient’s Values and Preferences* in considering what is included in his living will. She is *Acquiring Health Care Knowledge* from his doctors as she has been given the expectation that the need for the feeding tube and tracheostomy is temporary. She is *Considering Family Perspectives* at other points in the interview when she talks about interacting with her sister. And she is *Recognizing Personal Values* as she acknowledges her role as power of attorney, her responsibility for making the decisions, and her belief that the tubes should be placed. Each theme contributed to the final decision. Through integration of the four underlying themes, the participant was able to make decisions about her father’s care and plan for future decisions as well.

The wife of an 85-year-old man with a ruptured abdominal aortic aneurysm talked about the decision to agree to emergency surgery. Her husband had refused surgery just before his condition deteriorated rapidly and she subsequently agreed to emergency surgery. When asked if she believes that she made the decision that he would have, she said:

- “I think if his head were clear, they could convince him, if he could think and realize this is what he needed, he would decide the same.”
As he remained critically ill on full life support and developed kidney failure, she talked about the decision she made to agree to dialysis.

- “He’s really upset now that he has this dialysis but I don’t think he understands.”

She is *Understanding the Patient’s Values and Preferences* by acknowledging that her husband declined to consent to the operation that she agreed to in emergent circumstances. She is *Acquiring Health Care Knowledge* from his doctors as she learned about the operation and the need for dialysis. She is *Considering Family Perspectives* as she referred to discussing the situation with her son, though making clear that she was the one to make the decisions. And she is *Recognizing Personal Values* as she makes the decisions to consent to procedures that are needed to save his life. Through integration of the four underlying themes, the participant was able to negotiate the complex decision-making process and make decisions about her husband’s care.

Even in the ICU, decisions required of the surrogate were not always related to life-sustaining treatments. Some situations arose in decisions about routine care and activities. The wife of a previously healthy 48-year-old man with subarachnoid hemorrhage described this situation when a nurse offered him a milkshake:

- “He really reacts badly to ice cream, milk, creamed things. And he was like - I like chocolate shakes. And it was (I said) – no, you don’t like that!”

On the surface, this does not seem like an important “decision”, but his diet is certainly important to his recovery. In deciding to override his request for a chocolate shake, she is making a decision that involves integration of the four themes. She is *Understanding the Patient’s Values and Preferences* as it is clear that he wants the milkshake. She is *Acquiring Health Care Knowledge* in two ways. She has prior knowledge of his intolerance of milk-based products.
And she has knowledge from his doctors that impulsivity is one of the effects of the subarachnoid hemorrhage that he is experiencing. She is *Considering Family Perspectives* at other points in the interview though this plays only a minor part in this decision. And she is *Recognizing Personal Values* as she voices her own opinion on what her husband should be fed. Even in this small decision, integration of the underlying themes is demonstrated in the decision-making process.

This participant described another decision she needed to make about which rehabilitation facility to choose for her husband. The participant and her husband lived 2 hours from the hospital. The social worker offered to arrange placement in a rehabilitation facility close to home but the participant later learned that her husband would need to have procedures at the hospital during his rehab stay. She described:

- “They (social worker) said . . . but you said you were interested in that one (rehabilitation facility close to home). I actually wanted more choices after learning that he would need to come back to the hospital for procedures. So then they sent someone from the (hospital based) rehab to come and talk to me. And the main thing for me was - I want him close to where his doctors are...if he has to go back and forth...it took away that need to shop around. He (social worker) said it would be convenient for me to be at home but my main concern is not convenience, but what if something happens? It's all about timing and I’d rather have him right here.”

This situation again demonstrates the integration of the four underlying themes in the process of surrogate decision-making. She is *Understanding the Patient’s Values and Preferences* to return home. She is *Acquiring Health Care Knowledge* from his doctors as she learned that he would need to have several hospital-based procedures while he is in rehabilitation. She is *Considering*
Family Perspectives as her son and other family members would be more able to visit at the rehabilitation center close to home. And she is Recognizing Personal Values as she expresses that her primary concern is for her husband’s health and safety. Integration of the four underlying themes occurred in the surrogate decision-making process and the participant was able to make the choice for the hospital-based rehabilitation.

Participants repeatedly described using multiple themes in arriving at a final decision. Many expressed an awareness of the multiple pieces of information they were considering. They resolved the complexities of the decision-making process by not considering each theme individually, but by considering all of the themes simultaneously:

- “It’s gotta be the totality of the circumstances.”
- “I need all of the pieces together to make the best decision for him.”
- “I really need all of those put together.”
- “I know him and the doctors know what will help so those together is what you need to decide.”

In summary, the overarching theme of Integration was derived from participants’ description of how they conceptualized the decision-making process. Integration connects the four other themes and describes how they are considered as a whole that is larger than the sum of the individual parts.

**Model: Process of Surrogate Decision-Making in Critical Illness**

The four major themes of Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values emerged from the data in an ongoing iterative process. The final step in analysis of a grounded theory investigation is integration, defined by Corbin & Strauss (2015, p. 295) as
“linking categories around a core category and refining and trimming the theory.” In this investigation, final integration of the data identified the overarching theme of *Integration*. Data analysis revealed that just as the investigator aimed to identify links among the major themes, the participants linked the content of those themes in their process of making decisions. The themes are broad in scope and may not be specific to the critical care scenario. The developed model is designated as applicable to the context of critical illness since that is the population studied in the present investigation. The model of the *Process of Surrogate Decision-Making in Critical Illness* demonstrates the interconnections that occur during the process. The diagrammatic model is presented in Figure 4.1.

**Figure 4.1 Process of Surrogate Decision-Making in Critical Illness**
The model representation illustrates the dynamic nature of the process. The four major themes (*Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values*) appear in a circular pathway. The circular pathway does not have a beginning or an end, indicating the process is continuous rather than sequential. Each theme is considered but none is considered in isolation. *Integration*, leading to a Decision, is at the center of the model. The entire model as a whole displays *Integration*, as the outer circle encompasses the circular pathway of major themes, *Integration* of the themes, and the Decision.

An individual surrogate decision-maker may place more emphasis on some of the major themes than others, but all are considered within the process of coming to a decision. The model does not specify a hierarchy among the themes or demand a certain result within a theme. For example, a surrogate decision-maker who has a religious belief to prolong life at all costs and a surrogate decision-maker who has a belief in the appropriateness of physician-assisted suicide are both considering the theme of *Recognizing Personal Values*. In another example, the theme of *Considering Family Perspectives* is applicable to the surrogate decision-maker without identified family. It may include influences from family in the past, influences from friends (who are included in the broad definition of family), or influences that come from the absence of a family support system. Since the themes are broad, the model proves flexible enough to be applicable to the varied people who comprise the population of surrogate decision-makers for critically ill patients while still describing the themes pertinent to the process of making those decisions.
Chapter Summary

The goal of this study was to describe the process of surrogate decision-making for critically ill adults. This chapter includes an explanation of the findings, grounded in the data, and the development of the model of the *Process of Surrogate Decision-Making in Critical Illness*. Discussion of the findings, as related to current knowledge of dual process decision theory, the surrogate decision-making literature, bioethics theory, and the grounded theory methodology are discussed in Chapter 5.
Chapter 5

Discussion of Significant Findings

The purpose of this study was to explore and describe the process of surrogate decision-making during the acute phase of critical illness. Interviews with surrogate decision-makers of critically ill adult family members provided a wealth of data on the process. Four major themes emerged (Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values), connected by the overarching theme of Integration. This formed the basis for development of the model, Process of Surrogate Decision-Making in Critical Illness.

The findings of this study present a new approach to thinking about surrogate decision-making, both from a cognitive process-oriented and ethical perspective. This adds to the current body of knowledge in decision theory, empirical work on surrogate decision-making, and bioethical theory.

Findings in Relation to Dual Process Decision Theory

Many decision-making models exist in the fields of mathematics, psychology, and medicine (Ebell, 2010; Haidt, 2012; Mazur, 2012; Werner, 1995) but have not been applied to surrogate decision-making. Variations of dual process decision theory have been applied to both provider and patient clinical decision-making (Croskerry, 2009; Power et al., 2011). Though grounded theory studies generally do not require a pre-existing theoretical framework, dual process theory was used to guide development of the initial interview guide as it most closely reflected anecdotal clinical experience.

