THE PROCESS OF DEATH IMMINENCE AWARENESS BY FAMILY MEMBERS
OF PATIENTS IN ADULT CRITICAL CARE

by

Nancy Catherine Baumhover

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I dedicate this dissertation to all of the adult critical care patients and their families that I have served and cared for throughout my career, especially, to those who have suffered the loss of a loved one in the adult critical care. May you find peace and continued healing.

To Life!

Live Knowing that Death is Imminent.

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ABSTRACT

Quality end-of-life care in the adult critical care remains a high priority for numerous professional agencies and organizations due to advanced technologies that sustain or extent life, regardless of life quality. The purpose of this study was to describe how family members of patients in adult critical care attain awareness that their loved one is dying or near death in the adult critical care setting. Two research questions were addressed: 1) What is the human-environment health process of knowing that end-of-life is imminent by family members of patients in the adult critical care area?, and 2) What factors influence the human-environment health process of knowing that end-of-life is imminent by family members in the adult critical care area? A Glaserian grounded theory design was utilized to conduct this retrospective study. Both primary (interviews) and secondary (poem, nursing art, song, media and film) data sources supported the emerging theory. *The Process of Death Imminence Awareness by Family Members of Patients in Adult Critical Care* contained six phases: *Patient's Near Death Awareness*, *Dying Right in Front of Me*, *Turning Points in the Patient's Condition*, *No Longer the Person I Once Knew*, *Doing Right by Them*, and *Time to Let Go*. Influencing factors associated with this process were discussed as process facilitators and hindrances. Supportive nursing behaviors and actions as well as family member's emotional, behavioral, and physical reactions to having a critically ill family member were also discussed. This substantive theory will guide nursing education, practice, and research in the creation of nursing interventions, instrumentation, protocols, and policies and procedures aimed at providing cost effective quality end-of-life care in this specialized area of care.

Keywords: grounded theory, end-of-life, critical or intensive care, surrogate decision-making, death imminence awareness

CHAPTER ONE: STATEMENT OF THE PROBLEM

The number of adults that die using adult critical care services ranges annually from 10 to 29% (Society of Critical Care Medicine, 2012). Prior to death, life-sustaining advanced technologies are often withdrawn, withheld, or limited by family or someone close to the patient (Pochard et al., 2001; Swigart, Lidz, Butterworth, & Arnold, 1996). A growing national concern is that advanced technologies may be impeding or prolonging life, despite life quality. Because critically ill patients are often incapacitated and/or incompetent to make their own health decisions, patients are encouraged to select surrogate decision-makers (Patient Self-Determination Act, 1990). Families, as defined by patients and their families, are known to be surrogate decision-makers, defined as, “those who make decisions for people who no longer are able to participate in their own healthcare decisions” (Limerick, 2007, p. 331). However, a family’s lack of awareness or knowledge about a member’s imminent death may impede this decision making. Death is a social event and the process of dying is much more difficult to recognize within the context of adult critical care due to advanced technologies.

Advanced technologies help to sustain and/or extend life beyond what can be considered a reasonable amount of time, especially in futile cases. Unfortunately, these technologies mask signs of life making it difficult if not agonizing for families of patients in adult critical care to understand when death’s time has finally come. Families of patients in adult critical care are often responsible for difficult end-of-life surrogate decisions for their loved ones yet have potential for being a vulnerable population, addressing yet another end-of-life quality concern. Families have an instrumental right to know what is happening with their loved one. Health care providers can facilitate family understanding of the imminence of death. But this process of

coming to know when death is imminent has not been studied from the family's perspective. Therefore, the focus of this study is family awareness of imminent death of a family member.

Purpose of the Study

Family member roles include: supporter, protector, comforter, informer, and surrogate decision-maker (McAdam, Arai, & Puntillo, 2008; McKiernan & McCarthy, 2010). The decision-making process of families of patients in adult critical care has been abundantly investigated (Limerick, 2007; Meeker & Jezewski, 2008). Families prefer to be actively involved in shared decision-making about their loved one with the health team. Family preferences have been addressed in guidelines supporting family centered care (Clarke et al., 2003; Davidson et al., 2007; Truog et al., 2008). Families have an inherent need to know about their loved one's health condition and desire remaining present with their loved one as much as possible (Halm, 2005; McAdam, Arai, & Puntillo, 2008). Families provide crucial patient information to the health team and communicate patient preferences when the patient has lost their voice.

The death of a family member is a memorable social event and the death awareness process by family members of patients in adult critical care is unknown. A greater importance needs to be placed on how family members come to know that death is imminent in the context of adult critical care prior to any end-of-life surrogate decisions, since decisions arise from knowledge. Reed and Runquist (2007) assert that numerous human experiences extend beyond social experiences. The holistic nursing care of individuals and their families includes, but are not limited to the following factors: environmental, physiological, historical, metaphysical, sociocultural, psychological, spiritual, and physical. Reed and Runquist (2007) propose the *human-environment health process* as a reformulation of the basic social process (BSP) and psychosocial process to be more congruent with nursing ontology. This reform does not

jeopardize the methodology envisioned by originators of classical grounded theory; rather, it sheds additional perspective on a basic social process within the nursing paradigm. Therefore, the specific purpose of this study is to describe the human-environment health process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting.

Background and Significance

There has been increasing national concern about life quality and cost in the adult critical care, especially in an aging society, since the SUPPORT studies. Twenty-one percent of the population will be 65 years or older by the year 2050 (United States Census, 2010). Those aged 65 years or older account for approximately 44% of the adult critical care population whose healthcare is primarily provided by Medicare (Kersten, Milbrandt, & Rahim, 2003). Many individuals over the age of 65 years depend upon Medicare to cover their healthcare costs. The cost of these services is estimated between \$121 and \$263 billion dollars on an annual basis accounting for 5.2 to 11.2% of national healthcare expenditures (Coopersmith et al., 2012). Adult critical care services are the most expensive care in the acute care hospital setting being three times more costly than non-critical care areas (Cooper & Linde-Zwirble, 2004). The cost of adult critical care services ranges from \$2,000.00 to \$3,000.00 daily with up to 38% of total hospital costs spent on critical care services (Coopersmith et al., 2012; Cypress, 2010; Milbrandt, Kersten, & Rahim, 2008).

The National Institutes of Health (NIH), National Institute of Nursing Research (NINR), American College of Critical Care Medicine (ACCM), American Association of Critical Care Nurses (AACN), and the Center to Advance Palliative Care (CAPC) have all identified that end-of-life research in the adult critical care is essential, due to advanced technologies and aging

society concerning cost and quality end-of-life care. Palliative care once thought to be a distinctly separate area from adult critical care is now blending end-of-life philosophical approaches in achieving quality end-of-life care. The integration of a palliative care team in the critical care has become a standard of care for most adult critical care areas in response to quality and cost end-of-life concerns (O'Mahoney et al., 2010). CAPC with co-sponsorship from NIH, created the Integrating Palliative Care in the ICU (IPAL-ICU) project. IPAL-ICU recently published guidelines in 2010 to improve palliative care in the ICU (CPAC, 2010).

The landmark Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT, 1995) investigated the concerns of leading health professional organizations or entities. This study revealed disparities between end-of-life care practices and patient preferences. This comprehensive study found what was believed to be true concerning death being impeded and/or prolonged despite life quality in adult critical care. The most significant findings from this study included a lack of clear communication between patients and their families and the health team. Those aged 65 years or older undergo prolonged deaths characterized by the use of aggressive life-sustaining treatments. A subsequent two-year phase of SUPPORT interventional study focused on quality hospital deaths by enhancing communications between health professionals. The importance of this study is the facilitation of death awareness that can occur through clear and concise communication between the health team, patients and their families.

Family-centered care remains a high priority in adult critical care where family is considered client. Family-centered care is described as “an innovative approach to plan, deliver, and evaluate health care that is grounded in mutually beneficial partnerships among health care providers, patients, and their families” (n.p.) by the Institute for Patient-and Family-Centered

Care (2010). Family-centered care is an indicator of quality end-of-life care supported by published formal guidelines to be used in adult critical care to support families of patients in adult critical care written by the American College of Critical Care Medicine task force (Clarke et al., 2003; Davidson et al., 2007; Truog et al., 2008). Moreover, family centered care is recognized by The Joint Commission (2010) as an essential component for safe, effective, quality, and equitable healthcare.

The process used by surrogate decision-maker to withhold or withdraw life-sustaining measures in an intensive care environment has been investigated (Limerick, 2007). Surrogates repeatedly move back and forth between the personal and environmental domain before coming to a final decision (Limerick, 2007). The personal domain is how families gain information and weigh options. The environmental domain represents surrogate's actions or activities interacting with the health team. The decision domain is characterized by the decision to withdraw or withhold life support. A family's decision making process is linear, including three themes: (1) arriving at the belief that measures are futile, (2) self-retreat to make a surrogate decision, and (3) communicating the decision to the health team (Limerick, 2007).

The process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting has not been studied. Death awareness is the realization or awareness that family members experience in knowing that death's time has come for their dying loved one in adult critical care. Studying the family's surrogate decision-making process alludes to how families might gain death awareness, but no study can be found to explain this process. Therefore, a better understanding for how family members gain death awareness to manage difficult end-of-life decisions is needed to fill a gap missing from the body of

knowledge. The promotion of family-centered care that is sensitive to quality and cost will ensue by having a better understanding of what precedes surrogate decision-making within this context.

Philosophical Perspective

My interactive-integrative worldview embraces patients and their family members as holistic human beings (Newman, 1992). The importance of context and multiple subjective realities are essential beliefs within this paradigm (Fawcett, 1993). This means that a person's values, beliefs, social interactions, and experiences are important to me. End-of-life is a social event embedded in social interactions, practices, and rituals. Families share culture, rules, language, symbols, gestures, roles and responsibilities, and meanings, to name a few. Through family member social interactions, meanings and feelings are developed.

Symbolic interactionism, deeply rooted in sociology, informs grounded theory method (Munhall, 2012). The three basic assumptions of symbolic interactionism include: (a) persons act toward things based on their meanings for them, (b) derived meanings are customized through an interpretive process used by the person, and (c) our social interactions derive meaning (Blumer, 1969). A fundamental tenet of this philosophy is that persons learn from and by their social interactions with others. Symbolic interactionism applies to families who are emotionally bonded complex social units who live together, work together, play together, and die together. Person and environment co-exist and influence each other (Corbin & Strauss, 2008; Newman, 1992) supporting the congruency between my interactive-integrative worldview and chosen methodology of grounded theory.

Conceptual Framework

Conceptual frameworks are abstract and cannot be empirically tested. Conceptual frameworks "give birth to nursing theories and guide research" (Peterson & Bredow, 2009, pp.

18-19) and are useful in guiding the initial broad focus of a qualitative study. Conceptualizations arise from empirical, inductive, and deductive assumptions (Chinn & Kramer, 2011). Therefore, the concepts and their relationships identified in this paper are in no way stagnant and are not meant to represent the true interlocking relationships between concepts that we might expect from a theory. A conceptual model points direction in the search for relevant questions about the phenomenon of central interest to a discipline and suggests solutions to practical problems (Fawcett, 2000), hence, a starting point in theory development.

The development of a conceptual model to guide my study arose from my experiential knowledge, consultation with those that have experienced this phenomenon, analysis and synthesis theory strategy techniques outlined by Walker and Avant (2011), and heuristic methods. Walker and Avant (2011) discuss the interrelatedness of various theory development strategies and support a blend of strategies to progress theory development. Analysis involves examining and reexamining, clarifying, and redefining concepts (Walker & Avant, 2011). Synthesis involves extracting or pulling together concepts from a body of data, set of observations, or set of empirical statements (Walker & Avant, 2011). An analysis and synthesis of relevant literature that indirectly spoke to this process, due to literature scarcity, along with my experiential knowledge helped me to identify key concepts that might play an important role in the human-environment health process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting. The creation of word tables and graphic depictions helped to identify central concepts. Family member end-of-life knowing captured all of the identified concepts (Figure 1).

FIGURE 1. Proposed Framework for Studying Family Member Knowing that End-of-Life is Imminent.

The central concepts in my conceptual framework that may be potentially important to guide my dissertation studies are: (1) *family member active presence* (2) *death awareness*, and (3) *knowing the patient as family member* in the human-environment health process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting (Glaser & Strauss, 1965; Jenks, 1993; Jenny & Logan, 1992; Mantzorou & Mastrogiannis, 2011; McAdam, Arai, & Puntillo, 2008; Tilden, Tolle, Garland, & Nelson, 1995; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999). A description of the physical context followed by the concepts and their interrelationships is presented next.

Description of the Physical Environment

The adult critical care area may be the noisiest areas in the acute care setting, due to various advanced technologies. Patients are often stimulated by the noisy equipment and painful procedures, tests, or interventions at all hours of the day. Lighting is another issue. Oftentimes, the patient rooms do not have windows or clocks, thus, the lack natural light makes it difficult to determine if it is day or night for the critically ill. Or, the lighting is artificial leading to imbalances in the patient's wake and sleep time. Patients may suffer from sleep deprivation, loss of privacy, lack of physical contact (touch) with others, and sensory overload due to the physical

context. A movement toward more electronic intensive care units (eICUs), also referred to as telemedicine or tele-ICU, is becoming more prevalent, which entails the remote monitoring of patients. An intensivist or nurse receives patient data through two-way cameras, video monitors, smart alarms, and microphones (Urden, Stacy, & Lough, 2014). A concern with this form of telemedicine is the potential for lack of physical contact between the patients and others.

Family members describe the physical environment of the adult critical care setting as having rules and routines as well as fast paced, noisy, and highly technological (Agard & Harder, 2007; Hughes, Bryan, & Robbins, 2005; Kaufman, 2005). Family members describe feeling anxiety and stress, due to the physical environment of the adult critical care (McKiernan & McCarthy, 2010).

Family Member Active Presence

Family member active presence is described as “family member’s physical presence at the bedside and the desire to maintain a vigil while the patient is in the intensive care unit” (McAdam, Arai, & Puntillo, 2008, p. 1098). Family member active presence is common when their loved one is at high risk for dying in an adult critical care area. Patients have reported feeling safer and much more comfortable when family members are allowed to remain present with them (McAdam, Arai, & Puntillo, 2008).

Death Awareness

Death awareness is the realization or awareness that family members experience in knowing that death’s time has come for their dying loved one in adult critical care. Death awareness is described by Glaser and Strauss (1965) in their landmark study on Awareness of Dying as “what each interacting person knows of the patient’s defined status, along with his recognition of the others’ awareness of his own definition....awareness context....is the context

within which these people interact while taking cognizance of it” (p. 10). Glaser and Strauss determined four contexts for awareness to include: suspicion awareness, closed awareness, mutual-pretense awareness, and open awareness. Awareness can be brought about by critical hospital events, previous death experiences, observations, interpretations, and information and communications. Tilden, Tolle, Garland, and Nelson (1995) labeled the experience of realizing that a family member might die as “dawning awareness” (p. 634) and “recognition of futility” (Tilden, Tolle, Nelson, Thompson, & Eggman, 1999, p. 431).

Knowing the Patient as a Family Member

Knowing the patient has been described primarily from the perspective of health professionals. Jenks (1993) espoused that health professionals engage in ‘knowing the patient’ as personal knowledge about another person established through interpersonal relationships. Jenny and Logan (1992) describe health professionals ‘knowing the patient’ as rational and cognitive process of exploring important aspects of the patient and the situation that requires: perceiving and envisioning, communication, self-presentation, and showing concern. Mantzorou and Mastrogiannis (2011) contend that ‘knowing the patient’ by health professionals requires the integration of Carper’s (1978) patterns of knowing acquiring two broad dimensions: a) knowing the patient’s patterns of responses, and b) knowing the patient as a person. Tanner, Benner, Chesla, and Gordon (1993) discovered that knowing the patient meant knowing the patient as a person and knowing the patient’s usual pattern of responses. Only one study described patient knowing from the perspective of family members. Tilden, Tolle, Nelson, Thompson, and Eggman (1999) describe “knowing the person” by family members as knowing the patient’s character, values, preferences, personality, and life experiences.