Dual process theory was discussed in detail in Chapter 2. A dual process framework (Figure 5.1) could accommodate the major themes in the Process of Surrogate Decision-Making.
in Critical Illness (Figure 5.2). System 1 thinking is intuitive and based on what the surrogates already knows or has experienced. For many surrogates, this would include the themes of Understanding the Patient’s Values and Preferences, Considering Family Perspectives, and Recognizing Personal Values. System 2 thinking is rational and requires gathering information or considering information in new ways. For many surrogates, this would include the theme of Acquiring Health Care Knowledge.

Figure 5.1 Dual Process Model of Decision-Making

Comparison of the two models reveals that the difference is in the connections among the concepts or themes. Dual process theory describes the intuitive System 1 and the rational System 2 as separate pathways. It does allow for calibration between the two systems but they remain isolated with one system responsible for the final decision. Calibration determines which process (System 1 or System 2) has the most influence and determines the final decision. It is not a method of combining the influences of both processes. The model developed in this study,
Process of Surrogate Decision-Making in Critical Illness, describes use of all themes concurrently. The final decision is a result of consideration of all themes and their interactions. This model is firmly grounded in the study data. This does raise a new way of considering the process of surrogate decision-making. All of the themes have influence on the final decision. For example, consider the decision when there is no advance directive. This does not negate the contribution of Understanding the Patient’s Values and Preferences; the theme includes the idea that the surrogate must make decisions without the benefit of the advance directive. In this study, participants who did not have an advance directive felt that it would have been helpful to their decision-making process.
Tillman (2016) evaluated several dual-process theories from moral psychology as applied to moral decisions. Whether attributing moral decisions to intuitive processes (System 1) or rational processes (System 2), these theories could not completely explain the phenomenon. Based on further analysis of dual-process theory, Tillman (2016) developed a dual-process model of moral decision-making. Essentially, the model describes a process that begins with perceptual awareness (System 1), undergoes conceptual translation for rational conceptual analysis (System 2), undergoes aesthetic translation to move back to System 1 thought and then a decision is made. Tillman’s model does at least include consideration of both System 1 and System 2 but moves back and forth between the two. This does not adequately explain the findings in the current study in which participants chose to consider all of the themes as a whole.

Tunney and Ziegler (2015) proposed a domain-general theory of surrogate decision-making based on the surrogate weighing four different perspectives: maximizing their own outcome, modeling the goals and wishes of the recipient, what the surrogate would do in the recipient’s position, and what they believe is best for the recipient regardless of other factors. Though based on a psychological analysis of the surrogate decision-making process, this theory considers some of the themes in the current study’s model: *Understanding the Patient’s Values and Preferences, Recognizing Personal Values, and some component of Acquiring Health Care Knowledge*. Weighing the four perspectives to come to a decision is a different process than considering all of the themes together. As a result, this theory also does not fully explain the findings of the current study.

**Findings in Relation to Surrogate Decision-Making Empirical Literature**

There is little in the empirical literature about the process surrogates use in making decisions. There is some evidence that they prefer more control over value-laden decisions than
strictly medical decisions (Johnson et al., 2011). The findings in the current study are consistent with that perspective. When asked what decisions they had made on behalf of their family member, participants noted procedures like initiation of ventilator support, dialysis, invasive monitoring lines, and surgeries; all things that required written consent and were life-sustaining interventions. They did not consider the many decisions that were made daily for their critically ill family member. One participant said, “I don't know that I have to make (routine care) decisions. It’s not like that here; they’re trustworthy people. I don’t know that I need to tell them.”

The accuracy of surrogate decisions has been questioned, with evidence for congruence of surrogate and patient decisions only 68% of the time (Shalowitz et al., 2006). Factors positively associated with congruence of decisions are the patient and surrogate having spoken about end-of-life issues and higher education levels. Factors negatively associated with congruence of decisions are surrogate attendance at religious services, patient belief that they would live longer than 10 years, and surrogate experience with life-sustaining treatment (Sulmasy et al., 1998). Regardless of prior conversation, all participants in the current study reported that they understood what their family members would want and that they were making decisions in accordance with their wishes. It is not clear why participants made this interpretation. When queried, the responses were a variation on “I just know”. A possible interpretation is that the participant was making decisions based on their own values, under the presumption that the patient shared their value system. It is also possible that the participants were actually making decisions that would have been congruent with the patient’s if the patient had been aware of all of the details of the circumstances.
The current literature documents high levels of stress in surrogate decision-makers, particularly in the scenario of critical illness. Participants in the current study did describe stress, but not specifically related to the decision-making process. Schenker et al. (2012) relate this stress to the conflict between doing what the patient would want and not wanting to feel responsible for their death. Participants in the current study did not describe stress related to such a conflict. Instead, they described that while they chose to do all possible to save life, they anticipated a point at which they would stop treatment. In the five years since the Schenker et al. (2012) study, there has been an increase in conversations about end-of-life care. This may contribute to the current participants’ seeming increased acceptance of an end point to futile treatments. No participant’s family member died during the time they were enrolled in the study and no participants made decisions to withdraw treatment, which affects the ability to draw conclusions about end-of-life decisions. Anticipating what they would decide and actually making that decision are different. There is some support in the literature for the idea that hypothetical decisions reflect actual decisions (Heldt, Rudholm, & Weiberth, 2013; Kuhberger, Schulte-Mecklenbeck, & Perner, 2002; Wilson & Rule, 2016). These studies however, were not completed in the disciplines of healthcare, where the hypothetical situation can never fully reflect the specifics of the actual circumstances under which the decision must be reached.

Another study (Iverson et al., 2014) identified lack of clear information from providers as a source of stress. Consistent with the literature, the importance of communication was evident in the theme of Healthcare Knowledge. Participants in the current study readily identified the importance of communication and the stress created when communication was lacking.

Findings in relation to shared decision-making. Patients want family members to make decisions for them when they are incapacitated (Wendler et al., 2016) but they often prefer
that their surrogates use shared decision-making or even rely on the physician for decision-making (Sharma et al., 2011). The literature supports surrogate decision-maker preference for shared decision-making (Heyland et al., 2003). Medical societies currently recommend shared decision-making as well, in both provider-patient and provider-surrogate decision-maker situations (AMA, 2014; Davidson et al., 2007; Kon et al., 2015). Part of the difficulty is defining what is meant by the term. Shared decision-making has been described as a continuum between the patient/surrogate and the provider in making healthcare decisions (Kon, 2010). It does not necessarily refer to a 50-50 decision, just that both parties contribute.

Participants in the current study relied heavily on the providers for making decisions as seen in the discussion of the theme Acquiring Health Care Knowledge. At least during this acute phase of critical illness, the shared decision-making continuum leaned heavily toward the contribution of the providers. The surrogate decision-makers acknowledged the expertise of the providers and based decisions on that expert knowledge. Although the responsibility for shared decision-making was not balanced, this was by the surrogate decision-maker’s choice. The finding was consistent across all four ICUs in the study. It may have been related to the critical illness of the patients at the time. There is some support for allowing patients to choose paternalism (Hoffman, 2007; Gawande, 2014). The same criteria would apply to the surrogate who is making decisions on their behalf. Previous studies also demonstrate patient support for surrogate reliance on provider input (Sharma et al., 2011).

The empirical literature supports inclusion of physician recommendations in the shared decision-making process. And from an ethical perspective, such recommendations are justified. The surrogate is free to accept or refuse the provider recommendation. These decisions are
normative questions that cannot be broken down to values vs. facts (Prochaska & Sulmasy, 2015).

**Findings in Relation to Bioethical Theories**

**Ethical Basis for Surrogate Decision-Making.** Analysis of participants’ descriptions of their decision-making processes in the current study did not conform to any formal ethical theory. Based on the use of its individual principles in healthcare, Principlism was considered as a basis for the study. In short, principlism consists for the four principles of autonomy, beneficence, nonmaleficence, and justice that are balanced to reach the optimal decision. Participants primarily based their decisions on the principle of beneficence, with little to no consideration of the other principles. Their goal was to make choices that would benefit their family member (beneficence). They considered the principle of autonomy as included in the theme *Understanding the Patient’s Values and Preferences*. However, this was only a part of the decision-making process; and the participants often made decisions inconsistent with their family members’ previously expressed wishes. None of the participants discussed the ideas of nonmaleficence or justice. The principle of beneficence appeared as they balanced all of the themes in the developed model, *Process of Surrogate Decision-Making in Critical Illness*.