Interrelationships of Concepts

In this conceptual framework, a family member's ability to remain physically present at the bedside with the dying patient, known as *family member active presence*, facilitates family member knowing that death's time has come (McAdam, Arai, & Puntillo, 2008). Family members have a strong need to be in close proximity to the patient in order to understand what is going on with the patient (Plakas, Cant, & Taket, 2009). Family members gain more opportunities in acquiring information about their loved one through their active presence. Additional information raises family member death awareness or realization of impending death.

Death awareness is the realization or awareness that family members experience in knowing that death's time has come for their dying loved one in adult critical care. Death awareness by family members arises through information, previous death experiences, observations and cues from the patient, and interpretations (Hayes, 2003; Meeker & Jezewski, 2008; Swigart, Lidz, Butterworth, & Arnold, 1996; Tilden, Tolle, Garland, & Nelson, 1995; Tilden, Tolle, Nelson, Thompson, & Eggman, 1999). Clear and concise information exchange between the family and healthcare professionals facilitates their knowing that death is imminent (Kaufman, 2005). Information arises from various sources, which requires synthesis and decipherment among the family unit as well as negotiations and consensus within the family unit (Meeker & Jezewski, 2008). The death realization or awareness that death's time has come is individual and does not occur at the same time for all family members (Kaufman, 2005; Meeker & Jezewski, 2008; Wiegand, 2006).

Knowing the patient as a family member is how family members know what patients would want for themselves by words or stories shared with family through the years (Chambers-Evans & Carnevale, 2005). Patients' spoken words or affirmative gestures to their family during

critical illness aides in their knowing the patient as a family member, since families often probe their loved ones in various states to help support their knowing what to do for them (Hayes, 2003; Limerick, 2007). Reflections and recollections of what the patient was like prior to hospitalization as compared to the current illness state as well as knowing their loved one's preferences accounts for their knowing the patient as a family member (Chambers-Evans & Carnevale, 2005; Limerick, 2007). Family members describe how surrogate decisions made for their loved one often results a worsening health condition or outcome of their loved one. Family members become more aware realizing the seriousness of their loved one's declining health status (Kaufman, 2005).

The phenomenon of family member knowing that end-of-life is imminent occurs within context. This study may unveil information about *contextual elements* important to this human-environment health process, such as; cultural, historical, economic, political, and spiritual backgrounds of families. The one constant contextual element in this conceptual model is the unique environment or setting of the phenomenon. The concept of environment in Neuman's (1996, 2002) Systems Model aligns most with my own ideas about the *environmental context* of adult critical care and exchange between person and environment. Neuman (1996, 2002) identified three relevant environments: *internal*, *external*, and *created*. However, the definition of these relevant environments is slightly different from my own. Next, my own ideas about the environmental context are presented.

In my own perspective, the *internal environment* includes the patient's physiological and psychological status, through patient's willingness or unwillingness to live. The *external environment* includes the physical and social surroundings. The physical surroundings of the adult critical care are noisy, due to being highly technological. Numerous disruptions and

interruptions to the patient and their families occur in this setting, due to the critical nature of this environment and need for immediate interventions to improve patient outcomes. The social surroundings include the social interactions of the patient and their family and others. Person and environment interact, reciprocate, and respond to each other. Often, physiological findings (internal) are influenced by external environmental influences. The environment can have both positive and negative effects on the patient and their families. Critical care nurses strive to create an environment (*created environment*) that entails human touch, compassion, safety, rest, and healing for patients and their families.

Progression through the stages of a family member knowing that end-of-life is imminent is most likely nonlinear, due to various meanings, experiences, and interpretations of individual family members. Moreover, findings from this study will help to clarify whether or not this family knowing is even a process of stages that can be described. My conceptual framework does not encumber the development of a theory grounded in the data. The fit of my conceptual framework will be evaluated upon study completion in keeping with the constant comparative method. The constant comparative method entails the systematic analysis of data, which involves the collection of data in tandem with analysis (Glaser, 1978). A progression of original conceptualization to a theory grounded in the data will be evident upon study completion.

Aims and Research Questions

The aim of this study is to describe the human-environment health process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting. The two research questions are as follows:

1. What is the human-environment health process of knowing that end-of-life is imminent by family members of patients in the adult critical care area?

2. What factors influence the human-environment health process of knowing that end-of-life is imminent by family members in the adult critical care area?

Other areas that may be learned through this study include: (a) family members' sources for knowing that end-of-life is imminent within this context, (b) how or whether they determine these sources as trustworthy and credible, (c) how this process may influence the family members' overall well-being, and (c) how this process may influence family members' end-of-life surrogate decision-making.

Summary

Approximately, 10-29% of Americans die using adult critical care services (SCCM, 2012). A growing number of older adults comprise adult critical care settings due to an aging population. Adult critical care services are the most expensive services. Advanced technologies may be impeding and/or prolonging life, regardless of life quality. Advanced technologies mask signs of natural death making it difficult for family members to know when life has reached its end. A conceptual model to guide research was presented entailing active presence by family members, death awareness, and knowing the patient as a family member. The identified central concepts in the conceptual model guide research aimed at explicating the human-environment health process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting. Efforts aimed at concepts that might enhance a family member knowing that death is imminent are needed to facilitate the process of death awareness. The results of this study will significantly impact end-of-life care in this setting where cost and life quality concerns exist.

CHAPTER TWO: REVIEW OF THE LITERATURE

The extant literature does not directly address the human-environment health process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting. Therefore, the following literature review is organized into three main sections. The first section addresses the most relevant literature about death awareness in family members by key concepts identified in my conceptual model. The second main section of the research literature focuses on families of patients in adult critical care. The third main section presents end-of-life theories across disciplines.

This first section addresses the most relevant literature about death awareness in family members by key concepts identified in my conceptual model to include: (a) family member active presence, (b) death awareness, and (c) knowing the patient as a family member.

Family Member Active Presence

The concept of family presence is widespread in adult critical care. Family presence studies are helpful in understanding how a family member's active presence may facilitate the death awareness process. Family presence is described as "the presence of family in the patient care area, in a location that affords visual or physical contact with the patient during invasive procedures or resuscitation measures" (Emergency Nurses Association, 2010, p. 1). The American Association of Critical-Care Nurses (AACN) more broadly defines family presence as, "unrestricted presence and participation of a support person" that "can enhance patient and family satisfaction" in the adult critical care (AACN, 2011, para. 1). For the purpose of this study, *family member active presence* rather than *family presence* describes how family members gain death awareness, regardless of whether or not resuscitative measures were performed.

A literature review conducted by Halm (2005) described the benefits of allowing family members at the bedside of a patient receiving resuscitative measures or invasive procedures to include: (a) knowing that everything possible was done to save their loved one, (b) increases family awareness of the seriousness of situation, (c) facilitates family active participation in care, (d) reduces doubt, fear, and anxiety of family members, (e) provides opportunity for information and communication exchange between family and health team, (f) provides closure, (g) facilitates grief, (h) enhances patient-family connectedness, (i) offers one last chance to say goodbye, and (j) reminds the staff of the person's personhood (Halm, 2005). Family member active presence is an important concept in my conceptual model, since awareness is gained by their active presence.

McAdam, Arai, and Puntillo (2008) conducted a descriptive qualitative study with 25 family members to discover the unrecognized contributions of families of patients in the adult critical care. Family member roles and contributions include: active presence, protector, facilitator, historian, coach, and voluntary caregiver. Although this study does not address how family members gain death awareness, it does offer an important role expressed by family members. Active presence was the vigilant presence of family members at the bedside of a critically ill patient at high risk for dying. Family member active presence allowed patients to feel safe and more comfortable.

In a grounded theory study by Plakas, Cant, and Taket (2009) with 25 relatives of critically ill patients, "vigilant attendance" described a family's strong need to be in close proximity to the patient. Families in this study were willing to spend endless hours at the bedside of the patient often ignoring many of their own needs. Family members experienced intense dissatisfaction if restricted from visiting their loved one. Family members felt that they could

offer help, support, care, and comfort if allowed to be in close proximity to their loved one (Plakas, Cant, & Taket, 2009). This study highlighted two main experiences of families of patients in critical care to include: vigilant attendance and intense emotions. Families experienced intensive positive and negative emotions when a loved one was critically ill. Negative emotions were caused by the anticipation of loss of their loved one, conceptualized as anticipatory grief. This study conveys the importance of family member active presence.

Veteran next-of-kin perceptions for how nurses support family presence before, during, and after the death of a family member were studied in a qualitative content analysis study by Williams, Lewis, Burgio, and Goode (2012). Approximately forty-four percent of the location of patient deaths was in the intensive care unit and surgical intensive care unit. The following themes were found to illustrate the ways nurses supported family presence before, during, and after the death of a loved one: (a) keeping the family informed, (b) providing reassuring attentiveness, (c) being a compassionate presence, (d) facilitating final acts, (e) honoring patient dignity, and (f) preparing the room and position the deceased's body in a manner that is visually comforting, aesthetically acceptable, and worthy of a military veteran. This study exemplifies the nursing role to support and facilitate quality end-of-life care, including the family in being present through all of the dying phases.

Death Awareness

Sociologists Glaser and Strauss's (1965) context of awareness theory focused on awareness of death and dying experiences. This landmark grounded theory study found dying to be a process experienced by health professionals and patients and their families with the following types of awareness context: closed awareness, suspicious awareness, mutual pretense awareness, and open awareness. Closed awareness was described as when the patient and family

do not recognize an impending death yet the health team has the information. Suspicious awareness was described as when the patient and family suspect impending death with varying degrees of certainty while the health team believes the patient is dying. Mutual pretense awareness was described as when the patient, family, and health team know the patient is dying but pretend otherwise and all agree to act as if the patient is going to live. Mutual pretense ends when one party cannot sustain the pretense any longer. Open awareness was the acknowledgement and knowing that death's time has come through the actions of patient, family, and health team. This theory contends that there is an evolution from closed to open awareness. The transition from one level of awareness to another depended upon the amount of information being provided to the patient and family by the health team yet did not dismiss other variables influencing death awareness.

Glaser and Strauss (1965) offered an entire chapter in their text attributed to families of dying patients entitled, "The Aware Family" (pp. 155-176). This chapter outlined families' awareness of death imminence, which is particularly useful for my impending dissertation studies. The aware family had an extreme need to visit their dying family member and acquire health information concerning their loved one's condition. Families were found to ask multiple questions about their family member's condition to health professionals to aid their awareness. The lack of family presence or their ability to remain present with their loved one tended to obstruct their awareness of death imminence. Families portrayed hope by offering their dying family member unrealistic time left on earth to be lived. The unexpected death of a family member inhibited the awareness of other family members. Families were found to spend a great deal of time in death preparations such as funeral arrangements and informing others. The aware

family findings are pertinent to my impending studies to aid in conceptualizations for how families come to know that death is imminent.

Glaser and Strauss (1968) determined several years later that the dying process entailed the following three trajectories: unexpected (or sudden) death, expected (short-term or lingering), and entry-reentry death. The dying trajectories grounded theory is important to this study, since many deaths are unexpected, expected, or involve entry-reentry in adult critical care due to various chronic illnesses that cause patients to move in and out of stages of stability and deterioration in their wellness. The trajectory of a patient's death had an effect on the patient's awareness of the situation. An unexpected (or sudden) death placed the greatest deal of stress on patients and their families and was usually caused by a suspicious awareness (Glaser & Strauss, 1965). Therefore, the dying trajectory may have an effect on the death awareness process of family members.

The qualitative metasynthesis conducted by Meeker and Jezewski (2008) presented potential sources of family member knowing that end-of-life is imminent. These authors synthesized 13 qualitative investigations of families who had to withdraw or withhold life-sustaining treatments on seriously ill patients. The findings revealed that previous death experiences and personal observations of families served as contributors to their knowing death imminence. Families often relied on cues from the patient, such as their lack of response to determine death imminence. Time played an important role in families' ability to reframe the reality of their loved one's situation. Unanticipated health situations required more time by families to fully understand the uncertainty associated with the surprising health event. These authors noted that health professionals should pay particular attention to the choice of words that families use and whether they are in present or future tense. Future tense words indicated a future

for their loved one whereas past tensed phrases indicated that the family had moved with less hope for recovery of their ill family member. These authors found that families desperately sought clear and concise communication and information and did not appreciate conflicting information received from health professionals.

Additionally, Meeker and Jezewski (2008) found that the families tended to understand the patient's health preferences best through previous discussion about their wishes. Families spent time in intense observations of health professionals to better understand the seriousness of their family member's health status. Families recalled memories of their loved one while relating to each other to know if death had reached its time. Not all family members came to understand the seriousness of their loved one's condition at the same time. Individual family members tended to recall and reflect upon their own experiences with the ill family member. Thus, family negotiations and consensus occurred before surrogate decisions were made. Surrogate health decisions and the outcomes of these decisions seemed to either enhance or inhibit their knowing that death was imminent. Decisions that yielded poor health results raised death awareness whereas decisions that yielded hopeful or improved health results inhibited death imminence. The importance of this qualitative synthesis was that decision-making by family members either enhanced or inhibited the death awareness of family members, dependent upon the outcome of decisions made.

Ethnographer Kaufman (2005) conducted studies exclusively in critical care areas to include health professionals and dying patients and their families. Kaufman spent extensive time in the field at three community hospitals over the course of two years. Kaufman found that death was viewed as a problem or failure in American hospitals. The timing of hospital events such as procedures or diagnostics was not viewed the same by health professionals and families.

Families did not feel the same level of urgency or imminence as health professionals and staff was found to always be moving things along for the sake of hospital efficiency. Kaufman (2005) found that health professionals critically time hospital events whereas families did not seem to have the same critical temporal sense as health professionals for what needs to be done for patients. Thus, the timing of death awareness by family members was different from that by health professionals. Family members may not always be ready for poor news concerning their loved one, which may impede their surrogate decision-making.

Kaufman (2005) found that death was culturally orchestrated and shaped by American hospitals. Death awareness seemed to heighten only when there was a need for a life saving effort. Kaufman (2005) referred to families' vigilant watch over their loved ones as "deathwatch" (p. 89). Families sought to acquire health information about their ill family member to better understand death imminence. The families' ability to know the patient as a family member deeply influenced their ability to know what to do in the moment and whether or not death was knocking at the door. The results of surrogate decisions influenced their capacity for knowing whether or not death was imminent. Poor health outcomes from decisions made caused families to believe death was more likely as compared to decisions that caused improvement in the patient's condition or lack of deterioration caused the belief that death was unlikely.

Limerick's (2007) grounded theory described the process used by 17 surrogate decision-makers that withheld and withdrew life support in a critical care environment. The findings of this study were similar to many other studies concerning how death imminence unfolds. That is, families observed for physical signs of decline and failure of treatments to achieve appreciable effect in coming to know that death of their loved one was imminent. Nurses were found to be the most helpful to surrogate decision-makers in understanding their loved one's condition as a

source for information. Families were told repeatedly that their loved one would never recover and/or die, before realizing that surrogate decisions were necessary. Surrogates tended to retreat introspectively before rallying the rest of the family in end-of-life decisions. Trusting the health team was very important to family in knowing what to decide next. This study exemplifies the necessity of building trust with family members of patients in adult critical care in order to aide in their knowing.