Autonomy is the most prevalent principle discussed in the surrogate decision-making literature and a strongly held value in American culture. It is notable that it was not the most influential principle for the surrogate decision-makers. This may be related to the context of the acute phase of critical illness, a time in which the surrogate expected their family member to recover following intensive treatment. Considering the primacy of beneficence in the decision-making process of surrogates during the acute phase of critical illness, virtue ethics provides a stronger framework for the *Process of Surrogate Decision-Making in Critical Illness*. Virtue
ethics fits well with the ideas expressed by the surrogate decision-makers in this study (Bock, 2014; Gardiner, 2003; Hendricks, 2016; Sakellariou, 2015) but it is centered on the virtuous traits of the actor making decisions. The interview data here does not reveal the underlying character of the surrogate decision-maker, limiting the ability to apply virtue ethics to this study though it could emerge from further in depth interviews.

As discussed in Chapter 2, the bioethics literature does not provide support for any particular ethical theory linked to surrogate decision-making. Ethical factors considered by surrogates in one study were considered to include patient input, knowledge of the patient’s wishes, patient’s best interests, surrogate wishes and values, and family consensus (Fritsch et al., 2013). The relationships among the ethical factors and how they contributed to decision-making were not described. These factors are all included in the model developed in the current study, *Process of Surrogate Decision-Making in Critical Illness*.

In the current study, the ethical basis underlying participants’ decision focused on the value of life. This was described as more inclusive than only the theme of *Recognizing Personal Values*, though it was most apparent in that theme. Participant statements regarding *Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge*, and *Considering Family Perspectives* also reflected the importance of valuing the life of their critically ill family member. Though not consistent with any traditional ethical theory, respect for the value of life forms the ethical basis of surrogate decision-making during critical illness. The idea is richer than physical life, encompassing all aspects of the person’s being. There may be some commonalities with deontological theory in that the surrogate decision-makers described the intent of their decisions as achieving recovery and health of their family member. This was not described as a duty and it is unclear that they would choose to have their decisions
become universal laws applicable to all (as deontology would suggest). Similar to the discussion of virtue ethics above, deontology does not fit with the findings of this study perfectly, but may be a better fit than principlism.

It must be considered that this study was completed during the acute phase of critical illness, in the first 2-3 weeks. All of the participants noted that if at some time there was not hope of recovery, they would make different decisions. The ethical basis for surrogate decision-making in different scenarios or with different populations may be different as well.

**Ethics Guidance Principles for Surrogate Decision-Making.** Use of the ethics guidance principles for surrogate decision-making is a standard recommendation (Buchanan & Brock, 1986, 1990). The three guidance principles fit within the developed model, *Process of Surrogate Decision-Making in Critical Illness.* Use of the advance directive by the surrogate decision-maker is included in the theme *Understanding the Patient’s Values and Preferences* in the model. Use of substituted judgment (based on prior conversation/knowledge) is also included in the theme *Understanding the Patient’s Values and Preferences.* Use of the best interest principle (considering all aspects of the patient’s interests to determine the greatest benefit) generally focuses on determining the patient’s best interest by objective criteria. As such, it is included in the theme *Acquiring Health Care Knowledge.*

According to the guidance principles, surrogate decision-makers should base decisions on the advance directive if one is available, without regard for any other information. If an advance directive is not available, surrogate decision-makers should base their decisions on substituted judgment, or what the patient has said in the past. Finally, if they have no knowledge of the patient’s expressed wishes about the particular decision in question, surrogate decision-makers
should base their decisions on the patient’s best interest. Best interest primarily focuses on clinical prognosis for recovery.

As described in Chapter 2, conflicts do arise as to how the guidance principles should be applied. In a study of 1156 physicians, there was conflict about which principles should be used. Substituted Judgment was chosen over Best Interest by 78%, yet 40% believed the surrogate should base decision on Best Interest even if contradicts patient’s prior wishes (Combs et al., 2013). Participants in the current study resolved the conflict between the principles through integration of the guidance principles. This was a natural part of the surrogate decision-making process as they used Integration of the themes to reach a decision. They considered Advance Directive (when available), Substituted Judgment, and Best Interest concurrently when making decisions for their critically ill family member. This provided the surrogate decision-maker with a more complete picture of ethical issues involved, including both the patient wishes and how those wishes could be interpreted in the context of the present situation. The guidance principles were used in an integrated manner congruent to the decision-making process.

**Findings in Relation to Grounded Theory**

The *Process of Surrogate Decision-Making in Critical Illness* was developed, grounded in the findings presented in Chapter 4. Symbolic interactionism is the theory underlying grounded theory methodology. The core of symbolic interactionism consists of three premises. First, people act toward things based on the personal meaning of those things. Second, the meaning of things is a result of the social interaction a person has with others. Finally, the person uses an interpretive process to use and modify the derived meanings in determining actions toward things that are encountered (Blumer, 1969). Each of these premises was apparent in the analysis of data and development of the model in this study. Participants were acting as
surrogate decision-makers for critically ill family members. First, it was clear that the family member had personal meaning to the participant, though there were variations in the specific meaning. Second, that personal meaning was identifiable as a result of the participants’ social interactions that they described – with their critically ill family member, other family members, and members of the healthcare team. Finally, through their descriptions of their decision-making processes and experiences, the participants revealed how they interpreted meanings and determined actions (decisions) through the course of the study. The developed model of surrogate decision-making in the context of critical illness was unmistakably informed by symbolic interactionism.

**Implications of the Findings**

The findings of this study have implications for nursing and all healthcare providers who care for critically ill patients and their families. The themes that emerged from data analysis indicate the breadth of factors salient to the surrogate decision-maker. Attention to each theme is important to optimally support the surrogate through the decision-making process. Nurses are well positioned to be the coordinators and providers of that support.

There are recommendations in the literature to focus on the patient’s values to aid in surrogate decision-making (Lambert, Gibson, & Nathanson, 1990; Scheunemann et al., 2012). The model developed here tells us that focus is incomplete. Ongoing conversations with surrogate decision-makers throughout the critical illness of their family member should include topics within the themes of *Understanding the Patient’s Values and Preferences*, *Acquiring Health Care Knowledge*, *Considering Family Perspectives*, and *Recognizing Personal Values*, as well as the overarching theme of *Integration*. The surrogate decision-maker may not raise each
topic independently. The study findings provide us with the knowledge to enter into the conversation.

First, nurses and other health care providers must be educated about these multiple themes that affect the surrogate decision-making process. Only then can they act as an aid to the surrogate. There have been recommendations for nurses to serve as facilitators of high quality surrogate decision-making in critical care (Kageyama & Asano, 2017; D. B. White, 2011). Participants in the current study expressed a need for good communication and consistency of information, preferably from a single person. As one participant said, “Sometimes information is in bits and pieces. It would be nice if one person had all the information.” Nursing is the profession with both the psychosocial and clinical background to meet that need.

The model of the *Process of Surrogate Decision-Making in Critical Illness*, which emerged from the data in this study, adds to existing body of knowledge in both the cognitive process and moral reasoning aspects of surrogate decision-making. The model may inform the research of healthcare scholars studying surrogate decision-making in critical care or other settings. The model may also form the basis for the development of evidence-based interventions to improve the quality of surrogate decision-making and the experience of the surrogates.

The role of nurse/bioethics scholar disrupts and challenges the norms of bioethics practice and research. Bioethics scholars educated in philosophy or other non-clinical disciplines typically do not understand the clinical implications of ethics applied to health care. Clinicians commonly do not recognize ethical elements in their routine clinical encounters (Dresser, 2011; Truog et al., 2015). Both of these types of scholars leave a significant gap that can lead to misinterpretation or misapplication of findings. Three themes of ethical
consideration that frequently arise are respecting and constructing patient values and preferences, self-awareness and management of clinicians’ values and biases, and managing medical information (Truog et al., 2015). Each of these involves the clinician treating the patient and family. The American Society for Bioethics and Humanities’ Core Competencies for Healthcare Ethics Consultation (2011) defines the role of ethics consultation in health care as addressing “uncertainty or conflict regarding value-laden concerns that emerge in a healthcare context” (p. 4). The clinical knowledge competencies, however, do not require more than a cursory understanding of the clinical context. It is difficult to guide a discussion in a situation of uncertainty if one does not understand the true clinical status of the patient, including expectations for recovery and futility of interventions. The nurse/bioethics scholar bridges that gap.

The conduct of this study has implications for future research in the area of health care bioethics. Research on topics that cross ethics and healthcare is complex. Studies can be effectively managed by teams that include both expert clinical researchers and bioethicists. Difficulties can arise due to lack of a common language. The role of the dual educated scholar is to identify the commonalities, interpret both sides of the dilemma, and foster accurate design and interpretations from both the clinical and ethics perspectives.

Beyond the areas of practice and research, the dual educated scholar brings those same perspectives to education. Bioethicists working in the clinical arena must achieve an understanding of the clinical status of patients/families. Clinicians work with bioethical issues daily and must achieve an understanding of ethics beyond autonomy, particularly in the context of surrogate decision-making. Interprofessional education of the two groups by a dual educated
scholar who can speak both of their languages can optimize their function, and therefore the care provided to patients and families.

This study has implications for policy development on multiple levels. The *Process of Surrogate Decision-Making in Critical Illness* can be used to inform institutional policy on methods of providing assistance to surrogate decision-makers of the critically ill. It can inform the policy of professional organizations by defining the types of support most likely to be effective in aiding surrogate decision makers and provide an area for the research supported by those organizations. Ultimately, the findings of the study can be used to improve state and national policy regarding the use of the ethics guidance principles. Currently, most laws require the use of advance directive, followed by substituted judgment, followed by best interest in making surrogate decisions. This system of legal analysis may not be optimal, as it does not reflect what happens in actual practice. The study findings support a system that would allow the surrogate decision-makers to consider all three of those principles simultaneously in arriving at a final decision.

Finally, the findings of this study raise questions about the applicability of ideal ethics theory to real clinical practice and decision-making. As discussed earlier, the findings of this study do not fit any specific ethical theory. In considering principlism, surrogate decision-makers for patients in the acute phase of critical illness primarily made decisions based on beneficence. Virtue ethics and deontology were touched on as potential better fits with the data. The participants were not using a particular ethical theory or bioethical framework since they had not been trained in those methods. The theories could, at least partially, explain their descriptions of their decision-making processes. The question remains whether this is useful to clinical practice.
Knowledge of abstract ethics theories does not lead to a clear clinical decision in situations of conflict about value-laden choices. There is a clear disconnect between the recommendations for ethics consultants (American Society for Bioethics and Humanities, 2011) and the competencies required of clinicians. Some work has been done to attempt to connect ethics theory to clinical practice (Luna, 2015; F. G. Miller, Fins, & Bacchetta, 1997; ten Have, 1994). Clinicians have also attempted to apply ethical concepts to practice, though these relate most strongly to principlism (Kaldjian, Weir, & Duffy, 2005; Skold & Lesandrini, 2017). Other texts for clinicians include content on ethics theories but do not connect it directly to practice concerns (Davis et al., 2006; D. R. Thompson & Kaufman, 2014). Clinicians are left to deal with the divide between theory and practice. Knowledge of ethics theory, though not providing a “right decision”, can inform clinicians’ understanding of the surrogate decision-making process.

**Study Strengths and Limitations**

This study was undertaken with several assumptions. It was assumed that the sample would be representative of surrogate decision-makers with critically ill family members. It was assumed that the participants would discuss their interviews with family. This was acceptable since if it occurred, it was likely that a similar process was being used in making decisions.

The prospective design was a significant strength of the study. By interviewing each participant on two separate occasions during the time period in which they were required to make health care decisions for their critically ill family member, the researcher was able to gather data in real time. The participants’ descriptions of their decision-making processes did not rely on recall but clearly described the process as it was occurring. The result was the rich, detailed data that allowed for in depth analysis, confirmation of themes and a model grounded in the data.
Advisors with qualitative experience consulted to evaluate the researcher’s thinking on identification of themes and the emerging model. Their expertise strengthened the study and the findings. Advisors with bioethics expertise, both clinical and scholarly, strengthened the bioethics interpretation. The combined expertise of advisors fostered the development of connections between clinical practice and ethics application.

Data collection at a single institution in Central Pennsylvania was not expected to be a severe limitation to recruitment of an appropriate sample. Based on the institution’s status as a tertiary referral center and its geographic location, the patient population is drawn from a large diverse rural and urban area. Recruitment of participants from the families of four diverse ICU populations was expected to contribute to creation of a diverse sample. However, there was a significant absence of diversity in the recruited sample. All participants were Caucasian with the exception of one Pacific Islander. All were financially stable, had good family support, and were able to travel to the hospital without difficulty. During study recruitment, there were patients in all 4 ICUs of diverse racial, ethnic, family, and socioeconomic backgrounds. The surrogate decision-makers for those patients were either unable to be identified, unwilling to talk, or unable to travel to the hospital due to lack of transportation. This posed a limitation to the study and identified an additional challenge in providing support to the surrogate decision-makers in those situations. Racial, ethnic, and cultural factors have been associated with differences in end-of-life planning and treatment choices (R. W. Johnson et al., 2010; Kwak & Haley, 2005; Searight & Gafford, 2005). Differences in choices may be even more complex, reflecting the interaction of multiple factors that represent the political, social, and existential situation of the individual making decisions (Schweda, Schicktanz, Raz, & Silvers, 2017). The question persists whether
these study findings are applicable in diverse populations. That question can only be answered by investigating the question in those populations.

In the planning stages, it was unclear whether the diversity of diagnoses across 4 different ICUs would be a strength or a weakness. The findings were unchanged regardless of diagnosis, degree of acuity, or specific ICU. The diversity of diagnoses therefore strengthens the study, providing support for the potential to apply the findings to multiple populations.

The time frame for this study was in the acute phase of critical illness, covering the first 2-3 weeks in the ICU. As a result, the model *Process of Surrogate Decision-Making in Critical Illness* describes decision-making during the acute phase of critical illness. This is a unique contribution to the literature since prior studies of surrogate decision-making in critical care have focused on chronic critical illness. It does, however, limit the generalizability of the model to the context of chronic critical illness. Participants in the study did not face any end-of-life decisions about withdrawal of life sustaining treatments. Several were anticipating the possibility for the future but that did not occur during study enrollment. Surrogates facing end-of-life decisions experience more decisional conflict (Miller, Morris, Files, Gower, & Young, 2016). Study findings might be different in a population of surrogate decision-makers facing end-of-life decisions.

It is understood that qualitative results are not generalizable in the same sense as quantitative results. However, the consistency of data within and across participants and the saturation of data within the study sample leads to the expectation that the derived themes are broad enough to be applied beyond the study sample and setting, at minimum to similar populations (Corbin & Strauss, 2015).
Recommendations for Future Research

Recommendations for future research related to this study are two-fold. First, similar studies with samples consisting of diverse racial, ethnic, family, and socioeconomic backgrounds are recommended. Methodology or location of setting will need to be considered in order to enhance the ability of the target sample to participate. The themes in the developed model, *Process of Surrogate Decision-Making in Critical Illness*, are broad enough to hypothesize confirmation of model in diverse populations, though the specific ‘answers’ within each theme might differ in different populations.

The second area for future research lies in use of the developed model to create and test interventions to improve surrogate decision-making, enhance the experience of the surrogate, and decrease the symptom burden of the surrogate. A recent study demonstrated positive feedback from surrogates and clinicians regarding implementation of a nursing role of family navigator for the families of critically ill patients in the ICU to provide emotional and informational support (Torke et al., 2016). Further study of a similar role would be supported by the *Process of Surrogate Decision-Making in Critical Illness* model, expanding the role to include all of the themes. This would require education of the nurse family navigator in each of the themes in the model, sustained familiarity with the patients’ clinical status, and frequent family contact. The model could also be used to evaluate the effectiveness of family meetings for critically ill patients in fulfilling the needs of the surrogate for decision-making. In addition, the model could be used to drive research on any specific theme, e.g., completion or use of advance directives, surrogate knowledge of patient wishes, or surrogate understanding of the patient’s health care status.
Conclusions

Advances in technology and increasing numbers of ICU admission combine to increase the frequency and importance of surrogate decision-making in the context of critical illness. In recent years, professional healthcare organizations have made an effort to improve support for the family members of critically ill patients through initiating committees to address family support, development of educational programs, and creation of family support group networks. The existing body of knowledge remains insufficient. It is not known with any certainty which interventions are effective in aiding the surrogate decision-maker and other family members. This study was undertaken to study the process of surrogate decision-making. Only by understanding how the process works, can we design effective methods of improvement.