Wiegand (2006) conducted an interpretive phenomenological study with 56 family members to describe the units of meaning, clusters, categories between the interaction of families' of patients and health professionals and the healthcare system during withdrawal of life sustaining therapy after a sudden unexpected critical illness or injury. The results of this study yielded a high importance on the presence of attending physicians to explain and recommend treatment options. It was found that clear and frequent communication helped families to understand the seriousness of the situation, especially when consistency between the health professionals and families were maintained. Families were found to be extremely sensitive to time. Delayed treatments or conversations about treatments built anxiety for family members. Families desired more preparation for death. A family meeting when all family members could sit down and communicate with the health team was the most helpful in raising family members' awareness of death imminence. Families required more preparation as to what to expect in the dying process, due to a lack in understanding of how time played into the dying process. Families required preparation for physical signs and sensations of death too. This study exposed the high importance of not only family presence, but health professional presence too. Temporal components as well as family expectations may play significant roles in families understanding of death imminence.

Tilden, Tolle, Garland, and Nelson (1995) explored the behaviors of physicians and nurses that families found supportive or burdening in the context of decision-making about withdrawing life-support measures. These authors conducted semi-structured interviews with 32 family members of patients without advance directives whose death followed a stay in the intensive care unit and withdrawal of treatments. These authors described death imminence as a “dawning awareness” (p. 634) when family realized that the chances for recovery of their loved one diminished to zero. Dawning awareness was described as a gradual, steady, and incremental nature that often reflected a dawning or unfolding of realization that the patient was unlikely to regain cognition or function or to leave the hospital (Tilden, Tolle, Garland, & Nelson, 1995). Families held an acute awareness of phrases or statements made by health professionals to aide in their understanding or awareness that death’s time had come. Final health decisions required family consensus so that family conflict could be avoided after the fact. This study highlights the importance of family member active presence and family togetherness as well as shared decision-making with the health team in order to avoid family conflict or discord.

Chambers-Evans and Carnevale (2005) described the lived experiences of eight surrogates during the process of decision-making at end-of-life as a “dawning of awareness” (p. 28). They found that the steps in surrogate decision-making included: (1) struggling to understand, (2) coming to terms, (3) transforming reality, and (4) needing to find peace with the decisions. This hermeneutic study found that families find medical/health terminology difficult to understand. Families sought more information from other sources, such as; the internet, second opinions from physicians known to the family, and friends or colleagues who had been through similar situations to manage their surrogate decisions. Families were found to be dissatisfied in having to seek out other sources for information, because they didn’t understand it

from the health professionals. Families received information, digested it, and then came to terms before making surrogate decisions. Coming to terms was described as recognition of the reality and finality of the situation. Families expressed the need to visually see their loved one when physicians explained their findings so they could come to terms with the situation. In this study, families reached a turning point when treatment was not longer helpful or the patient would not want to endure certain treatments as knowing when to stop treatment. Families reported that death confirmed how life was unsustainable without machines, which seemed to be something that health professionals instinctively know.

Knowing the Patient as a Family Member

A grounded theory study conducted by Swigart, Lidz, Butterworth, and Arnold (1996) with 30 family members found that family members relied upon personal observations and interpretations of the environment to base their surrogate decisions. Their theory espoused the following process of surrogate decision making for families: (1) believing, (2) trusting, (3) ordering, and (4) integrating information from the environment to understand the critical nature of events. The likelihood of death was perceived only when family had a reliable, trustworthy, and consistent source for information. Personification of the patient's life was found to be a consistent part of decision-making. This was described as understanding the patient's life story, values, and preferences. Family members were found to relive, reflect, remember, and review the life of the dying patient. This study found that advance directives provided family with a sense of clarity, peace, and resolution in their surrogate decision-making. The concept of personification closely resembles *knowing the patient as a family member* concept in my conceptual model. This study conveys the importance of other factors that may influence death awareness in family members.

Tanner, Benner, Chesla, and Gordon (1993) conducted an interpretive phenomenological study to describe what nurses mean by knowing the patient and to understand what difference it can make in nursing care that is provided to the patient. These authors interviewed 130 neonatal, pediatric, and adult nurses. Knowing the patient as a person and understanding the patient's pattern of responses were the two main themes. Knowing the patient as a person meant knowing the patient in an involved, attached way by knowing their concerns, personality, habits, hopes, fears, and enthusiasm for life. It meant knowing the patient as a person beyond their life in the critical care unit. These authors explain how in presence of family, the patient is viewed as more than a patient. The patient is viewed as a wife, husband, daughter, son, to name a few. Additionally, knowing the patient as a person derived through the family.

Tilden, Tolle, Nelson, Thompson, and Eggman (1999) interviewed thirty family members at one and six months post-patient death following aggressive medical treatments to describe the process to withdraw life support on a dying family member. These authors reported the following steps in this process: (1) recognition of futility, (2) coming to terms, (3) shouldering the surrogate role, and (4) facing the question. Families described the importance of "knowing the person" to manage their loved ones health decisions at end-of-life. This meant knowing the patient's character, values, preferences, personality, and life experiences. "Knowing the patient" was the most significant finding of certainty in families feeling that they did the right thing six months after surrogate decisions were made that ended their loved one's life. The past experiences of family members were found to influence their surrogate decisions. Families appreciated point blank or direct communication when death's time had come so that final decisions could be made. Families described a period of gradual recognition in the face of

aggressive medical treatments when the outcome was poor. Families spent an extensive amount of time intensely observing and interpreting as well as listening and watching for health professional's behaviors and subtle cues to better understand the situation. The recognition of futility was highly influenced by whether or not the health situation was acute or chronic. The abrupt illness or trauma was the most difficult for family to realize when there was no chance for recovery. Chronic conditions suggested that more time allows family to adjust and absorb information more easily. Family members did not want their loved one to suffer, thus moved quicker in making health decisions to alleviate any discomfort the patient might have been experiencing. Family envisioned what it would feel or be like to be the ill or injured patient to better understand or know what to do.

Hayes (2003) completed a phenomenological study to describe the experience and meaning of surrogate decision-making to withhold or withdraw life-support on incapacitated adults who suffered an unanticipated illness. Thirteen participants who made a decision that resulted in the death of a loved one were interviewed 6 to 18 months after the decision making experience. The two major themes that emerged from this research were: the representation of other and memory manipulation. The significance of this study was how surrogate decision-makers represented the patient in their lives, relationships, values, and personalities. My conceptual model uses the phrase "knowing the patient as a family member" rather than "representation of other" or what other studies have referred to as "knowing the patient." The reconciled memories of family members were found to set the stage for surrogate decision-making. Families recalled and recollected on memories shared with their loved one in order to make fitting health decisions for them. The knowledge families had about their loved one to manage difficult end-of-life decisions were found consoling after the loss of the decedent.

Medical terminology was confusing for families and required translation for understanding, which altered the timing of many health decisions. Previous death and surrogate decision-making were found to highly influence families' abilities to manage decisions and understand the seriousness of the situation.

A grounded theory study by Meeker (2004) found that the active presence of 20 surrogates of terminally ill patients was vital to their ability to perceive terminality of the patient, thus manage surrogate end-of-life decisions. The two principal strategies for providing active presence included family member: supporting and vigilance. Knowing the patient as a family member was a primary source of information about the patient's wishes for family members. Meeker (2004) described the process within the context of "perceiving terminality," yet this was not fully described, except that one surrogate suddenly knew to cease life supporting measures and for another surrogate it did not precede the actual death. The importance of this study is the phrase "perceiving terminality" as being similar to death awareness, yet the process for how these surrogates came to know was not explored. Surrogates reported that they came to know and understand the patient's wishes through reoccurring end-of-life discussions with their loved one. Brokering information described how families constantly seek and receive health information. Information arrived from various sources, such as; the internet, healthcare providers, observations, interpretations, medical texts, personal network of friends or associates, and other patients and their families. Surrogate decision-makers were found to advocate for their loved one, protect them from harm or suffering, and honor their wishes.

Fridh, Forsberg, and Bergbom (2009) discovered seven themes of 17 close relatives' experiences of caring and physical environment of a loved one dies in adult critical care as: (a) being comforted with the threat of loss, (b) maintaining a vigil, (c) trusting the care, (d) adapting

and trying to understand, (e) facing death, (f) the need for privacy and togetherness, (g) and experiencing reconciliation in their hermeneutic investigation. Honest and open communication from health professionals raised the realization of futile measures. Families wished to remain present with the dying patient at all times by maintaining a vigil. Families were found not to be frightened of the highly technological environment as much as they were innately interested in it. Families were found to interpret monitors by information received from the bedside nurses. Families understood where things were going based off parameters of monitor values provided to families. Serious misconceptions were found in some families where no information about the monitors or waveforms was provided. Death became extremely obvious when monitors and medical equipment were turned off with family present. Relatives of patients in adult critical care described the environment as quiet and controlled. Privacy was of utmost importance to families. The death event was viewed as sacred and was only allowed for close family members. Family members reconciled within themselves that they did everything they could for their loved one in order to move on in life.

Families of Patients in Adult Critical Care

Families of patients in adult critical care have been studied to include their unrecognized contributions, roles and responsibilities, experiences, met and unmet needs, vulnerability, and psychological and physical symptoms. Other studies have investigated the usefulness of end-of-life family conferences, visitation hours, and the inclusion of family in patient rounding procedures. These studies are helpful in understanding the overall body of knowledge as it relates to families of patients in adult critical care, since no study has sought to determine the process of death awareness by families of patients in adult critical care.

McAdam, Arai, and Puntillo (2008) reported the unrecognized contributions of 25 family members of patients at high risk for dying in the critical care area. These authors completed a qualitative descriptive study, deriving six major themes of their contributions to care and their roles from the data. The six family role themes were: (a) active presence, (b) protector, (c) facilitator, (d) historian, (e) coach, and (f) voluntary caregiver. Families reported that their active presence at the bedside provided the patient with safety and comfort. Families were found to play the role of patient protector acting as advocates of the patients and watchdog at all times. The facilitator role encompassed translating, explaining, and interpreting information for the patient. Families keep health care workers informed about the patient's health history and status in the historian role. Families were described as coaches to patients, because they motivate, inspire, comfort, and maintain hope in challenging situations. Families were coined voluntary caregivers to describe their role in actual care, such as; repositioning the patient and performing activities of daily living.

Johnson et al. (1995) conducted a qualitative content validity study to ensure reliability of the Iowa ICU Family Scale (IIFS), a 25-item instrument designed to measure the family member self-perceived roles and responsibilities during a critical illness of a family member. Content validity was established by means of systematic review of all items by the health team. The instrument had not been tested for reliability. This qualitative study found the following seven themes: (a) pulling together, (b) fragmentation of families, (c) increased dependence, (d) increased responsibilities, (e) change in routine, and (f) a change in their feelings about the situation. Family members experienced burden when a family member was ill. This caused a disruption in the open and dynamic family system, which led to either a pulling together of family or fragmentation. Role and responsibility and routine shifts were common to

accommodate a critically ill family member and this lead to a state of more dependence and/or independence.

Agard and Harder's (2007) grounded theory study described the experiences of 14 relatives of patients in the adult critical care. This study found the following three themes: (a) enduring uncertainty, (b) putting self aside, and (c) forming personal cues. Families constructed personal cues about their loved one's situation by information provided to them, thus enhanced their awareness of the criticality of the situation. Information was shared with families face-to-face or by pamphlets. Families observed the nurses and patient, monitors, intravenous (IV) lines, contents of drainage tubes, and listened to sounds and noticed the physical surroundings to form personal cues. This study offers some understanding for how family members might gain death awareness.

Cypress' (2010) phenomenological study was able to elucidate the experiences of 15 patients, families, and their nurses in critical care. This study determined the following five themes: (a) family as a unit, (b) physical care and/or comfort, (c) physiological care, (d) psychosocial support (communication is the precursor for psychosocial support), and (e) transformation. Nurses viewed family as a unit and family viewed the nurse as part of the family. The involvement of the family in the patient's care was a common finding. The quality of empathy was found to be important in providing care to the patient. The physical care and comfort and physiological and psychological support of the patient was priority for the families. Families expressed transformation in strengthened faith due to the critical illness. This study determined nurse-specific, patient-specific, and family-specific themes. The family-specific theme related to families confidence in the nurse and health team. Families felt peace and trust in situations where they felt confidence in the nurse and health team caring for their loved one.

Eggenberger and Nelms (2007) completed a phenomenological study using Van Manen's framework to study the experiences of families in critical care. Semi-structured 'family as a group' interviews were performed with 11 families. The constitutive pattern of "being family" was found from this study. This study revealed that families' intense observations and conversations heard helped them to understand what was happening with their loved one in the critical care area. Cues about their family member's condition came from their interpretations of the technology in the patient's room. Families expressed a deep need to always be with their loved one. The critical illness either intensified the closeness and connections within the family unit or caused family discord. One of the most important ways that nurses connect with families was by sharing information with them. Families described constantly carrying a heavy weight of uncertainty and unknowing yet these states were not described. Families waited for health decisions to unfold to learn the outcome of their decisions, always waiting for the next thing to happen. Members of a family often have different perspectives or the same perspective at different times.

Hughes, Bryan, and Robbins (2005) conducted a qualitative study on the experiences of eight female relatives of patients in adult critical care. Families without critical care experience shared their perceptions of the environment stemmed from media and television programs. The relatives first 24 to 48 hours appeared to be the most critical wherein relatives were unable to comprehend information and emotions, such as; shock, fear and frustration were at the forefront. Problems with communication between the family and health team caused families the most distress and dissatisfaction. Families who felt they were provided adequate information and communication expressed reduced fear and the ability to cope with the situation.

McKiernan and McCarthy (2010) described the lived experience of six family members in adult critical care through in-depth interviews in this phenomenological study. The four main themes that emerged were: (a) the need to know, (b) making sense of it all, (c) being there with them, and (d) caring support. This study exemplified the deep need for families to remain present or be within close proximity to their loved-on along with the need for clear and concise information about their health condition. The need to know was not found to be dependent upon on the patient's diagnosis or ultimate outcome. In other words, the authors concluded that even if the outcome or diagnosis was poor, families expected comprehensible, clear, and truthful information. Information required repeating for families to fully understand. Families were not disturbed by the critical care environment and found nurses to be the one factor in receiving honest communication and personal care and concern for their loved one. Family members' main concern was that the best possible care was provided to their loved one. Families must reconcile the patient prior to hospitalization to their critical state to make sense of things, especially in the case of a life-threatening or poor prognosis.

Fry and Warren (2007) addressed the perceived needs of 15 family members of patients in critical care in their hermeneutic study. The following family needs were found: (a) seeking information, (b) trusting the professionals, (c) being a part of the care, and (d) maintaining a positive outlook. The most pressing need for family members was to receive understandable, clear, and honest communication about the patient's medical condition. The unmet needs of families were the lack of information and absence of explanations about medical equipment being used. In contrast, Browning and Warren (2006) found the unmet needs of family members to include: their ability to talk about their negative feelings (anger and guilt), talk about the possibility of the patient's death, explanations of the critical care environment, to visit anytime,

to talk to the same nurse every day, to be provided comprehensible information, to feel there is hope, to feel accepted by the staff, to be given the option to leave the hospital for short periods, and to have good food available to them. Death awareness can be raised by information exchange and explanation of medical events between family members and health professionals. These studies describe the needs and unmet needs of family members in relation to the great need for information exchange and acknowledgement of family member's psychological well-being.

Baumhover and May (2013) explicated the concept of vulnerability of families of patients in adult critical care through analysis and synthesis of relevant literature outlined by Walker and Avant (2011). The five antecedents of family member vulnerability were: family system disruption due to a critical illness or injury of a family member, powerlessness, helplessness, lack of proximity to the patient, and lack of access to information. The four defining attributes were: exposed to burden, defenseless, unprotected, and susceptible or open to harm, injury, neglect or persuasion. There are both positive and negative consequences of concepts (Purdy, 2004). The positive consequences were: opportunity for growth and change, endurance, resilience, strength, autonomy, and empowerment. The negative consequences were in these three domain areas: psychological, physiological, and social. The negative consequences were: disruption in the roles, routines and responsibilities of the family, postintensive care syndrome-family (PICS-F), uncertainty, guilt, anger, lack of self-care, poor nutritional habits, to name a few. The vulnerability of family members may have an effect on the process of death awareness.

A plethora of studies have focused on the psychological and physical health effects of critical illness on family members (Davidson, Jones, & Bienvenu, 2012; Society for Critical Care Medicine, 2011). A literature review by Davidson, Jones, & Bienvenu (2012) revealed that

family members were burdened by acute stress, anxiety, grief, posttraumatic stress, and depression, to name a few. Pochard et al. (2001) surveyed 920 family members using the Hospital Anxiety and Depression Scale (HADS) and found that more than two-thirds of family members experienced anxiety or depression. The reliability and validity of HADS was not reported. Kentish-Barnes, Lemiale, Chaize, Pochard, and Azoulay (2009) literature review found that family member's psychological symptoms were found to be present at various points in time during hospitalization, such as within the first 48 hours of critical care admission and when care shifted from curative to carative. Van Horn and Tesh (2000) surveyed 50 family members using a modified version of the IIFS and the Social Readjustment Rating Scale (SRRS) and reported that family members experienced altered sleep, nutrition, and activity patterns when a family member was critically ill. The modified IIFS internal consistency reliabilities were from 0.73 to 0.82, with the exception of family roles and responsibilities, which had an internal consistency reliability of 0.41. The validity of the modified IIFS was established by an expert panel review. The internal consistency reliability for the SRRS was 0.86. The authors reported that validity of the SRRS had been established by its extensive use in subsequent research. The psychological and physical health effects of critical illness on family members may affect their death awareness process.

Numerous studies have been conducted on family conferences, visitation hours, and family rounding with the interdisciplinary health team. Jacobowski, Girard, Mulder, and Ely (2010) surveyed 227 family members using the Family Satisfaction in the ICU (FS-ICU) with a Cronbach α coefficient of 0.94. The survey's validity had been established by a significant correlation with results of the previous established Family-Quality of Death and Dying survey. This study reported that as many as 50% of family members do not understand a diagnosis,

prognosis, or treatment and that structured interdisciplinary conferences improved families' satisfaction. In a literature review by Sims and Miracle (2006), liberal visitation improved patient outcomes, reduced anxiety, improved patient and family satisfaction, and improved communications between the health team and patient and their families. These studies highlight the need for family member presence in order to allow for opportunities for information exchange, which may be cornerstone in the death awareness process of family members.

End-of-Life Theories Across Disciplines

End-of-life theories have derived primarily from the sociological and psychological disciplines. These theories are helpful in understanding death and dying in reference to people's awareness of death imminence. However, these theories do not address the present day challenges of advanced technologies and quality end-of-life care. This section elucidates the need for an end-of-life theory, to include family, in the context of adult critical care nursing.

Glaser and Strauss (1965, 1968) context of awareness theory and dying trajectories theories preceded all other death and dying theories. The psychological stage or phase dying theories (Buckman, 1993; Doka, 1993, 1995-96; Kubler-Ross, 1969; Rosen, 1998; Swanson & Cooper, 2004) followed, incorporating the dying person's emotional reactions and responses to dying. Criticisms of the stage (or phase) theories have received attention, because of little empirical evidence to support the stages. Individuals may not move from stage one to stage six and may even skip stages with some stages potentially missing emotional reactions to dying. On the other hand, the living-dying model by Pattison (1977) took into account the dying person's emotional feelings and reactions, but assumed death as a nonstop downward spiral even though some dying individuals stabilize prior to the terminal phase or point of death. The task-based

dying models focus on tasks that must be completed by the dying person prior to their death (Corr, 1992).

Copp's Body-Person Split and Readiness to Die theory (1998) was the first theory to view dying from a nursing paradigm. This theory takes into account the importance of the nurse-patient relationship in the dying process. Copp (1998) found that patients and their nurses continually engage in a process termed as encountering. The nurse-patient encountering involves complex caring strategies, dialogue, and nurse-patient interactions in coping with the dying process (Copp, 1998). The body-person split theory is the first of all dying theories to take into account how a dying individual may separate body from self in the dying process. This was the first of all dying theories to propose the idea that the person may split from their body to cope with the dying process. One limitation of this theory is the lack of generalizability, since the context was in an incurable cancer hospice area. The psychological influences of anger and denial, borrowed from the psychological domain, were included in Copp's theory. However, other types of psychological reactions such as bargaining, fear, anxiety, guilt, and acceptance, to name a few, were not included in Copp's theory. The families' death and dying perspectives are missing from this theory, since the patient and nurse relationship was the primary goal of study.

Nurse researchers, Ruland and Moore (1998), developed the Peaceful End-of-Life theory. The five themes of this nursing theory were: experience of comfort, not being in pain, being at peace, dignity and respect, closeness to significant other and others who care. Nurses were found to foster closeness between the patient and family members by: (a) facilitating participation of family members in patient care, (b) attending to family member's grief, questions, and worries, and (c) facilitating opportunities for family closeness, such as allowing family members to stay

within close proximity to the patient. This theory is unique in that it focused on peaceful life ending, to include family members as integral to this process.

To summarize, the present day end-of-life theories address death and dying experiences from various perspectives. A substantive death and dying theory in the context of adult critical care is needed to guide nursing practice and end-of-life care in this highly specialized technological environment. A theory grounded in the data will be useful in establishing ways to improve life quality to life end. The effects of dying on others around the dying person, i.e. family of the dying person, are important to explore, since no other end-of-life theories have addressed this important aspect of the dying process.

Synthesis Critique of Literature

Human death is a natural life event and ritual entailing social interactions. Qualitative research seeks to gain a better understanding of a participant's stories, meanings, perceptions, experiences, interpretations, understandings, processes, and important life events, such as death. A qualitative design will allow me to discover the unique meaning and experience of our humanity. To date, no qualitative studies have examined how family members come to know that end-of-life is imminent in adult critical care. Overall, a paucity of research exists on specific ethnicities and cultures concerning their death and dying practices. A diverse study sample may provide more information about cultural death and dying practices, rituals, and traditions in specific ethnicities and cultures.

The literature reiterates the importance of family to be in close proximity to the patient, referred to as family member active presence. A heightened awareness of death is relevant when there is a need for life saving efforts. Death awareness is raised when families are in close proximity to the dying patient. Family members' intensely observe the patient for physical signs

of death. Family members' intensely observe the health team with varying interpretation and decipherment. A temporal element cannot be dismissed in the process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting. Not all family members come to know that death is imminent at the same time. Personal experiences with death enhance death awareness. Adequate preparation and anticipation of impending death causes an open awareness. Knowing the patient as a family member emerges as another common theme found in the literature. Studies indicate that family members utilize an array of information sources to manage difficult end-of-life surrogate decisions. Regular communication from the trusted health team needs to be understandable to family as well as clear and concise. Family members wish to avoid conflict by coming to a consensus and negotiation with other family members in the family unit. Family members report that stacking poor health outcomes from decisions surrogates make bring about resounding death awareness. The effect of the adult critical care environment on family may not be as daunting as expected.

Death awareness is prevented in family members when conflicting and less frequent communication is provided by the health team. Surrogate decisions that cause improvement or stability in the patient's health condition seems to prevent death awareness. The lack of proximity to the patient prevents death awareness, since family member active presence allows for more opportunities for information exchange between family and the health team. Unexpected or unanticipated death of a family member prevents death awareness in surviving family members.

This study will describe how family members view the context and its effect on their process of death awareness. End-of-life theories are helpful in explaining or describing death experiences primarily from the dying patient perspective. No end-of-life theory addresses the

present day challenges of the adult critical care setting, including the family perspective. The obvious gap in the body of knowledge is the process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting.

CHAPTER THREE: METHODOLOGY

The purpose of this chapter is to discuss my Glaserian grounded theory approach in studying the human-environment health process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting. This chapter includes the presentation of the study design, sample and setting and recruitment of participants. This chapter discusses the data collection, management, and analysis techniques of this study. The protection of human subjects and procedural steps taken to ensure rigor and trustworthiness are discussed.

Study Design

The study design was descriptive, retrospective. This study utilized a classical Glaserian grounded theory approach to better understand the human-environment health process as described in chapter one. Grounded theory methodology is a research method used to develop a theory that is grounded in the data. This methodology is embedded in the sociological symbolic interactionism philosophical perspective (Crotty, 1998). There are three basic tenets of symbolic interactionism: (1) individuals respond to things and others based upon their perceptions of things or others, (2) our interactions with others encompass meanings, and (3) meanings are modified through an interpretive process used to make sense of the family member's social worlds (Blumer, 1969). Symbolic interactionism provides a perspective for studying the human-environment health process of how family members attain awareness that their family member is dying or near death while in the adult critical care setting. Together, social family units construct meaning about their death and dying experiences. The human-environment health process to describe how family members attain awareness that their loved one is dying or near death while

in the adult critical care setting is unknown. A theory is needed to guide quality nursing care at end-of-life in the adult critical care setting.

Sample and Setting

Theoretical sampling guided the sample selection and determination of the final sample size for this study. Theoretical sampling is the sampling of data from an array of sources based upon the direction suggested by the emerging theory. The investigator collects, codes, and analyzes the data deciding where to go next to collect additional data to develop the emerging theory. The primary data source was family members of the deceased person, with a targeted range from 20 to 30 participants. This range, including other sources of data, was sufficient to attain theoretical saturation for this grounded theory study (Mayan, 2001; Morse, 1994). The precise number of participants was ultimately determined by theoretical saturation achievement. Theoretical saturation is achieved when “no new properties emerge and the same properties continually emerge as one goes through the full extent of the data” (Glaser, 1978, p. 53). Glaser (1978) asserts that theoretical saturation is achieved once the data fit, explain, and resolve the social-psychological phenomenon of interest.

Family is defined by the Institute for Patient-and Family-Centered Care as “two or more persons who are related in any way-biologically, legally, or emotionally” and that “patients and families define their families” (IPFCC, 2010, para. 3). The term *family* in this study included individuals that described themselves as a significant family member and who were present during the patient’s final month of life. The family member may or may not be a blood related relative. Potential family members included: parents, significant others, spouses, children, grandparents or other relatives, and friends of the patient.

Setting

The family member participants included participants recruited by an employee of a hospital located in the Southwestern United States after hospital Institutional Board Review approval. Family member participants were also friends or acquaintances known to the investigator who met the inclusion criteria. Additionally, participants that knew of other potential participants, if interested, were referred to contact the investigator, known as snowball sampling technique (Trochim & Donnelly, 2008).

Various types of adult critical care settings (or units) were used for this study to add variation, depth, and breadth on the topic of study. The following types of adult critical care units were considered for this study: medical, surgical, trauma, neurological, burns, and cardiovascular. Adult critical care units are similar in that all units offer the same aggressive therapies and/or procedures. Nurses require specific technical skills dependent upon the type of critical care unit (burn, trauma, cardiac, to name a few). Adult critical care units differ in that some units care for patients with medical diagnoses whereas other units focus on the care of patients with burns or with post-surgical needs. Patients admitted to medical adult critical care tend to endure longer lengths of stay as compared to surgical units, which tend to be more progressive in care due to the nature of the patient's illness or injury. Patients and their families build stronger rapport with nurses in longer staying units, such as burns and medical units. Typically, patients enduring a more chronic critical illness or injury are admitted to medical units whereas patients with acute critical illness or injuries are admitted to surgical or trauma units.

Participant Inclusion Criteria

The meaning of family is broad and various family structures exist. No one was excluded from this study due to gender, religion, ethnicity, or race. The meaning of family follows the inclusion criteria for this study listed below.

- 1) The participants were a family member of patients that had died in the adult critical care area from six to sixty months ago.
- 2) The participants included family members who were present the final month of their loved one's life, which may or may not have included their presence at the time of death.
- 3) The participants were able to read and speak English.
- 4) The participants were 18 years or older.

Studies indicate that family members' symptoms of anxiety complicate grief, post-traumatic stress, and depression diminish over time. Thus, six-months post patient death was determined as the minimum amount of time for participant inclusion in this study (Anderson, Arnold, Angus, & Bryce, 2008; Davidson, Jones, & Bienvenu, 2012; Kentish-Barnes, Lemaile, Chaize, Pochard, & Azoulay, 2009). Recall bias is always a possibility when participants are being asked to recall retrospective events. Recall bias is when participants have difficulties recollecting experiences or events in the past. However, no study was found to determine the maximum length of time for participant interviewing post patient death yet memorable momentary events, such as death, are typically recalled without recall bias (Schwarz & Oyserman, 2001). Five years was determined to be the maximum time frame for interviewing in this study, based upon my experiential knowledge. Additionally, family members do not experience recall problems concerning specific, single, and memorable death experiences (Schwarz & Oyserman, 2001; Stone & Shiffman, 2002).

Secondary Data Sources

Glaser (1978) contends that “all is data” (p. 8). Researchers generate good ideas by using a variety of data sources. Thus, multiple sources of data were utilized in this study to yield a robust grounded theory concerning the human-environment health process of interest. Sources in addition to the participant interviews included the following: song, nursing art, media and film, and poems. These other sources of data assisted in gathering dense rich descriptive data about this human-environment health process. The incorporation of secondary data sources were collected and analyzed in keeping with the constant comparative method.

Recruitment Strategies

The recruitment process commenced once permission and approval were received from Institutional Review Boards (Appendix A and B). The three sources of recruitment for this study were: (1) friends and acquaintances known to the investigator who were not related to the hospital participants, (2) snowball sampling technique, and (3) eligible participants obtained from a designated hospital member with access to the hospital database. Snowball sampling is when participants recommend others that meet the inclusion criteria to the investigator (Trochim & Donnelly, 2008). The hospital member contacted next of kin of deceased patients who died in the adult critical care. The adult family members were screened for inclusion criteria during the initial phone call made by the hospital representative and were asked about their interest in participating in this study using a recruitment script (Appendix C). Family members that showed interest in being in the study were asked if the primary investigator may contact them. The investigator explained the process of interviewing once inclusion eligibility was attained and interest was expressed.

Protection of Human Subjects

Prior to the implementation of this study, permission and approval was sought from the Institutional Review Board at The University of Arizona and hospital organization. A study protocol using a verbal consent (disclaimer format) was approved. The participants who met eligibility criteria and agreed to be interviewed received information about the study and throughout the consent process about the informed consent and their freedom to choose not to participate in the study or the freedom to discontinue their participation in the study at any time without fear of repercussion (Appendix D). Informed consents were U.S. mailed to participants who verbally agreed to participate to phone interviews along with a thank you card. Once verbal consent was received, the investigator scheduled a date and time with the participant for a phone interview. The date and time for the phone interview was based upon the participant's choice. The participants were assured of their anonymity and confidentiality on the informed consent. The participants were informed of the risks regarding this study due to the sensitive nature and possible emotional distress concerning their death and dying experiences. Participants were informed and reminded that they may withdraw from the study at any time without repercussion. Participants that exhibited incompetence or expressed that their participation was too emotionally difficult were asked if they wanted to withdraw from the study and were provided referral for counseling services (Appendix E). The participants were made aware of the time commitment and energy required to participate in the study. The participants were told that a potential benefit of this study are the implications that it has for nursing practice in assuring quality end-of-life care in critical care.

Procedure

The interviews were conducted by the investigator (Baumhover). The phone interviews were audio-taped. The interview sessions did not exceed two hours in length, but were shorter depending on the participant's needs. No participant was interviewed more than once. Data collection was guided by theoretical sampling and preceded in tandem with data analysis, known as the constant comparative method. Theoretical sampling begins deductively and purposively and becomes more inductive and selective as core categories emerge through data analysis.