The 19 participants in the study provided a rich, detailed description of all aspects of their process of surrogate decision-making while their family members were critically ill. They represented a range of patient types, from acute illness with no prior medical problems to critical exacerbations of chronic illness. Grounded in the data, the Process of Surrogate Decision-Making in Critical Illness model emerged to describe the cognitive process of surrogate decision-making. Themes included in the model involved patient, surrogate, family, and clinician. Bioethical aspects were analyzed and found to correlate with the model as well. When the surrogate makes healthcare decisions for a family member, all of the varied themes are integrated and considered together to arrive at a decision. The four major themes included in the model (Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values) and the overarching theme of Integration were derived from participants descriptions of their mental processes in making decisions about the health care of their critically ill family member. The qualitative study of
cognition uses a reflective stance to understand high-level cognition that is multifactorial and done over time (Omerod & Ball, 2008). By use of the qualitative method, the concrete factors used in decision-making became apparent.

It is vital for healthcare providers to understand the process by which surrogate decision-makers in the ICU think. Theory driven interventions can assist surrogates and optimize the decisions to benefit patients. Testing of the developed model can result in a generalizable theory to inform program development and policy across critical care areas. This study provides the context to move the process forward.
Chapter 6

The Bioethics of Surrogate Decision-Making in Critical Care

Individuals who are not able to make independent health care decisions require a surrogate decision-maker to do so on their behalf. These individuals may be incapacitated for a variety of reasons, both chronically and acutely. In the context of critical illness, the individual’s incapacity is most often related to the physiological and psychological effects of their critical illness. Use of a surrogate decision-maker to represent another individual raises ethical questions. Who best represents the person’s interest? Is the surrogate capable of making the necessary decision? Can the surrogate override decisions the person has made in the past?

The current study investigated the process of surrogate decision-making in the context of critical illness. The relationship of bioethics to the surrogate decision-making theory and the use of bioethics in surrogate decision-making are discussed in Chapter 5. Chapter 6 discusses the bioethics of surrogate decision-making. First, several approaches to the process of surrogate decision-making are discussed. Next, justification for the surrogate decision-making process in critical care is discussed. Finally, conclusions are drawn pertaining to the bioethics of surrogate decision-making in critical care in the context of the present study.

Approaches to Surrogate Decision-Making

Traditional Approach – Three Guidance Principles

Buchanan and Brock (1986) describe three guidance principles (advance directive, substituted judgment, and best interest) for surrogate decision-making along with conflicts that may occur among them. Conflicts among the principles arise when a different decision can be reached depending on which principle is used to make the decision. Though written 28 years ago, these decision-making principles and their related conflicts remain pertinent to current
clinical practice. The three hierarchical principles are expected to be a guide for the surrogate decision-maker (Beauchamp & Childress, 2013). These principles are intended to be used when a person cannot make their own healthcare decisions. An important point is that they are intended to be used in the specified order: advance directive, substituted judgment, best interest (Buchanan & Brock, 1986).

The construct of individual autonomy developed from Western democracy’s respect for personal liberty (Beauchamp & Childress, 2013). The decisional hierarchy is based on autonomy and the notion that the role of the surrogate decision-maker is to preserve the patient’s autonomy. Therefore, the first principle to apply is the advance directive. The advance directive principle states that when an advance directive exists, it is to be followed (Buchanan & Brock, 1986, 1990). This is a formal written document previously completed by a competent patient to direct decisions about their medical care should they become incapacitated. Designation of a medical power of attorney to make decisions may be part of the written document; it identifies the surrogate decision-maker and whether they have the authority to override the decisions in the advance directive. In the absence of an advance directive, the surrogate is required to make a decision and either substituted judgment or best interest will apply.

The second principle to apply is substituted judgment. The substituted judgment principle states that the surrogate should make the decision that the patient would choose given the current circumstances (Buchanan & Brock, 1986, 1990). Braun et al. (2009) posit that substituted judgment actually calls for the surrogate to provide a report rather than make a decision since the decision is based on what was previously expressed by the patient. The decision is made on the basis of what the patient has indicated in the past or what the surrogate
believes the patient would decide if able based on prior discussion with and knowledge of the patient and their values.

When the surrogate decision-maker is not certain of the patient’s wishes (either expressed or able to be determined by consideration of their known values), the best interest principle is applied. The best interest principle states that the surrogate should make the decision by considering all aspects of the patient’s interests to determine the greatest benefit (Buchanan & Brock, 1986, 1990). In health care decision-making, this may involve seeking out information about the disease process, treatment options, and prognosis.

The conflicts among the three guidance principles become apparent in practice. A decision based on an advance directive may be different from the surrogate’s substituted judgment because current conditions may not have been anticipated in the patient’s advance directive document. The advance directive and substituted judgment principles may both conflict with the patient’s best interest at that point in time. The best interest principle considers only the patient’s status at the time of the decision, while advance directive and substituted judgment principles consider the patient’s prior expressed wishes and values in arriving at a decision. The fact that the conflicts described by Buchanan and Brock (1986, 1990) have not yet been resolved to achieve an agreed upon mode of surrogate decision-making indicates the complexity of the issue.

Others have made similar arguments about the conflicts and limitations of substituted judgment and best interest standards (Arnold & Kellum, 2003; Torke, Alexander, & Lantos, 2008). Substituted judgment is justified as the equivalent of the patient’s right to autonomy carried out by the surrogate who understands what that autonomous decision would be based on previous discussion with and knowledge of the patient. The principle is not complete; a
competent person can change their mind. In addition, the specific health care situation with all of the current variables is unlikely to have been discussed by the patient in the past. The surrogate may be influenced by their own values and best interests (Arnold & Kellum, 2003; Eliott & Olver, 2007a; Eliott & Olver, 2007b; Hyun, 2003; Nelson & Lindemann, 2007). They may hesitate to make a decision by which they feel responsible for the patient’s death (Schenker et al., 2012). Advance directive principle has similar justification and limitations to substituted judgment. Best interest is justified as decided by the surrogate, who best understands the patient’s values and interests. The principle is also not complete because best interest standards consider what is ‘best’ based on populations of averages, not necessarily the individual.

Other Bioethical Perspectives

Sulmasy and Snyder (2010) propose an integrated model of surrogate decision-making – substituted interests. Their intent is to reframe surrogate decision-making to apply “the patient’s authentic values, wishes, and real interests, as best they can be known.” Wendler and Phillips (2015) point out that substituted judgment cannot replicate a person’s autonomous decision and propose the endorsed life approach to surrogate decision-making. This involves making decisions consistent with promoting the course of life the patient valued (Phillips & Wendler, 2015). Dresser (2015) argues that the endorsed life approach is not superior to the original concept of substituted judgment, acknowledging that application of any of these principles in real life is “messy”.

Torke, Alexander, and Lantos (2008) proposed that the ethical principle of respect for persons resolves the conflicts among the three ethical principles as described above. Respect for persons involves consideration of the patient’s life story. In doing so, it is a broader principle than autonomy. In the context of surrogate decision-making, the principle of autonomy can only
include decisions in which the patient’s wishes were explicitly expressed in the past. Basing decisions on the principle of respect for persons, however, includes consideration of the patient’s values and interests within the current situation. Others describe essentially the same concept using the term authenticity. Brudney (2009) describes authenticity as the ability to be a distinctive individual with beliefs and values and to make decisions (or have the surrogate make decisions) based on those beliefs and values. Scheuenemann et al. (2012) state that an authentic decision is a decision informed by knowledge of the patient’s values and motivated by an intention to deliver care that respects the patient as a person. Both respect for persons and authenticity could be used within the context of the three guidance principles. They place the considerations of the surrogate in the context of the patient when making either a substituted judgment or a best interest based decision, allowing for a decision based on the patient’s values and needs.

Ultimately, each of these approaches is an attempt to make decisions consistent with patient values that are likely to have a result also consistent with those values. Clinical situations requiring surrogate decision-making are complex and may require multiple considerations and approaches.

**Surrogate Decision-Making in Healthcare**

Surrogate decision-making in healthcare is complex and even more so in the context of critical illness. Health care clinicians are educated in ethics based on the principles included in principlism with a strong emphasis on autonomy. This perspective is consistent with the predominant culture in the United States. In practice, the three guidance principles of advance directive, substituted judgment, and best interest are used as the guide to surrogate decision-making since they are proscribed by law. Clinicians, however, often note the same conflicts and
contradictions that have been noted by bioethicists. J. T. Berger et al. (2008) discuss the
difficulty in applying the ethical principles to clinical practice. They discuss substituted
judgment and best interest at opposite ends of a continuum with recommendations for clinical
practice falling in the middle. The implication is that both the patient values and medical
condition and prognosis must be considered in making an optimal decision.