Telephone interviews were conducted on a date and time convenient to the participant as well as the investigator. No participant requested an in-person interview; therefore, telephone interviews were conducted. Telephone interviews are a convenient way to overcome time and distance research issues without jeopardizing the quality of the interview data (Novick, 2008). In the role of the instrument, the investigator remained open, flexible, and adaptable by responding to the participants by telephone with tact, skill, and understanding (Denzin & Lincoln, 2011). Telephone interviews easily assisted in the collection of 'data bits' (Glaser, 1978) for this emerging theory. Rapport was established by: (a) understanding the needs of the participants concerning the best time of day to discuss the topic; (b) providing personal connections or stories when applicable during the conversation; (c) using a prepared script, yet maintaining flexibility in the prepared script; (d) clarifying, acknowledging, and responding adequately during the telephone conversation, (e) awareness of auditory cues, such as; pauses, crying, or voice fluctuations; (f) using a careful choice of words, (g) allowing and reminding the participant to take his or her time describing difficult events, (h) providing directivity and steer in the conversation, and (i) responding empathetically non-judgmentally to sensitive information (Holt, 2010; Irvine, Drew, Sainsbury, 2012; Novick, 2008; Sturges & Hanrahan, 2004; Trier-Bieniek,

2012). The investigator documented all auditory cues during transcription, such as crying, pauses, and voice raising, lowering, or silence.

Telephone interviews differ from in-person interviews in that the investigator is unable to observe the nonverbal communication of the participants. Therefore, voice fluctuations and pauses from the participants were noted during telephone interview data collection for this study. The investigator adhered to promised interview timeframes, remained self-aware, and used active listening skills (Cote-Arsenault & Morrison-Beedy, 2005; Fontana & Frey, 1994). Participants that were related to the same patient were interviewed separately, and not together. The employment of active listening skills involved: (a) paying attention, (b) showing the person that you're listening, (c) providing feedback, (d) deferring judgment, and (e) responding appropriately (Manktelow & Carlson, n.d.).

Data Sources

Participant Responses Using an Interview Guide with the Family Member

The initial interview questions were derived from the conceptual framework and independent studies completed by the investigator (Baumhover, 2012). The initial interview questions were refined as the study progressed. Initial questions included a focus on the death awareness of family members that had experienced death of a loved one in adult critical care. The direction of the interview was driven in part by the participant's responses to the questions and prompt questions. Participant demographics were obtained during the interview (Appendix F). Please see Appendix G for a list of potential questions that were asked of the family members.

Data analysis included the constant comparative method, a recursive process entailing the constant comparison of data explained further in the data analysis section of this paper. This

analysis was based upon ongoing findings from the data; decisions were made for subsequent sampling of data from various sources, primarily individuals. The data were collected, coded, and analyzed in this recursive process dictating where to go next to collect data. Sampling of data ceased once theoretical saturation was achieved.

A data-rich grounded theory study yields a robust grounded theory (Bryant & Charmaz, 2010). Several secondary data sources were incorporated as the analysis proceeded. The secondary data sources are discussed next.

Field Notes

Field notes were written by the investigator following each interview. The investigator kept field notes that recorded personal thoughts, hunches, and observations gained during the data collection process (Baker, Wuest, & Stern, 1992). The participant's reflections on voice tones, pauses, emotions and observations were noted upon interview completion. These notes included the investigator's awareness of non-verbal communication gestures displayed by the participants during interview proceedings.

Reflexive Journal

Qualitative research is a reflexive process since the researcher has an effect on the research and the research has an effect on the researcher (Cutcliffe, 2003). The investigator engaged in reflexive journal writing of events while conducting this research to ensure ongoing self-critique and self-appraisal as well as reduce bias in the interpretation of data coded for analysis during the research process (Koch & Harrington, 1998). A reflexive journal consisted of the investigator's ideas, reflections, feelings, biases, and interpretations throughout the research process.

Song, Nursing Art, Media and Film, and Poem

The investigator integrated song, nursing art, media and film, and poems related to families' experiences with end-of-life. These sources of data conveyed meaning about the death and dying experiences echoed by the participants during the open interviews, which shed further light on this phenomenon. These additional data sources provided richer dimensions and variations within the concepts.

Data Management

The data collected from the audio-taped interviews were immediately transcribed verbatim into a Word text file following each interview. The audiotape recordings were destroyed upon transcription completion. The interview transcriptions did not include names but were numbered and labeled with the appropriate relationship of the person to the patient such as "daughter" or "spouse" or "significant other," to name a few, as well as the date and time. The transcripts were placed in the investigator's computer storage in a secured file that required password access only. The password was created by the investigator. The verbal informed consents complied with The University of Arizona, Office of Nursing Research at the College of Nursing storage guidelines. The investigator explained the study to the participants verbally, providing all pertinent information (purpose, risks, benefits, withdrawal at any time without repercussion) and allowed ample time for the participant to ask questions about the study and decide whether or not to participate in the study. The participants were made aware that their agreeing to be interviewed implied consent. The third page of the participant demographic questionnaire (Appendix F) was completed by the investigator and kept separate from other data and removed and shredded upon study completion. The additional sources of data (song, nursing art, media and film, and poems) became data for analysis in the open-substantive coding phase,

before solidification of core categories developed. The names, phone numbers, and addresses of participants were kept locked up in the investigator's work office cabinet, so that there was no damage or loss of sensitive materials. No one other than the investigator had access to the final list of participants that agreed to participate (or their personal information).

Theoretical Sensitivity

Theoretical sensitivity refers to the researcher's ability to conceptualize data through insightful experiences and theoretical knowledge in a given area (Glaser, 1978). The awareness of meaning in the data as well as subtleties discovered in the data during data collection is imperative to classical grounded theorists. The researcher must first put aside as many as possible preconceived or pre-existing beliefs, hypothesis, and biases about the phenomenon of interest as the initial step in gaining theoretical sensitivity (Glaser, 1978). The challenge is that preconceived ideas or notions about phenomena by the researcher may force data into predetermined categories rather than allowing for an emergence of the data to form a theory, meaning that preconceived ideas or notions are counter-emergent. This investigator attempted to put aside beliefs and assumptions concerning how family members might gain death awareness aside in order to render a theory grounded in the data. The investigator's reflexive journal and theoretical memoing helped to establish trustworthiness of the study findings. However, Glaserian style does not completely dismiss the researcher's experiential knowledge in a discipline. The investigator's experiential knowledge served to establish the initial conceptual framework from which the initial research questions were derived.

Theoretical Pacing

Glaser (1978) describes the development of grounded theory as a "delayed action effect" (p. 6) or "delayed action phenomenon" (p. 18). In other words, grounded theories require time to

develop, mature, and grow and cannot be produced overnight. The ability to theoretically pace is what keeps researchers fresh with their ideas and abilities to conceptualize. Glaser (1978) offers numerous suggestions for how best to pace including the use of the investigator's own pacing approaches. Glaser (1978) offers several ideas on how researchers can pace, even though there is no sacred recipe for self-pacing, since researchers must consider their own way to self-pace. For example, the investigator did not rush to develop theory by skipping any steps and scheduled between two to four hours on a daily basis to code and analyzes data. The investigator's creativity and self-awareness of theoretical pacing helped the investigator to discover and grow the theory grounded in the data. Glaser (1978) goes to great lengths in explaining how the theoretical pacing of the researcher is essential to the construction of a well formed robust theory.

Theoretical Memos

Theoretical memos provide insights useful in theoretical sampling and data analysis. Theoretical memoing slows the researcher's pace to fully conceptualize and generate concepts (Glaser, 1978). Glaser (1978) refers to this slowing mechanism as "cooking time" (p. 89) to fully conceptualize ideas to grow and mature. Theoretical memos are written records of analysis that the researcher should begin with the first analytic session and continue throughout the research process (Glaser, 1978). The researcher's ideas and conceptualizations are never lost throughout the research process, because of theoretical memoing by the researcher. Theoretical memoing is crucial for the establishment of a theory grounded in the data. Theoretical memos develop ideas (codes or notions) with complete freedom in a highly sortable memo collection (Glaser, 1978).

My procedure for theoretical memoing in this study included: (a) memoing spontaneously throughout the research process whenever an idea occurred or immediately

following each interview, (b) titling each memo with a caption for sortibility later, (c) keeping the emergent codes handy, (d) comparing indicator to indicator, then indicator to concept, and (e) comparing codes on their dimensions for similarities and differences between the two codes, collapsing the two into one if they are still the same. A latent benefit of theoretical memoing is the possibility of additional ideas for later studies.

Data Analysis

The *constant comparative method* was used for data analysis (Munhall, 2012). This method incorporated evaluation of similarities and differences in perceptions of death awareness by family members of patients in adult critical care. Initial hypotheses were formed based upon the data analysis, which in turn influenced decisions about subsequent data sources and areas of questioning. Analysis involved a systematic coding scheme.

Glaser (1992) defines coding as “conceptualizing data by constant comparison of incident with incident, and incident with concept” (p. 38). There are two types of data analysis coding procedures supported by Glaser (1978) which include both substantive and theoretical coding. Substantive coding entails both open coding and selective coding. The substantive codes are claimed to “conceptualize the empirical substance of the area of research” while “theoretical codes show how the substantive codes may relate to each other as hypotheses to be integrated into the theory” (Glaser, 1978, p. 55). The investigator focused more on substantive coding when discovering codes in the data, and more on theoretical coding when theoretical sorting (Glaser, 1978). Data collection and analysis occurred daily for approximately two to four hours per day (Glaser, 1978, p. 23) during the research process. This activity heightened theoretical sensitivity and achieved a steady flow to allow for theoretical pacing.

Glaserian Coding Phases

The *substantive coding phase* begins with open coding and ends with more selective coding. The investigator, “ran the data open” (Glaser, 1978, p. 56) during the open coding phase. This means that the data were coded inductively line-by-line, generating as many codes as possible before becoming focused and selective during open coding. Glaser (1978) describes this phase as “fracturing the data in analytic pieces which can later to be raised to a conceptual level” (p. 56). A line-by-line approach ensured that there is no missing data and the full saturation of core categories.

The investigator *selectively codes* for a core variable in the selective phase. The investigator delimited coding to only those variables that related to the core variable, which became the guide for further data collection and analysis. The core codes were compared to each other, grouped and named. Glaser (1978) mentions that approximately “10 to 15 codes is a sufficient number for a monograph on a parsimonious substantive theory” (p. 71). The fitting and refitting of the codes was necessary to ensure that all the data fit. Glaser (1978) describes several types of categories to include: in vivo and sociological constructs. The participant’s own words also known as “in vivo” codes were integrated into core categories.

Theoretical coding relates concepts of a theory to each other in a clearly distinct and meaningful way (Giske & Artinian, 2007). Theoretical coding is much more deductive in nature compared to beginning inductive coding phases. Glaser (1978) describes discoveries in one property or characteristics of a code to another as “en vivo” or “theoretically coded connections” (p. 85) during the theoretical coding phase. The use of conceptual models and/or concept mapping assisted the investigator in better understanding how the core categories related in a

meaningful way, their linkages and relationships. Glaser (1978) describes the theoretical coding phase as “weaving the fractured story back together again” (p. 72).

The final step in coding is the identification of a core category. The core category covers all of the data and links the other categories together, enveloping the entire process. The core category has grab and cannot be easily forgotten (Glaser, 1999). Core categories have two or more stages and capture the majority of the theoretical codes. Glaser’s view of negative or deviant cases is not the same as other grounded theorists. Glaser (1978) believes that negative cases aren’t necessarily deviant cases, because these may “highlight further conditions” of the process or core category (p. 106). More than one core category may surface; however, Glaser (1978) encourages developing only one core category at a time in theory development. According to Glaser (1978), core categories sometimes require promotion and/or demotion.

Finally, this study utilized the “*process*” theoretical coding family to assist in making the connections between theoretical relationships. Processes have two or more stages or phases. Glaser (1978) also uses the following terms to describe stages in the process family: “phases, progressions, passages, gradations, transitions, steps, ranks, careers, orderings, trajectories, chains, sequencings, temporalizing, shaping, and cycling” (p. 74). The concept of temporality is intricately linked to a theoretical coding process family. In other words, time plays an important role in how and when a process unfolds. Therefore, temporality refers to processing that requires the passage of time and/or occurs in stages as an event happening over time (Glaser, 1978).

Final Steps of Analysis and Interpretation

The investigator revisited the conceptual framework used to guide this study upon completion. The investigator described the similarities and differences between the guiding conceptual framework and the substantive theory grounded in the data in the final chapter of this

paper. A substantive theory is more commonly generated from grounded theory as compared to a formal theory. Formal theories tend to be more general and tend to cross multiple disciplines of inquiry whereas substantive theories are more specific and focused in a specific discipline. The investigator also compared and contrasted study findings with existing knowledge after theory explication. Glaser (1978) mentions “footnoting the literature” (p. 137) to gain clarity in which the newly discovered theory fits with extant literature on the topic. Developed theories transcend and extend beyond what was previously known about the phenomenon (Glaser, 1978). Ultimately, the results of this study led to refinement or modification or elimination of the originally proposed conceptual framework, which is discussed in the final chapter.

Theoretical Sorting

Glaser (1978) refers to theoretical sorting as conceptual sorting, because it involves a sorting of the researcher’s ideas and not the data. The act of theoretical sorting does not reside in one specific coding phase, yet remains an essential step in the formation of a dense, complete, and fully integrated theory. Glaser (1978) recommends that theoretical sorting occur prior to codes becoming fully saturated. Theoretical sorting of the researcher’s memos produces a theoretically integrated outline. Glaser (1978) does not recommend an outline for integration, but to allow for the theoretical sorting of memos to lead the way to integration. The researcher should “simply start sorting the categories and properties in his memos by similarities, connections, and conceptual orderings” (Glaser, 1978, p. 117). Theoretical sorting permits the researcher to get out of data or “conceptual out,” (Glaser, 1978, p. 119) so that the researcher can remain focused on a higher conceptual ground integrating concepts into the theory.

Human-Environment Health Process

The identification of a core category results from the constant comparative method. The type of core category for this nursing study was the *human-environment health process*. This study incorporated health-related categories and patterns that emerged from the data to ensure theory relevancy to nursing practice. The nursing processes that underlie the data as well as multiple human dimensions (environment, spiritual, physiological, physical, psychological, to name a few) was acknowledged and considered as the core category emerged in this study.

Rigour and Trustworthiness

Lincoln and Guba's (1985) criteria for trustworthiness was used in this study. Lincoln and Guba's (1985) four criteria for trustworthiness are: *credibility*, *transferability*, *dependability*, and *confirmability*.

The *credibility* criterion refers to the truth in findings of the study. The credibility criteria were met by peer debriefing and coding with the chairperson as well as keeping a clear audit trail, including theoretical memos. Peer debriefing entailed working with a peer qualified in grounded theory methodology to offer suggestions, questions, and/or arguments about this study. Other ways that credibility was achieved for this study included: (a) length of interview sessions with participants, (b) accounting for negative cases, (c) collecting data from multiple sources to support the emerging theory, and (d) member checking. Member checking is participant acknowledgement and recognition of their experiences in the data (Lincoln & Guba, 1985).

Transferability refers to the ability of others to make judgments about the similarities between contexts. Transferability was achieved by the collection and analysis of various data until data saturation was achieved to ensure diverse contextual findings, using the participant's

own words in coding, also known as in-vivo codes, and length of interview sessions with participants to ensure the obtainment of thick rich description.

The *dependability* criterion refers to the stability of the data as well as the tracking of data over a period of time. Dependability was achieved using the same investigator/interviewer to ensure consistency in family member interviews and chair examination of coding. The audit trail clearly described how the findings reached arose from the data collection and analysis procedures to assure dependability.

Confirmability refers to the objectivity of the study findings. The audit trail helped to establish confirmability as well as the data being collected and analyzed from multiple sources. The interview questions and/or prompts were constructed in a manner that ensured consistency in participant's responses by posing similar questions and checking for their responses. Lastly, following the Glaserian methodology approach was accomplished by coding for only what was in the data to ensure the objectivity or *confirmability* of the findings.

Summary

This chapter covered the methodology for this Glaserian grounded theory study. This chapter discussed the study design, sample and setting, recruitment of participants, and procedure for protecting human subjects. The sources of data were presented. Last, data collection and management and data analysis were discussed. The techniques to ensure study rigor and trustworthiness of findings were presented for this study.

CHAPTER FOUR: RESULTS

The purpose of this chapter is to discuss the results of data analysis. The first section of this chapter describes the sample, including information about the deceased. The next section presents and explains the middle range theory that emerged, titled *The Process of Death Imminence Awareness by Family Members of Patients in Adult Critical Care*.

Description of Sample

Table 1 describes the demographics of the sample population. There were 14 family members that participated in this study. All of the participants preferred phone interviews rather than in-person interviews. The interviews were audio-taped and included the demographic questionnaire and interview questions based upon the conceptual model presented in chapter one. The interview questions were modified as the interviews progressed to be congruent with Glaser's (1978) principles of theoretical sampling and the constant comparative method.

TABLE 1. Sample Demographic Characteristics

Age	
Range	22 to 76 years
Mean	55 years, 4 months
Gender	n
Male	5
Female	9
Current Marital Status	n
Single with children	1
Single without children	1
Married with children	4
Widowed with children	2
Widowed without children	4
Divorced with children	2
Ethnicity	n
Asian	1
African American	1
Caucasian	10
Hispanic/Latino	2

TABLE 1. - *Continued*

Education	n
High school	3
Community college or university coursework or degree	10
College/university graduate degree	1
Employment	n
Unemployed	2
Employed (part-time)	1
Employed (full-time)	7
Retired	4
Religion	n
Atheist	1
Buddhist	1
Catholic	10
Non-denominational	1
Protestant (Presbyterian)	1
Present at time of death	n
Yes	11
No	3
Relationship to deceased	n
Spouse	4
Child	7
Sibling	2
Parent	1
Previous experience with death in adult critical care	n
Yes	8
No	6
Surrogate Decision Maker	n
Yes	9
No	5
% of surrogate decision makers that had to limit, withhold, or withdraw life support	86% (12 out of 14)

The participants were interviewed six to 60 months after the death of their loved one. The participants were only interviewed once. The average length for an interview was 61 minutes. A participant mortality of four is reported by this study: three participants never returned the investigator's phone message and one participant stated that she was no longer interested in being interviewed after initially expressing interest to the hospital resource person. Only two out

of the 14 family members were related to the same deceased patient, because the investigator quickly realized that related family members shared similar responses to the interview questions. Thus, a decision was made by the investigator not to interview related family members of the same deceased patient. The conformity of responses in related participants is supported by a theory, known as conformity orientation, which is a communication pattern whereby related family members share similar values, attitudes, and beliefs (Koerner & Cvancara, 2002). The investigator was concerned that the theory would not demonstrate breadth, depth, and variation interviewing related participants of the same deceased patient.

Only one health professional (nurse) was interviewed for this study, because of a second decision that was made by the investigator to limit interviews with health professionals. Health professionals tend to know end-of-life phenomena much differently than non-health employed participants. The nurse participant was able to identify low oxygen levels, unlike the non-health employed participants who were unsure about adequate oxygen levels. The nurse participant told me that she was much more capable of noticing her mother's rapidly deteriorating health status as compared to her siblings (non-health employed) and knew what questions to ask the health professionals caring for her mother.

An open-ended question was asked related to the participant's religious and/or spiritual views as being significant or insignificant during the loved one's illness, and ultimate death. Ten out of the 14 participants agreed that their religion and/or spiritual views helped them to cope with the situation. Five of the 10 participants mentioned "*prayer*" as being important for both themselves and their loved one. Prayer helped them to cope through the situation and prayer for their loved one to be relieved of suffering. Two of the participants mentioned that their religion and/or spiritual views helped them to realize that their loved one would be "*relieved from their*

illness or injury” and had a “*better place to go.*” One participant mentioned that she hoped her husband trusted her with “*his spirit*” just as much as “*his life*” concerning decisions that had to be made. Another participant stated that there is a “*time for everything*” and a “*time to go Home.*”

Description of Deceased

Table 2 describes pertinent demographic information pertaining to the deceased. All of the deceased died in the adult critical care area. The length of time the deceased spent in the adult critical care until their death ranged from three hours to six weeks, with an approximate median of three days spent in adult critical care prior to their death. Various reasons for their death are presented in Table 2. Several of the reasons for their deaths were interpreted by the investigator, since family members were unable to articulate the exact reason for their loved one’s death.

TABLE 2. Characteristics of Deceased

Age of deceased, at time of death	
Range	42 to 89 years
Mean	69 years, 9 months
Duration in time since death	
Range	9 to 59 months
Mean	31.2 months
Death Trajectory	
Expected	3
Unexpected	11 (or 78.6%)
Reason for Death	
Acute Hemorrhagic Stroke	2
Cancer	3
Cardiovascular event	2
Drug Overdose	1
Respiratory event	4
Unknown	2

Presentation of Results

- 1) The findings are organized and presented as they were identified from the data analysis process. This study began with general research questions listed below used to guide this study.
- 2) What is the human-environment health process of family member knowing that end-of-life is imminent by family members of patients in the adult critical care area?
- 3) What factors influence the human-environment health process of family member knowing that end-of-life is imminent by family members in the adult critical care area?

The primary data source for this study was the participant interviews, yet secondary data sources supported these findings. The secondary data sources (song, nursing art, media and film, and poems) were interwoven supporting the key categories and are shown with brackets in this paper. Readers of this paper will also notice that certain data are underlined in the presentation of primary and secondary data results. These emphasized areas are temporal factors of data that will be explained in more detail in chapter five discussion and recommendations. Appendix H can be viewed for additional study findings supporting the six key categories since representative quotes were used to support each key category.

Grounded theory methodology generated a middle range theory on the process of death imminence awareness by family members of patients in adult critical care. Theory generation “occurs around a core category” and is “an account for most of the variation in a pattern of behavior” (Glaser, 1978, p. 93). The core category links the other categories for completeness, density, and saturation. According to Glaser (1978), the basic social process (BSP) has “two or more clear emergent stages” that “process out” (pp. 96-97). This study identified the *human-*

environment health process of Death Imminence Awareness by Family Members of Patients in Adult Critical Care (Figure 2).

FIGURE 2. The Process of Death Imminence Awareness by Family Members of Patients in Adult Critical Care.

Human-Environment Health Process

The Process of Death Imminence Awareness by Family Members of Patients in Adult Critical Care is defined as the family member's awareness that his or her loved one in adult critical care is dying. Figure 2 illustrates that life and death are on a progressive continuum toward death since all living beings eventually die. Primary and secondary data sources (song, nursing art, media and film, and poems) supported the adult critical care environment as the apex between life and death, since those that enter the adult critical care environment either live or die (Gibbard & Harmer, 2005, track 9; Navasky & O'Connor, 2010). *Patient's Near Death Awareness* preceded all other phases in the process, if communicated by the deceased with their

family members. The other phases occurred simultaneously with movement in-and-out of each phase. In other words, family members may move in-and-out of *Dying Right in Front of Me* to understanding the *Turning Points in the Patient's Condition* to *No Longer the Person They Once Knew* to *Doing Right by Them*, leading them to a *Time to Let Go*. The potential facilitators of this process include: trust, information, accessibility, and education. The potential hindrances of this process include: denial, hope, uncertainty, and family discord. These influencing factors (facilitators or hindrances) are presented as potential moderator or mediators based upon the findings of this study to be discussed further in the influencing factor section of this paper.

Core Category: Death Imminence Awareness

The core category in this human-environment health process is death imminence awareness. Glaser (1978) states that “all basic social processes are core variables, but not all core variables are basic social processes” (p. 96). This means that a core category can be both a core category and basic social process, but the difference is that a basic social process will process out having two or more phases. Death imminence awareness is defined by this investigator as a heightened consciousness to the inevitability of death, derived intra-and-interpersonally from sensory and temporal cues, overarching all phases of the dying process.

Key Categories in Death Imminence Awareness

The six key categories that emerged from the constant comparative method are found in Table 3. *The Process of Death Imminence Awareness by Family Members of Patients in Adult Critical Care* linked these six categories for “theoretical completeness” (Glaser, 1978, p. 93). The core category has a “primary function of integrating the theory and rendering the theory dense and saturated as the relationships increase” (Glaser, 1978, p. 93).

TABLE 3. Key Categories in Death Imminence Awareness

Key Category	Sub-Categories
Patient's Near Death Awareness	Never coming home again Going someplace else Gathering important or favorite things
Dying Right in Front of Me	Graphic physical changes No signs of life Body losing control and shutting down Family foreknowledge of impending death
Turning Points in Patient's Condition	Nothing more can be done to save their life Running out of time Already gone
No Longer the Person I Once Knew	Not the same person as before
Doing Right by Them	Cannot see them living like that Honoring the patient's health wishes
Time to Let Go	Permission to go

Key Category: Patient's Near Death Awareness

Patient's Near Death Awareness emerged as an initial key category in the process of this study preceding all other phases, if communicated with the family member by the deceased.

Patient's Near Death Awareness describes the patient's ability to know that his or her own death is imminent. Nearly half of the participants interviewed for this study described a patient near death awareness. A patient near death awareness may not always be evident in adult critical care dependent upon the nature of their illness or injury. The critical injury or illness occurs so abruptly that imminent self-death awareness may not get communicated to family member. Several of the participants expressed that their loved one sensed their own impending death. A representative quote for this initial core category is:

Someone was coming around, it may have been the hospital chaplain, and she came by the room. She asked if she could come in and pray for him. It was just me, my dad, and her. I asked my dad and he said "Well, if she wants to, but I really don't think it's going to do much good." It was kind of like, at the very moment, for me, that I just knew that he knew (the patient) that this was it (meaning, he was going to die).

The three sub-categories of *Patient's Death Awareness* include: *Never Coming Home Again*, *Going Someplace Else*, and *Gathering Important or Favorite Things*.

Never Coming Home Again

Many people find home to be a place of rest, peace, and comfort. Several of the deceased in this study expressed a fear of entering the hospital, because of an uneasy feeling of possibly never returning home again. The following statements exemplify a feeling of never coming home again.

He didn't want to go see the doctor, because he was afraid he'd put him in the hospital and he wouldn't ever come out.

My mom didn't want to go to the hospital. She feared going to the hospital. She kept fighting us on going to the hospital, because I think she knew she wouldn't ever make it home and this was not like her to act.

Going Someplace Else

Dying individuals may sense their own departure from this world by showing signs of going someplace else. Dying individuals may also sense they are in the presence of those who have already passed on or get dressed to go somewhere. Two participants shared the following with me:

When she was losing consciousness she cried out "Mom" and her mother has been dead a long time. I thought that this was so weird, but felt good about it too, knowing that maybe she was going to see her mother.

He woke me up at 3:00 am and said he had a headache that was going to kill him. He got up and got dressed. I didn't even know, because I was deeply asleep. I

thought he was having a stroke. He did not want me to call 911. He asked me to lie in bed with him, because he wanted to die at home in my arms.

Another participant shared the following story about her father who survived resuscitation. Her father remained inpatient in the critical care unit and was about to be transferred to a nursing home against his wishes, however, died a few days later before ever making that transfer.

One of my sisters said he had this look on his face, like that's never going to happen. Basically, that's how I just knew that he wasn't getting out of the hospital to go to a nursing home. He would have never allowed it! It was almost like he decided it was time to go (die).

Gathering Important or Favorite Things

Dying persons were found to gather important or favorite things in preparation for their deaths. The following stories express how the dying may plan and prepare for their own deaths by gathering important or favorite things.

One of my sisters told me that she went to his house to get some things for him..... I guess before the paramedics got there, he went and got his Will and put it on the table and she found it sitting there. And so when I heard THAT story, I thought, Oh Boy....that was very telling...he knew that he wasn't going to come back, so he put his Will on the table.

Before the paramedics arrived to another home, the participant stated:

He started to ask for a picture of his deceased mother, his favorite shirt, and pictures of the grandkids. I think that we all knew it, that he was never coming back. A few months prior, he was clearing out files in the garage. I think that he was doing this because he knew he was well enough to get rid of files while he was well enough. This is when I really knew he was probably not going to make it home again.

Another participant mentioned the following in regard to her husband having an awareness of his impending death and planning for such.

I know that he went up to see our financial planner more frequently and made arrangements to close up his business. I think this was all unusual behavior thinking back over most of his life.

Key Category: Dying Right in Front of Me

Dying Right in Front of Me emerged as the most prominent theme in this study. Family members strongly rely on sensory cues (intuitive, sight, touch, sound, smell, and hearing) to determine the seriousness of their loved one's overall condition. Their sensory cues helped them make sense of what was happening and how their loved one's life was approaching the end. Family members provided a detailed description of their loved one's deteriorating health condition through their sensory cues. The four sub-categories of *Dying Right in Front of Me* include: *Graphic Physical Changes*, *No Signs of Life*, *Body Losing Control and Shutting Down*, and *Family Member Foreknowledge of Impending Death*.

Graphic Physical Changes

Family members have problems recognizing their loved ones due to their extensive physical changes. The family members spoke of their loved one's being extremely tired, losing weight, motionless, speechless, and difficulties moving and breathing, to name a few.

I can tell you that I really came to realize how sick he was when I was all alone in my house thinking about things. I went through my phone pictures. I just kept thinking about how he was dying right in front of my eyes over the past year.

She was in a coma and her body was like double the size.

His tongue had purple dots all over it.

He wasn't responding to when they would scrape him with a syringe to see if he would respond. Let's see, it was about 10:00 am when she wiggled that tube (endotracheal tube) and nothing happened, then she'd do it harder and nothing happened (Laughing).....I thought she was going to drag it up and out, she was wiggling it up and down so hard and nothing happened. At that point, I pretty much knew, he wasn't coming back. He wasn't even trying to come back.

No Signs of Life

Participants expressed how their loved one's showed no signs of life. Showing no signs of life helped to convince them that their loved one was in fact dying.

They took it out (endotracheal tube). I stood there and watched and she gasped for about 20 or 30 minutes. I don't know exactly. Then, she stopped breathing...finally.

I saw no signs of life. Her eyes were not alive. There was just nothing.

Body Losing Control and Shutting Down

Family members remember how their loved one's physical body changed throughout the dying process. The deceased experienced bodily loss of control and shutting down. The shutdown of their loved one's physical body conveyed that death was imminent.

The doctors and nurses put some kind of needles, lots of needles in her body. Her body was not controlling anything; she couldn't control anything on her own.

A plethora of things started happening, such as her kidneys shut down and she was also having funky heart rhythms.

Family Foreknowledge of Impending Death

Several family members were unable to describe it, but they just had a feeling or intuitive hunch that their loved one was dying. The following representative quote expresses family members' innate knowledge that their loved one's death was imminent.

Everyone just has that knowledge of knowing. I just knew and cannot describe it, but deep down had a suspicion that things were coming to an end.

Another participant stated that her sister-in-law (the deceased's sister) and her husband left to return to their home state after visiting with their critically ill family member, yet turned their car around about half-way home because of a feeling that they just knew they needed to be back to the hospital. The patient died a few hours later.

Key Category: Turning Points in Patient's Condition

Turning Points in the Patient's Condition describes critical points in the patient's condition that indicated to the family members that their loved one's life was ending. The stacking or compiling of diagnostic test results or the observation of a medical scan indicated their loved one's life was ending. These turning points indicated that nothing more could be done to save their loved one's life. Time was running out. Other family members felt that their loved one was already gone from this world, so there was no reason to keep their physical body lingering. Thus, the withdrawal of life support was becoming more and more necessary. Sometimes their loved one's health appeared to be improving, but then another medical test or situation came along removing all hope in the chance for a recovery. One family described it as stacking bad news and "*back-stepping*" and never being able to move forward. Every surrogate health decision impacted the next. This was an unwinnable battle for family members. The three sub-categories of *Turning Points in the Patient's Condition* include: *Nothing More Can Be Done to Save Their Life*, *Running Out of Time*, and *Already Gone*. Some examples of turning points in the patient's condition are below:

*We were always getting bad news and poor test results.
Things did not look good and they (health professionals) just kept telling us bad news.
It was just adding up and apparent to me that he wasn't really going to be able to live and breathe on his own anymore. I feel like this was the turning point.*

Nothing More Can Be Done to Save Their Life

Family members realized that nothing more could be done to save their loved one's life even with the most advanced life saving technologies as evidenced by:

Pretty much once they told us that there was nothing more they could do or could have done, it was just a matter of calling everyone in...(crying, very shaken up).