**Justification for the Choice of Surrogate Decision-Maker in Critical Care**

The need for surrogate decision-making to exist is incontestable. When a person loses
decisional capacity, whether due to mental or physiological reasons, another person must make
those decisions. Justification for the optimal person to serve as surrogate decision-maker is
complex. In the scenario of critical illness, the complexities in decision-making are compounded
by complexities in the clinical situation, including life-threatening illness and use of advanced
technology and devices.

Laws related to identification of surrogate decision-makers are clear. The Patient Self
Determination Act (1990) gives people the right to determine own healthcare and make an
advance directive to define their healthcare decisions. In the absence of an advance directive,
most states require that the surrogate make decisions by using the substituted judgment and best
interest standards (Wynn, 2014). Most states have enacted statutes that identify the default
authority for healthcare decision-making for incapacitated persons, usually by kinship priority
(Wynn, 2014). If a health care representative has not been identified by a person, the order of
priority in Pennsylvania is: (a) the spouse unless an action for divorce is pending and the adult
children of the person who are not children of the spouse, (b) an adult child, (c) a parent, (d) an
adult brother or sister, (e) an adult grandchild, and (f) an adult who has knowledge of the
person’s preferences and values, including, but not limited to, religious and moral beliefs (Pennsylvania [PA] Code, Title 20, Chapter 54, 2006).

The requirements of law do not always correlate with moral justification. In considering the moral arguments for choice of surrogate decision-maker, there are three primary options: the incapacitated person, family, and healthcare provider.

Use of an advance directive allows an individual to serve as their own decision-maker even after they are incapacitated. Kring (2007) argues that the Patient Self Determination Act is supported by the ethical principles and values of “autonomy, informed consent, freedom, and privacy” and that “these ethical principles provide a strong argument for all providers to seek out and secure advance directives and, most importantly, to ensure that these are followed” (p. 129). The American College of Critical Care Medicine guideline on Shared Decision-Making in Critical Care (Kon et al., 2016) states that honoring patient decision-making as documented in the advance directive demonstrates respect for persons, a core ethical obligation of health care professions. It ensures that care decisions are made consistent with the patient’s values and preferences, preserving their autonomy that they can no longer exert independently.

Perhaps preservation of patient autonomy should not be the ethical goal of surrogate decision-making. Dawson and Wrigley (2010), among others, argue that autonomy should not always be given priority. Even if strictly adhering to principlism (Beauchamp and Childress, 2013), autonomy can have conflicts with justice, beneficence, and nonmaleficence. When evaluating an individual clinical situation in demand of a decision, principlism may not be the best guide. Perhaps virtue ethics, or the ethic of care, or even consequentialism provides a more correct view of what that particular patient would have decided for himself or herself if able to do so. As Dawson and Wrigley (2010) state, there is “still doubt whether an advance directive
has the moral authority equivalent to that of a contemporaneous autonomous agent” (p. 24). The advance directive cannot ever anticipate all of the variables at play in a particular clinical situation. Therefore, it is questionable whether the advance directive can reflect what the patient’s autonomous decision would be at that point in time.

If the advance directive cannot serve alone as the voice of the incapacitated person, their family may be able to do so by acting as surrogate decision-maker. Kelly et al. (2012), in a systematic review of individuals’ goals for surrogate decision-making, found that the majority of individuals wanted family members to serve as surrogate, primarily because of a belief that they understood what the patient would decide. Those studies support the notion that individuals prefers family members to decide based on their knowledge of the person, rather than hold to their own prior decision. This is valid from an ethical viewpoint. Discussion of the moral justification for family surrogate decision-making often relies on the same standards of substituted judgment and best interest as the legal justification (Arnold & Kellum, 2003).

Potential conflicts in the surrogate’s moral authority have been identified (Arnold & Kellum, 2003; Eliott & Olver, 2007a; Eliott & Olver, 2007b; Hyun, 2003; Nelson & Lindemann, 2007). These conflicts can be categorized as the surrogate making decisions based on their own values and best interests, rather than the patient’s values and best interests; the surrogate being incapacitated by emotional involvement with the patient; and the surrogate lacking the requisite medical knowledge to make appropriate decisions. Family surrogates’ decisions are congruent with the person for whom they are making decisions only 68% of the time (Shalowitz et al., 2006). However, these studies are based on hypothetical scenarios rather than real-life situations so may not represent decision-making in the face of incapacity. Nevertheless, these multiple issues raise questions about the appropriateness of the family acting as surrogate decision-maker.
Finally, the healthcare provider directly managing the incapacitated person has been proposed as a potential surrogate decision-maker. Though most individuals want their family to make treatment decisions for them in the event of decisional incapacity, survey of patients at a tertiary care center revealed that 34% of respondents who had not designated a surrogate and 22% who had designated a surrogate wanted their doctors to make treatment decisions for them in the event of decisional incapacity (Wendler et al., 2016). Though not the majority, this is significant. The healthcare provider has the knowledge and expertise to make the best medical decision for the patient. The same level of knowledge could not reasonably be provided to the surrogate decision-maker.

Individuals identify family members as their chosen surrogates but often prefer that their surrogates use shared decision-making or even rely on the physician for decision-making (Sharma et al., 2011). The literature supports family surrogate decision-maker preference for shared decision-making (Heyland et al., 2003). A qualitative study of physicians about the ethical framework for surrogate decision-making indicates that physicians consider surrogates’ wishes and interests and their own clinical judgment as well as the patients’ wishes and interests (Torke, Simmerling, et al., 2008), supporting a model of shared decision-making authority. Medical societies currently recommend shared decision-making as well. It has become the preferred model as recommended by the American Medical Association (AMA, 2014), the American College of Critical Care Medicine, and the American Thoracic Society (Davidson et al., 2007; Kon et al., 2015).

Shared decision-making has been described as a continuum between the patient/surrogate and the provider in making healthcare decisions (Kon, 2010). Both parties contribute to the decision with the goal of achieving consensus. The family surrogate decision-maker has unique
knowledge of the patient. The healthcare provider has unique knowledge of the medical situation. This combination serves both patient preferences – to have family and healthcare provider make decisions.

Shared decision-making is consistent with the process described by Berger et al. (2008) in which the best decision for the patient is on the continuum between substituted judgment and best interest, between autonomy and paternalism, between the clinician and the surrogate decision-maker. From all aspects, shared decision-making provides the most morally defensible approach to making health care decisions for an incapacitated individual.

**PERSPECTIVES GAINED – PROCESS OF SURROGATE DECISION-MAKING IN CRITICAL ILLNESS**

The *Process of Surrogate Decision-Making in Critical Illness*, as developed in this study, can effectively bridge the gap between surrogate and clinician. The four core themes, *Understanding the Patient’s Values and Preferences, Acquiring Health Care Knowledge, Considering Family Perspectives, and Recognizing Personal Values* include information brought to the discussion by the surrogate and by the clinician. *Integration* of the four themes, at the core of the model, melds well with the model of shared decision-making.

Further study is recommended to develop and evaluate interventions based on the *Process of Surrogate Decision-Making in Critical Illness*. It is the responsibility of all healthcare clinicians to create systems that provide the best services for both patients and their families. Surrogate decision-making is an every-day need. Education on the *Process of Surrogate Decision-Making in Critical Illness* and the methods of shared decision-making must occur. Nurses are positioned to lead the change in practice.
References


APPENDIX A

EVALUATION OF STUDIES – GRADE METHOD

Grading of Recommendations Assessment, Development and Evaluation

www.gradeworkinggroup.org

QUALITY OF EVIDENCE

A (high) - well done randomized controlled trials (RCTs)
B (moderate) – downgraded RCTs or upgraded observational studies
C (low) – well done observational studies
D (very low) – downgraded controlled studies or expert opinion

Downgrade if: study limitations, inconsistency, indirectness, imprecision, bias
Upgrade if: high consistency, large magnitude of effect or dose response

LEVEL OF RECOMMENDATION

Strong – strong methods, benefits clearly outweigh downside
Weak – weak methods, balance of benefits and downside are unclear or close
**APPENDIX B**