Running Out of Time

The family members understood that their loved one's time left in this world was limited and that their time was running out.

They told him that he really didn't have much time left, because his lungs might fill up with fluid or whatever was happening to him, the choking, it was just adding up and apparent to me that he wasn't really going to be able to live and breathe on his own anymore.

Running out of time also meant that: (a) family were called to come back to the hospital, (b) it was time to call hospice, or (c) it was time to call in other family members in order to say their goodbyes. These indicated more turning points for family members.

Already Gone

Family members described how they felt that their loved one was already gone or no longer present, in spite of life saving technologies. Hope was lost. Other family members discussed the observations of diagnostic images, such as a computer axial tomography (CAT) scan or electroencephalography (EEG) shown to them.

(Patient name) never moved. His chest compressed with the last breath, it just decompressed and didn't move. He lay there, the heart starting skipping and then it quit. His chest just fell, he never struggled, he never gasped, he never gagged, and he never made a sound. He was gone. (Patient name) clock just stopped. It maybe took about 45 seconds.

I said oh bleeding in his brain, they said, yes, a lot. (the physician showed the family member the brain CT scan). He (physician) said to me, "I can crack his skull and if he doesn't hemorrhage out completely, than I might be able to get in there and stitch up what's broke, but if I do, he'll never be able to be off the ventilator. He will never be able to open his eyes and speak to you again, because his brain was all crushed to the right side and back side of his head." It was just horrible. Basically, no one had any hope. It was a hopeless situation.

There were no brain waves on the electric machine.

Key Category: No Longer the Person I Once Knew

No Longer the Person I Once Knew describes how family members are unable to recognize the patient (person) as someone they once knew. Family members remembered what the person was like before the critical illness or injury and the changes in the person as a result. The person was not the same as they were before the injury or illness, aiding in family members' ability to move along in the process of death imminence awareness. The dying loved ones are viewed as too far gone to ever return to the functioning and viable person they were before the critical illness or injury event. Family members desperately desire the person to be the person they were before the critical illness or injury (the person they knew) for as long as possible. The sub-category of *No Longer the Person I Once Knew* is: *Not the Same Person as Before*.

Not the Same Person as Before

Family members were told by physicians that their loved one would either be exactly as they saw them lying there in the critical care bed or they would never be the same again. Not the same person as before meant changes in who the person was at that moment compared to who they were before the critical illness or injury, including changes in their eating patterns or energy level or hobbies the patient once enjoyed.

The doctor told us that he wouldn't be the person that we once knew. He would have been like a robot if we kept him alive.

For me, it was when those two doctors talked to me that morning. Basically, they said what you see is what he's going to be.

You being you. One family member knew when his loved one was no longer themselves or someone he once knew. This family member desired for his or her loved one to continue living and being the same person he was before the critical illness or injury. This statement allowed the dying person to continue living while he or she was still alive.

I told him to be you for just as long as you can be. I told him, “That’s what life is about, it’s about living it.”

Key Category: Doing Right by Them

Doing Right by Them describes how family members want to do the right thing for their loved one based upon conversations about end-of-life shared with them through the course of spending their lives together. These life and death decisions about their end-of-life health preferences included their preferences related to the need for surgery or medical diagnostic tests, nutrition (feeding), mechanical ventilation, autopsy, and organ donation, to name a few. This meant honoring their end-of-life wishes exactly how they were once told or knew about according to their wishes. The sub-categories of *Doing Right by Them* include: *Cannot See Them Living Like That* and *Honoring the Patient’s Health Wishes*. The family member statement below exemplifies his or her wanting to do the right thing for them:

We were married for 30 years; I knew what he wanted and didn’t want. I knew what he thought and what he felt and he knew that I would do the right thing for him.

Cannot See Them Living Like That

Participants expressed how they just couldn’t envision their loved one living in the condition they might be left to live. The patient’s poor state of health made family members realize that there was no way their loved one would want to live like that.

I told him (a friend), we could keep him (the patient) alive, but not the way he wants to live. He’d be in a nursing home with all of these tubes and wires and hoses in him connected to him for the rest of his life. I can’t see him living like that.

Honoring the Patient's Health Wishes

Most all of the participants knew what health decisions to make for their loved ones when their loved ones were unable to make decisions for themselves, because of previous conversations or stories they had with their loved one through the years.

We made our decisions by what she told us in the past. What she would have wanted or didn't want.

Key Category: Time to Let Go

A *Time to Let Go* describes the letting go of the dying person's physical being from this world by the family members. Family members come to realize that this time (time of death) may not be on their time; however, it's the right time. During this final phase, the family members give permission to the dying person to die by telling their loved ones that it's okay to go and they will be okay, too. The family members tell the dying person goodbye, so that they may return to their lives and homes, with the prospect of the dying spirit return to its Home, too. Family members continue to sense a connection or presence with the deceased person even after their physical death in order to stay connected to their loved ones described as *Let Go, but Not Let Gone*. The sub-category of a *Time to Let Go* is the *Permission to Go*. Below are some statements from the family members indicating a *Time to Let Go*.

The nurse came to us two or three times to tell us that we need to start thinking about letting her go.

It was time that we got ourselves back into our own lives and for (patient name) life that she was supposed to be in. It was time for us to go home and for her to go Home too.

Permission to Go

The *Permission to Go* entailed letting the dying person know that everyone would be okay and that it was okay to leave this world.

We told her how much everyone loved her and would miss her and that it was ok to go.

My mom got there and told him that everyone was there and it was okay to go now. Your family is here and then he died in my mom's arms.

One participant mentioned that she felt that the dying sense when others are trying to keep them here, by the following statement:

There were just so many people there and so many people that wanted him to stay. I think that dying people know and can feel when people are trying to keep them here.

Let go, but not let gone. Family members let go of their loved one in a physical sense, but not in a spiritual sense. Family members still want to feel connected to their loved ones. Family members sense their passed loved ones' presence through sensory mechanisms, such as; song, smell, and hearing. Those that have lost a loved one may be reminded of their loved one still being present in various ways supported by the following statement.

Ok, now....this is something that is very, very weird that I want to share with you.....Sometimes now, when I think or wonder if I'm doing the right thing, I ask him for an answer, so what do I hear....his favorite song. This has happened on more than one occasion. I am telling you, on more than one occasion!

One family member shared with me that when her husband was bored, he used to flip a Swiss Army knife open and closed. This family member continues to hear this unique sound in her home every now and then. She told me that there is no sound quite like it, but that she still hears it flipping open and closed. She told me that she was not frightened by this sound, but that she found it comforting to know that he's still with her.

Another participant told me that her husband smoked and that both she and their daughter smell smoke in their homes every now and again. She told me that no one even smokes at her

daughter's house, so she truly believes that her husband is letting them know that he might be (physically) gone, but not for good.

This same participant stated the following:

He would lay with his head at the foot of the bed and watch TV. He'd be laying on his left side and have a cup of coffee in his hand. I was making the bed not too long ago. I was sort of smoothing the sheets. I happen to put my hand down where his shoulder would have been. I remember pulling my hand back really fast because I felt a vibration. That is where his pacemaker would have been. I kept thinking that I must be tired. The air conditioning wasn't even on. I went to smooth the sheets again and it happened again. I thought, he shouldn't be playing these tricks on me.

A summarization of the key categories and sub-categories with supporting quotes can be found in Table 4.

TABLE 4. Key Categories and Sub-Categories with Supporting Quotes

Key Category	Sub-Categories	Supporting Quote
Patient's Near Death Awareness	Never coming home again	<i>My mom didn't want to go to the hospital. She feared going to the hospital. She kept fighting us on going to the hospital, because I think she knew she wouldn't ever make it home and this was not like her to act.</i>
	Going someplace else	<i>When she was losing consciousness she cried out "Mom" and her mother has been dead a long time. I thought that this was so weird, but felt good about it too, knowing that maybe she was going to see her mother.</i>
	Gathering important or favorite things	<i>He started to ask for a picture of his deceased mother, his favorite shirt, and pictures of the grandkids. I think that we all knew it, that he was never coming back.</i>
Dying Right in Front of Me	Graphic physical changes	<i>Her feet were first blue, then they turned black. His hands looked like they had boxing gloves on, they were so swollen. She was in a coma and her body was like double the size. His tongue had purple dots all over it.</i>
	No signs of life	<i>I saw no signs of life. Her eyes were not alive. There was just nothing.</i>
	Body losing control and shutting down	<i>It's like they totally start losing control over their body. He could move from the head up, but his whole body was shutting down.</i>
	Family Foreknowledge of impending death	<i>Everyone just has that knowledge of knowing. I just knew and cannot describe it, but deep down had a suspicion that things were coming to an end.</i>
Turning Points in Patient's Condition	Nothing more can be done to save their life	<i>They just said there was nothing they could do.</i>
	Running out of time	<i>They told him that he really didn't have much time left because his lungs might fill up with fluid or whatever was happening to him, the choking, it was just adding up and apparent to me that he wasn't really going to be able to live and breathe on his own anymore.</i>
	Already gone	<i>I don't think he was ever in there, but I don't know. From then on, it was like nobody was home, there was no response. He was pretty much gone.</i>
No Longer the Person I Once Knew	Not the same person as before	<i>The doctor told us that he wouldn't be the person that we once knew. He would have been like a robot if we kept him alive.</i>

TABLE 4. - *Continued*

Key Category	Sub-Categories	Supporting Quote
Doing Right by Them	Cannot see them living like that	<i>I told him (a friend), we could keep him (the patient) alive, but not the way he wants to live. He'd be in a nursing home with all of these tubes and wires and hoses in him connected to him for the rest of his life. I can't see him living like that.</i>
	Honoring patient's health wishes	<i>I knew exactly what he wanted and didn't want, because he told me.</i>
Time to Let Go	Permission to go	<i>We told her how much everyone loved her and would miss her and that it was ok to go.</i>

Secondary Data Sources

The investigator reviewed song, nursing art, media and film, and poems related to end-of-life in the adult critical care environment. The secondary data sources were analyzed using the constant comparative method and interwoven into the key core categories before solidification. The secondary data sources were found to support the emergent key core categories, adding breadth, depth, and variation to the emerging middle range theory. Table 5 contains a partial list of the secondary sources used in this study. A complete list of media and film is found in Appendix I.

TABLE 5. Secondary Data Sources

Source	Title	Artist, Author, or Director	Year
Song	• All Things Must Pass	• George Harrison	• 1970
	• Arc of Time	• Bright Eyes	• 2007
	• Candle in the Wind	• Elton John	• 1973
	• Dead	• My Chemical Romance	• 2007
	• Don't Fear the Reaper	• Blue Oyster Cult	• 1976
	• One Sweet Day	• Mariah Carey/Boyz II Men	• 1995
	• Seasons in the Sun	• Terry Jacks	• 1974
	• Tears in Heaven	• Eric Clapton	• 1992
	• The End of the End	• Paul McCartney	• 1969
	• The Show Must Go On	• Queen	• 1992
	• What Sarah Said	• Death Cab for Cutie	• 2006

TABLE 5. - *Continued*

Source	Title	Artist, Author, or Director	Year
Nursing Art	<ul style="list-style-type: none"> • Nursing the Finest Art (3rd ed.) • The Heart of Nursing: Expressions of Creative Art in Nursing (2nd ed.) 	<ul style="list-style-type: none"> • M. Donahue • C. Wendler 	<ul style="list-style-type: none"> • 2011 • 2005
Media and Film	<ul style="list-style-type: none"> • About Schmidt • Afterlife • Beaches • Ghost • On Golden Pond • PBS Frontline: Facing Death Documentary • Steel Magnolias • Terms of Endearment • The Bucket List • The Descendants • The Notebook • Tuesdays with Morrie 	<ul style="list-style-type: none"> • James Brooks • Hirokazu Koreeda • Garry Marshall • Jerry Zucker • Mark Rydell • Public Broadcasting Service • Herbert Ross • James Brooks • Rob Reiner • Alexander Payne • Nick Cassavetes • Mick Jackson 	<ul style="list-style-type: none"> • 2002 • 1998 • 1988 • 1990 • 1981 • 2010 • 1989 • 1983 • 2007 • 2011 • 2004 • 1999
Poems	<ul style="list-style-type: none"> • Cancer • Do Not Stand on My Grave and Weep • Escape Velocity • How I'm Able to Love • I Wasn't Ready to Let you Go • It's Ok to Go • Last Fight • Letting You Go • Numb • Rocky's Horror Dying Show (short story) • The Butterfly of Healing (short story) • The Pause Between: Looking Back on Life • The Poetry of Nursing: Poems and Commentaries of Leading Nurse Poets 	<ul style="list-style-type: none"> • B. Raingruber • E. Frye • S. Lamont • C. Davis • D. Wilson • L. Daoust • L. Ferguson • I. Torres • R. Hower • L. Norlander • J. Werner • B. Raingruber • Schaefer 	<ul style="list-style-type: none"> • 2005 • 1932 • 2005 • 2006 • n.d. • n.d. • n.d. • n.d. • 2005 • 2005 • 2005 • 2005 • 2006

Song

An internet search was conducted using the following terms: “songs about death” and “songs about dying.” Over 189 songs were found related to death and dying; however, only one song was found that addressed the adult critical care area (Gibbard & Harmer, 2005, track 9). The lyrics of the song, *What Sarah Said*, are in Appendix J. Specific song lyrics that supported key categories of the middle range theory are *italic* in the poem and contain brackets in the additional study findings (Appendix H).

Nursing Art

Nursing art was observed for illustrations depicting death in the adult critical care. My search was limited to photography, visual and digital design using the internet and one historical nursing art textbook (Donahue, 2011). Historical nursing art was not found to illustrate critical care units, due to the fact that these units did not exist until the 1960s (Fairman & Lynaugh, 2000). Therefore, a Google image search using the terms “death in critical care” and “death in intensive care” was conducted. This search revealed pictures of patients appearing unresponsive and intubated (advanced airway) on mechanical ventilation (Figure 3). The physical appearance of patients is severely altered and/or grossly disfigured providing explanation for the reason family members remember graphic physical changes (Figures 4 and 5).

FIGURE 3. Intubated Trauma Patient with Family Member
Retrieved from <http://www.cbsnews.com/video/watch/?id=4086439n>.

FIGURE 4. Patient Suffering from Disseminated Intravascular Coagulation (DIC)
Retrieved from <http://www.inflammation.dk/iir/08vasc/sepDIC.htm>.

FIGURE 5. Patient with Burns to Legs

Retrieved from <http://www.emsworld.com/article/10839933/thermal-burn-care-a-review-of-best-practices>.

Media and Film

Media and film on the topic of death and dying were searched on the internet and by a visit to a local movie rental store by the investigator (Appendix I). The media or film had to meet the following specifications for my review: (a) the dying person was human (non-animated), (b) the actual death was covered in the media or film, (c) the dying person was an adult, not a child, and (d) the dying person died in the adult critical care. My experiential knowledge informed me as to whether or not the setting was an adult critical care area. Only one public television broadcast and two movie films directly met the specifications outlined for my review.

In a Public Broadcasting Service (PBS) Frontline documentary (Navasky & O'Connor, 2010) titled, *Facing Death*, physicians are filmed discussing end-of-life decisions with patients and their families in the adult critical care. A summary of the physicians' comments about death and dying can be found in Appendix K. Dialogue that supported specific key categories in my middle range theory was embedded in Appendix H with brackets.

The two movie films that supported my emerging middle range theory include: *Steel Magnolia's* (1989) and *The Descendants* (2011). A summary of these movies can be found in

Appendix L and M. *Steel Magnolia's* (1989) supported the following key categories: *Dying Right in Front of Me* and *Time to Let Go*. *The Descendants* (2011) supported *all* of the key categories of my middle range theory, except *Patient's Near Death Awareness*. An excerpt from this movie can be found in Appendix H with brackets.

Poem

An internet search for poems about death was conducted using a combination of terms: death, family, friend, intensive care, and critical care. One website displayed 691 poems on death, dependent about the relationship to the deceased (mother, brother, parent, to name a few). The uncertainty rested in whether or not the context of the poem was in the critical care due to the abstract nature of poetry. In addition, two nursing poetry texts were reviewed in addition to the review of poems found on the internet related to death of a family member. One nursing text had with a chapter specifically on poems and short stories related to birth and death, written by nurse artists (Wendler, 2005). The other nursing poetry text contained poems written by leading nurse poets (Schaefer, 2006). The poems that were analyzed about death in Table 5 are not meant to be an exhaustive search, yet several poems reviewed supported the key categories of the middle range theory. Phrases from these sources have brackets and can be found in the additional study findings in Appendix H.

Influencing Factors: Proposed Moderators and Mediators

My second research question sought to determine influencing factors in the process of death imminence awareness by family members of patients in adult critical care. These factors can be viewed as potential mediator and moderator variables helpful in the advancement of description to validation for later studies. In the quantitative paradigm, *moderators* are variables or concepts that affect the direction and/or strength between two variables (Baron & Kenny,

1986). In the quantitative paradigm, *mediators* are variables or concepts that specify how or why a relationship or effect occurs between independent and dependent variables Kazdin (2003) mentions how “theory directs our attention to which moderators to study” (p. 127). Kazdin (2003) reminds researchers that an infinite number of moderator variables can be proposed from a research study. The challenge rests in the determination of which variables are most important. Once variables are operationalized, they can be statistically tested to learn if they are a moderator or mediator.

One of the biggest concerns in adult critical care is that life is being impeded or prolonged, regardless of life quality, especially in futile cases. This study found that 86% of the participants made an affirmative surrogate decision to withdraw life support (*Time to Let Go*). Figure 6 illustrates just one example of a moderator-mediator model. The proposed model attempted to illustrate a few of the variables from this grounded theory, if measurable, may explain how family members *Let Go*.

Proposed Moderator-Mediator Model

FIGURE 6. Proposed Moderator-Mediator Model

In the proposed model, numerous independent variables may have some influence on either how or why a family member makes an affirmative surrogate decision to *Let Go*. The trajectory of one's illness (expected or unexpected) may have some effect on the family member's ability to *Let Go*. A *Patient's Near Death Awareness* may also have some effect on the family member's ability to *Let Go*. Other measurable independent variables might include the following: (a) family member's work experience (health related or not), and (b) duration of time the patient was in the adult critical care, to name a few. The independent variables proposed include some of the demographic variables obtained from this study as well as one of the key categories (*Patient's Near Death Awareness*). The investigator performed a literature search and was unable to find whether or not the theory of "nearing death awareness" has ever been tested. The proposed moderators and mediators, discovered from this grounded theory study, include, but are not limited to: (a) communications with the health team, (b) family structure (who makes

the decisions and how decisions are made), (c) presence (or not) of family discord, (d) emotional state of the family member, (e) role of the nurse, (f) health information, (g) health education, (h) accessibility (to both the patient and primary care practitioners), and (i) honoring the patient's health wishes.

The role of the nurse in the process of death imminence awareness cannot be underestimated. First, nurses facilitate communications to honor the patient's end-of-life wishes. Second, nurses are in a prime position to help family members see with their own eyes, and other sensory mechanisms, the seriousness of their loved one's health situation (*Dying Right in Front of Me*). Third, nurses provide health education for family members. The investigator found that participants seriously lacked a general understanding of how the human body functions and overall health information (Appendix N). Fourth, bedside nurses serve as the liaison between family and primary care practitioners, speaking to accessibility (to the primary care practitioners) and communication factors. Nurses are also the gatekeepers of deciding when to allow or not allow family to visit their loved ones (accessibility to the patient). Family cannot understand the seriousness of their loved one's situation, unless, they are able to spend time with their loved one and communicate with other health team members. Fifth, nurses facilitate conversations between the family member and health team and within the family, too. Family discord, or conflict within the family, was prevalent in this study (Appendix O). For one participant, this distraction had an effect on his ability to gain death imminence awareness or understanding of what was happening. Sixth, nurses spend the most time with family members and are the first to recognize their physical, behavioral, or emotional reactions. Appendix P contains a list of emotional, physical, and behavioral reactions that family members experienced dealing with a dying loved one. Family member reactions may have some influence in the process of death imminence

awareness. For example, many of the participants discussed feeling tired to the point of complete exhaustion. One family member said that due to this, she couldn't even remember half of what she heard.

Through the conversations and descriptions with family members, the investigator proposed facilitators and hindrances of *Death Imminence Awareness* as shown in Figure 2 earlier in this chapter 4. The facilitators of this process include: the establishment of trust with the health team, health information, accessibility (to both the patient and primary care practitioners), and health education. The hindrances include: denial, hope, uncertainty, and family discord all based upon the findings of this study. Table 6 contains supportive nursing behaviors and actions that ensure quality end-of-life care in this acute care setting based upon good and bad experiences of the family members of this study.

The proposed model offers numerous important concepts from this middle range theory or a few of the demographic variables that could be tested once operationalized (measurable). The proposed model is not meant to portray all possible mediator and moderators variables associated with this phenomenon. All potential variables and explanations would need to ultimately be addressed for research to be considered valid. Research does not limit the number of measurable variables; however, too many variables involve complex statistical analyses leading to a risk for bias and lack of control. In other words, this model may be mistaken, until statistical methods are employed. In fact, the mediators may truly be moderators and the moderators may be mediators.

TABLE 6. Supportive Nursing Behaviors and Actions

Nursing Behavior	Specific Nursing Actions to Facilitate Behavior
Show genuine care and concern	<ul style="list-style-type: none"> • Be sure that the patient is clean, comfortable, and presentable • Show genuine concern not only for the patient's well-being, but the family members too. Ask the family members how they are doing too. Ask what they might need or how you can help. • Maintain the patient's dignity with curtains pulled and doors closed • Assess and tend to family member's needs: drink and nutrition, sleep, blankets, pillows, and transportation. For example, rather than asking, bring them food. • Anticipate spiritual needs of patient (and family) • Anticipate emotional needs of family (consult social work) • Grant special requests from the patient • Frequently check on patient • Be gentle during procedures or general care, such as turning the patient • Express sorrow (tears) with family • Share religion (rituals, prayer, etc.) with family if it is your own • Acknowledge (do not ignore) and actively listen to family member's emotions/feelings (sadness, anger, etc.) • Show kindness in everything you do! • Spend time with the patient-sit with them, listen to their stories, share some of yourself with them • Keep a tidy and clean patient room • Maintain continuity of care by assigning the same nurse to the same patient • Visit with patient and family on days off work, if at hospital site • Family members find it comforting when nurses set up a work station or desk directly outside of the patient's room-in close proximity to the patient
Prepare and plan for events	<ul style="list-style-type: none"> • Discuss code status <i>before</i> admission or <i>before</i> the patient's condition worsens • Discuss advance directive <i>before</i> admission • Consult palliative care team early • Prepare family members for impending need for name of a mortuary • Prepare family members for need to ask about autopsy and organ donation • Give family foresight on situations that may occur, such as a difficult extubation and possible need for tracheostomy before the event • Be mindful about the timing of turning off equipment (life support)-do not turn off equipment with family present • Prepare family members for what will happen once the patient is extubated. For example, the patient may gasp a few times before taking final breathes. • Provide sedation to patients prior to withdrawing life saving devices • Help family to give dying person permission to go, reconcile any relationships needing reconciliation to allow for peaceful death of dying person • Alert families to when patients may be placed in a medically induced coma or prior to any sedation, so that family members can say have needed conversations with their loved-ones

TABLE 6. - *Continued*

Nursing Behavior	Specific Nursing Actions to Facilitate Behavior
Foster death awareness	<ul style="list-style-type: none"> • Help the family member to “see with their own eyes” the compromised health status of their loved-one • Be clear and be honest about the health status of their loved-one. Use understandable terminology with family members, do not assume they understand • Help family members to recognize cues of patient’s near death awareness: need to prepare for travel, change, or going someplace else, mention of people or places that only they alone can see-mention of those who have already passed, wish for the reconciliation of relationships, events, or situations, knowing precise time of own death, and puzzlement, agitation, distraction or preoccupation of patient • Help family to know that their doing the right thing for their dying loved-one • Help family to know the person is no longer the person they knew before • Be honest about artificial signs of life-help them to know when signs of life cease despite technologies, such as signs of body system shut down or loss of control • Ask family members what ideas or hunches they have about their loved-one’s condition • Help the family to understand their loved-one’s wishes and whether or not their condition warrants their wanting to continue living in such a way • Assist family members in understanding the temporality factor associated with their loved-one, such as how many hours they’ve been unresponsive or how long they’ve been in the critical care
Provide for information and communications	<ul style="list-style-type: none"> • Facilitate communications between the family and primary care practitioner-make calls to primary care practitioners to speak with the family and/or schedule family conferences • Ensure the accuracy of records, such as ensuring the correct phone number for the next-of-kin, birthdates and names on armbands • Encourage family members to journal for therapeutic and tracking reasons (one family member stated this helped her to make sense of the insurance bills later) • Educate family on all health information, don’t assume they understand the meaning of terms or procedures • Assist family members in compiling a list of questions for the primary care practitioner. Help them to know what important questions to ask. • Provide straightforward communication, do not offer indecisive or inconclusive information • Maintain confidential communications. Do not hold family meetings in open areas. Be mindful about location of communications. • Family members desire communication with the hospital agency after the death event to discuss how they are managing and to offer grief counseling services • Establish trust by being reliable, open, keeping their confidence and doing what and when you say you will do something • Let family know when it’s time for other family members to come visit the dying person or if it were your loved-one, would it be the right time to leave the hospital or not

TABLE 6. - *Continued*

Nursing Behavior	Specific Nursing Actions to Facilitate Behavior
Be fully present	<ul style="list-style-type: none"> • Stop to talk with family members, don't be so rushed in that you have no time to offer them with your full attention in all communications with them • Clear your mind of any distractions, use fully present non-verbal communication: eye contact and face the person you are having a conversation with, allow them to speak freely without any interruptions
Encourage contact between the patient and family	<ul style="list-style-type: none"> • Allow for liberal visitation: family presence • Encourage touch and verbal communication between the family and patient • Allow children to visit, if the family wishes • Allow family to be involved in helping to care for the patient, groom the patient • Allow family to sing, read, pray with patient
Be mindful of sensitive topics or situations	<ul style="list-style-type: none"> • Be gentle and kind when handing over personal items of the deceased to family members: clothes, shoes, etc. • Listen to family member's wishes for their loved-one concerning organ donation. If the patient was against this prospect, hear it the first time-protect their wishes • Hospitals might consider employing an end-of-life advocate to stay with a family and help them navigate through the experience
Personify the patient as a person: Personification	<ul style="list-style-type: none"> • Ask family to bring in pictures of their loved-one, family, or animals • Ask family to bring in items that are favorites of the patient, such as a blanket or other item • Allow family to bring the patient's favorite music or other hobbies • Ask family to bring in items that tell others about the patient's life, career, or aspirations • Know the patient by preferred name and family members too

Summary

This chapter summarized the results of this grounded theory study. The chapter began with a description of the sample and deceased. The analysis of data revealed *The Process of Death Imminence Awareness by Family Members in Adult Critical Care* to be the human-environment health process as reformulation of the basic social process with six key categories. *Patient's Near Death Awareness* preceded all other phases in the process when present. Family members moved in-and-out of the following phases simultaneously: *Dying Right in Front of Me*, *Turning Points in the Patient's Condition*, *No Longer the Person I Once Knew*, *Doing Right by Them*. Family members uniformly came to the conclusion that their letting go of their loved one in a physical sense was necessary. *A Time to Let Go* was found to be the final phase in this process. *Dying Right in Front of Me* was a prominent theme voiced by family members. The chapter ended with answering the second research question, which sought to determine potential influential factors, proposing possible mediator and moderator variables in this process. A discussion about family member reactions (emotional, behavioral, and physical) as well as supportive nursing actions was discussed as potential moderators and mediators in this process.

CHAPTER FIVE: DISCUSSION AND RECOMMENDATIONS

The purpose of this chapter is to discuss the results of this study. The findings of this study will be explained and integrated with extant literature and in relation to the originally proposed conceptual framework used to guide this study. The study strengths, limitations, and surprises will be discussed. The chapter concludes with recommendations for nursing education, practice, and research.

The Process of Death Imminence Awareness by Family Members

The Process of Death Imminence Awareness by Family Members of Patients in Adult Critical Care was found to be the core human-environment health process as reformulation of the basic social process. This type of process (i.e. human-environment health process) was a nursing reformulation of the basic social process as originally labeled by Glaser (1978).

The core process has six core categories: *Patient's Near Death Awareness*, *Dying Right in Front of Me*, *Turning Points in the Patient's Condition*, *No Longer the Person I Once Knew*, *Doing Right by Them*, and a *Time to Let Go*. This process is used by family members to gain death imminence awareness when a loved one is dying in the context of adult critical care. Family members understand that end-of-life is imminent by conversations shared with them by the dying person. They recall changes in the physical appearance of the patient, aiding their ability to know that their loved one is dying. The patient experiences turning points in their condition when nothing more can be done to save their loved one as time is running out and their loved one appears to already be gone. Family members want to be sure they are doing right by them in honoring the patient's health wishes in their surrogate decision making. Family members remember the person for who they once were and realize that they will never be this person again. An outcome of this process was found to be a *Time to Let Go*, describing when family

members realize their loved one is dying and they need to let go, so that their loved one can have a comfortable, peaceful, and dignified death.

Integration with the Literature

The integration of findings with extant literature is to determine how the findings either support, extend, or refute the originally proposed conceptual framework and literature on the topic (P. Reed, personal communication, December 10, 2012). The integration of my findings will be presented by each core category described in the process of death imminence awareness by family members of patients in adult critical care.

Death Imminence Awareness

Glaser and Strauss' (1965) seminal work on death awareness was the first to describe patient and family dying awareness within four social contexts: suspicious, mutual pretense, open, and closed. Seale, Addington-Hall, and McCarthy (1997) described open awareness as the most prevalent type of awareness as compared to the other three contexts. Open awareness is described as when the dying person and family are completely aware that the person is dying. Seminal work described the types of death awareness, but did not define or describe the process in any particular context. This study extends death awareness by defining and describing the process of death imminence awareness in the context of adult critical care.

Similar to the findings of Glaser and Strauss (1965), family members in this study required health information and proximity to the patient to enhance their death awareness. Health information was not fully comprehended by the participants in this study. Unlike Glaser and Strauss (1965), this study had more unexpected deaths. The degree this had on their death awareness was not determined, since it sought to describe the process for their awareness and not the extent of their death awareness. Family members in this study did not feel prepared enough

for impending death and funeral arrangements like the “aware family” (pp. 155-176) described by Glaser and Strauss (1965). Certainly, seminal authors of death awareness did not dismiss other factors besides proximity and information that might influence death awareness. Results of this study have identified additional factors involved in influencing death awareness, such as; intra and interpersonal sensory and temporal cues, family member reactions (emotional, behavioral, and physical), and presence or lack thereof family discord, to name a few.

Tilden, Tolle, Garland, and Nelson (1995) described “dawning awareness” (p. 634) to be congruent with death awareness. Family members described how cautionary statements from