**IRB Approval Letter**

---

**APPROVAL OF SUBMISSION**

**Date:** March 16, 2016  
**From:** Daniel McBride, IRB Analyst  
**To:** Barbara Birriel

<table>
<thead>
<tr>
<th>Type of Submission:</th>
<th>Initial Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Title of Study:</td>
<td>Surrogate Decision-Making in the Context of Critical Illness</td>
</tr>
<tr>
<td>Principal Investigator:</td>
<td>Barbara Birriel</td>
</tr>
<tr>
<td>Study ID:</td>
<td>STUDY00004454</td>
</tr>
<tr>
<td>Submission ID:</td>
<td>STUDY00004454</td>
</tr>
<tr>
<td>Funding:</td>
<td>Not Applicable</td>
</tr>
<tr>
<td>IND, IDE, or HDE:</td>
<td>Not Applicable</td>
</tr>
</tbody>
</table>
| Documents Approved: | • HSPO Consent Form - Surrogate Decision-MakerDYAD_8March2016 (3/8/2016), Category: Consent Form  
• Research Data Plan Review Form Surrogate Decision-Making ICU_16March2016 (3.01), Category: IRB Protocol  
• HSPO Consent Form - PatientAddendum_8March2016 (3/8/2016), Category: Consent Form  
• Demographic Sheet (2/10/2016), Category: Data Collection Instrument  
• Interview Guide (2/10/2016), Category: Data Collection Instrument |
| Review Level:       | Expedited |
| IRB Board Meeting Date: | |

On 3/16/2016, the IRB approved the above-referenced Initial Study. This approval is effective through 3/15/2017 inclusive. You must submit a continuing review form with all required explanations for this study at least 45 days before the study’s approval end date. You can submit a continuing review by navigating to the active study and clicking ‘Create Modification / CR’.

If continuing review approval is not granted before 3/15/2017, approval of this study expires on that date.

To document consent, use the consent documents that were approved and stamped by the IRB. Go to the Documents tab to download them.
APPENDIX C

CONSENT FOR RESEARCH
Penn State College of Medicine
The Milton S. Hershey Medical Center

Title of Project: Surrogate Decision-Making in the Context of Critical Illness
Principal Investigator: Barbara Birriel, MSN, ACNP-BC, FCCM

Address: The Pennsylvania State University College of Nursing, 90 Hope Drive, 1300 ASB / A110, Hershey, PA 17033

Telephone Numbers: Weekdays: 8:00 a.m. to 5:00 p.m. (717) 531-4211.

Subject’s Printed Name: _______________________

We are asking you to be in a research study.

Whether or not you take part is up to you. You can choose not to take part. You can agree to take part and later change your mind. Your decision will not be held against you.

This form gives you information about the research. Please ask questions about anything that is unclear to you and take your time to make your choice.

Some of the people who are eligible to take part in this research study are not able to give consent to take part because of their medical condition. Instead, the legally authorized representative who is also the patient’s caregiver will be asked to give consent for both the patient and caregiver. Throughout the consent form, “you” will refer to the caregiver/legally authorized representative who takes part in the research study. Both the patient and caregiver/legally authorized representative will be participants in this research as a pair.

1. Why is this research study being done?

   We are asking you to be in this research because you are making health care decisions for a family member in the intensive care unit who is unable make those decisions themself. This research is being done to find out how people make decisions for family members who are critically ill, what the experience is like, and what can be done to help them. Approximately 40 people (20 pairs of patients and their caregiver/legally authorized representative) will take part in this research study at Hershey Medical Center.

2. What will happen in this research study?

   What are my responsibilities if I take part in this research?
   If you take part in this research, your major responsibilities will include:
   - To read and sign this consent form.
• To take part in up to 3 audio-recorded interviews about your experiences making decisions for a critically ill family member. The interviews will be in private rooms in the hospital while you are here to visit.
  o First interview when you enroll in the study. This will last 20-60 minutes.
  o Follow-up interview in 6-9 days if your family member is still in the ICU. This will last 10-20 minutes.
  o Final interview either in 14-17 days or when your family member is discharged from the ICU or regains their ability to make health care decisions independently. This will last about 30 minutes.

There will be no direct interaction with the patient participant. Instead, the research team will review the patient’s medical record to collect information about the patient's current status, diagnoses, plan of care, and prognosis.

3. What are the risks and possible discomforts from being in this research study?
   There is a risk of loss of confidentiality if your information or your identity is obtained by someone other than the investigators, but precautions will be taken to prevent this from happening. The confidentiality of your electronic data created by the researchers will be maintained to the degree permitted by the technology used. Absolute confidentiality cannot be guaranteed.

   Some of the questions are personal and might cause discomfort. You can take a break or stop at any time. Pastoral services is available to help if you would like to talk to them.

4. What are the possible benefits from being in this research study?
   4a. What are the possible benefits to me?

       You will not benefit from this research study.

   4b. What are the possible benefits to others?

       The results of this research may be used to guide future research studies and to develop ways to help the families of critically ill patients who need to make health care decisions for them.

5. What other options are available instead of being in this research study?

   You may choose not to be in this research study. Your choice will not affect the medical care that your family member receives in any way.

6. How long will I take part in this research study?

   If you agree to take part, it will take you no more than 18 days to complete this research study. You will be interviewed up to 3 times. Each caregiver/LAR interview will occur while you are at the hospital for a visit with your family member. The study ends when your family member is discharged from the ICU or on the 18th day.

7. How will you protect my privacy and confidentiality if I decide to take part in this research study?
7a. What happens to the information collected for the research?
Efforts will be made to limit the use and sharing of your personal research information. In our research files at The Milton S. Hershey Medical Center (HMC) and Penn State College of Medicine (PSU) we will include these identifiers: your name, dates, phone number, your voice (recorded during the research interviews) a code number assigned to you, and your family member's medical record number.
• A list that matches your name with your code number will be kept in a locked file cabinet in Barbara Birriel’s office.
• Your research records will be labeled with your code number and will be kept in a safe area in Barbara Birriel’s research office.
• Your audio-recorded interviews will be encrypted and kept on a password-protected computer and electronic data storage system at The Pennsylvania State University. The audio recordings will be deleted from the recorder once uploaded to the computer and from the computer at completion of the study.
• The interviews will be transcribed by a transcriptionist and uploaded to the password-protected electronic data storage system. All identifying information (e.g., participant name, physician name, facility name) will be removed.

In the event of any publication or presentation resulting from the research, no personally identifiable information will be shared.
7b. How will my identifiable health information be used?
If you give your consent, health information that can be traced to you will be collected for this research study. In general, under federal law, health information is private. However, there are exceptions to this rule, and you should know who may be able to see, use, and share your health information for research and why they may need to do so. We will use and disclose your information only as described in this form and in the HMC Privacy Notice.

The research team may use the following health information:
• Past and present medical records
• New health information from interviews done as part of this research study.

The following people/groups may see, use, and share your identifiable health information:
• HMC/PSU research staff involved in this study
• The HMC/PSU Institutional Review Board (IRB), a group of people who review the research study to protect subjects’ rights and welfare
• The HMC/PSU Human Subjects Protection Office
• The HMC/PSU Research Quality Assurance Office
• Federal and state agencies (such as the U.S. Food and Drug Administration, the Office for Human Research Protections, the Department of Health and Human Services, the National Institutes of Health, and other U.S. or foreign government bodies that oversee or review research)

These groups may also review and/or copy your original PSU/HMC records while looking at the results of the research study. It is possible that some of the other people/groups who receive your health information may not be required by Federal privacy laws to protect your information. We share your information only when we must, and we ask anyone who receives it from us to protect your privacy.
Your permission for access to medical records will end at the conclusion of this study. Interview recordings will be deleted after transcribed. Identifiable health information will be deleted from transcribed interviews. Because research is an ongoing process, your permission for the use, storage, and sharing of the transcribed interviews without identifiable health information will continue indefinitely.

Your privacy rights:

- You have the right to refuse to sign this form that allows us to use and share your health information for research; however, if you don’t sign it, you will not be able to take part in this research study.
- You have the right to withdraw your permission for us to use or share your health information for this research study. If you want to withdraw your permission, you must notify the person in charge of this research study in writing using the address on the front of this form. Once permission is withdrawn, you cannot continue to take part in the study.
- If you withdraw your permission, we will stop collecting health information about you for this study; we may continue to use and share your health information that we already have if it is necessary for safety and scientific soundness of the research study; and we will not be able to take back information that has already been used or shared with others.
- You have the right to see and get a copy of your health information that is used or shared for treatment or for payment. However, you may not be allowed to see or copy certain health information that is a part of this research study. This is only for the period of the study. You will be allowed to see that information when the entire research study is complete.

8. What are the costs of taking part in this research study?
   8a. What will I have to pay for if I take part in this research study?

   There is no cost to you for taking part in this study.

9. Will I be paid to take part in this research study?

   You will not receive any payment or compensation for being in this research study.

10. Who is paying for this research study?

   The institution and investigators are not receiving any funds to support this research study.

11. What are my rights if I take part in this research study?

   Taking part in this research study is voluntary.
   - You do not have to be in this research.
   - If you choose to be in this research, you have the right to stop at any time.
   - If you decide not to be in this research or if you decide to stop at a later date, there will be no penalty or loss of benefits to which you are entitled.
   - If you decide to stop being in the research, already collected data will not be removed from the database. No further information will be collected.

   During the course of the research you will be provided with any new information that may affect your health, welfare or your decision to continue participating in this research.

12. If I have questions or concerns about this research study, whom should I call?
Please call the head of the research study (principal investigator), Barbara Birriel at 717-531-4211 if you:

- Have questions, complaints or concerns about the research.
- Believe you may have been harmed by being in the research study.

You may also contact the research protection advocate in the HMC Human Subjects Protection Office (HSPO) at 717-531-5687 if you:

- Have questions regarding your rights as a person in a research study.
- Have concerns or general questions about the research.
- Have questions about your privacy and the use of your personal health information.
- You may also call this number if you cannot reach the research team or wish to offer input or to talk to someone else about any concerns related to the research.

You may visit the HSPO’s web site at http://pennstatehershey.org/irb under research subject information for:

- Information about your rights when you are in a research study;
- Information about the Institutional Review Board (IRB), a group of people who review the research to protect your rights; and
- Links to the federal regulations and information about the protection of people who are in research studies. If you do not have access to the internet, copies of these federal regulations are available by calling the HSPO at (717) 531-5687.

**INFORMED CONSENT AND AUTHORIZATION TO TAKE PART IN RESEARCH**

*Signature of Person Obtaining Informed Consent*

Your signature below means that you have explained the research to the subject or subject representative and have answered any questions he/she has about the research.

____________________________  __________  __________  __________  
Signature of person who explained this research   Date   Time   Printed Name

(Only approved investigators for this research may explain the research and obtain informed consent.)

*Signature of Person Giving Informed Consent and Authorization*

Before making the decision about being in this research you should have:

- Discussed this research study with an investigator,
- Read the information in this form, and
- Had the opportunity to ask any questions you may have.

Your signature below means that you have received this information, have asked the questions you currently have about the research and those questions have been answered. You will receive a copy of the signed and dated form to keep for future reference.

*Signature of Subject*
By signing this consent form, you indicate that you voluntarily choose to be in this research and agree to allow your information to be used and shared as described above.

___________________________  __________  ____  Time  __________
Signature of Subject         Date           Time       Printed Name

**Subject’s Legally Authorized Representative**

By signing below, you indicate that you give permission for the subject to be in this research and agree to allow his/her information to be used and shared as described above.

___________________________  __________  ____  Time  __________
Signature of Legally Authorized Representative  Date           Time       Printed Name

Check the applicable box below indicating authority to act for subject:

☐ Court-appointed legal guardian
☐ Health Care Power of Attorney
☐ Health Care Representative: ________________________________

Relationship to Subject

**ASSENT FOR RESEARCH**

The research study has been explained to you. You have had a chance to ask questions to help you understand what will happen in this research.

You **Do Not** have to be in the research study. If you agree to participate and later change your mind, you can tell the researchers, and the research will be stopped.

You have decided:   **(Initial one)**   __ To take part in the research.

                            __ NOT to take part in the research.

___________________________  __  ____  ______________________
Signature of subject         Date       Printed Name
APPENDIX D

Surrogate Decision-Making in the Context of Critical Illness

Interview Guide

Initial Interview
- Tell me about your experience as the person making decisions for (patient).
  - How do you feel about making health care decisions for (patient)?
- What led up to (patient)’s admission?
  - Has (patient) had health problems?
  - How has (patient) been doing since admission?
- Have you ever had to make health care decisions for anyone else?
  - What was that like? Were they in an ICU?
  - How do those experiences affect your current situation?
- What do you know about (patient)’s preferences for care? What they would want?
  - Have you discussed this with (patient)?
  - Does (patient) have an Advance Directive? A Health Care Power of Attorney?
    - Are you / do you plan to follow these preferences? Why or why not?
- When you are making health care decisions for (patient), do you feel more comfortable deciding on your own, letting the doctor decide, or deciding jointly with the doctor?
  - Are there any decisions you would let up to the doctor alone?
  - Are there any decisions you want to make alone even if the doctor disagrees?
  - Are you satisfied with how much you’ve been able to participate in making decisions about (patient)’s care?
- When you are making health care decisions for (patient), do you know what your decision is right away or do you need to gather information first?
  - What kinds of decisions do you make right away; after gathering information?
    - What do you rely on for information in making decisions?
    - What other resources would you use if they were available?
- Influence of others
  - Tell me about anything the doctors do that makes it easier or more difficult to make decisions. The nurses? Anyone else on the health care team?
  - Tell me about your relationship with (patient). Talk about anything regarding your relationship with (patient) that makes it easier or more difficult to make decisions for them.
  - Tell me about your relationship with your family. Talk about anything regarding your family that makes it easier or more difficult to make decisions?
- What kind of decisions have you had to make about (patient)’s care at this point?
  - Probes: What kinds of things did you consider in making that decisions? Consistent with (patient)’s wishes? Alone/doctor/joint? Right away/gathered information? Can you explain what it felt like to make that decision? Was there anything that made it easier or more difficult?
- How have you been doing since (patient)’s admission? Do you have help from anyone else?
• Is there anything else that you would like to share?

**Follow-up Interview**

• How have things been going since we last talked?
  o With (patient)? With you?
• How have your interactions been with the health care team?
  o Any new providers? Any new services?
• What kind of decisions have you had to make about (patient)’s care?
  o Probes: What kinds of things did you consider in making that decisions? Consistent with (patient)’s wishes? Alone/doctor/joint? Right away/gathered information? Can you explain what it felt like to make that decision? Was there anything that made it easier or more difficult? Is there anything you can think of that might have been helpful?
• What decisions do you think are coming up?
• Is there anything else that you would like to share?

**Final Interview**

• How have things been going since we last talked?
  o With (patient)? What do you expect moving forward?
  o With you?
• How do you feel about the process you went through making decisions for (patient)?
  o Did you feel prepared to make those decisions?
  o What was most difficult about making decisions?
  o Looking back, is there anything you can think of that would have made it easier?
  o Do you think you made the decisions that (patient) would have made if he could?
  - Why or why not?
• Overall, do you think you or the doctors made most decisions? Or both? Are you satisfied with that process?
• Overall, do you think you knew the answers to your decisions quickly or had to gather information first? What kind of information? Are you satisfied with that process?
• Is there anything else that you would like to share?
APPENDIX E
Demographic Sheet

Participant Demographics

Preferred method of contact

Age

Gender

Ethnicity, Race

Relationship to patient

Occupation

Distance from hospital

Patient Demographics

Age

Gender

Ethnicity, Race

Occupation

Admitting diagnosis

Other diagnoses

Advance directive (Y/N; date)
VITA

Barbara Birriel, PhD, ACNP-BC, FCCM

Home Address: 180 Reeser Road
Camp Hill, PA  17011
Email: bab44@psu.edu

Education:
2017  PhD in Nursing and Bioethics
       The Pennsylvania State University, University Park, PA
1997  Post-Graduate Acute Care Nurse Practitioner
       University of Pennsylvania, Philadelphia, PA
1993  Master of Science in Nursing, Critical Care/Trauma
       Thomas Jefferson University, Philadelphia, PA
1981  Bachelor of Science in Nursing
       Bloomsburg University, Bloomsburg, PA

Professional Experience:
2011 – present  Instructor, Nursing, The Pennsylvania State University, College of Nursing, Hershey, PA
2011 – present  Critical Care Nurse Practitioner, Penn State Hershey Medical Center, Intensivist Service, Hershey, PA
2004 – 2011  Acute Care Nurse Practitioner, Heritage Cardiology, Camp Hill, PA
1997 – 2004  Acute Care Nurse Practitioner, Shaffer Cardiovascular Associates, Lemoyne, PA
2001-2002  Cardiac Surgery Nurse Educator, Holy Spirit Hospital, Camp Hill, PA
1992-1997  Clinical Nurse Specialist, Polyclinic Medical Center, Harrisburg, PA
1981-1992  Staff Nurse, Nurse Manager, Polyclinic Medical Center, Harrisburg, PA

Publications:


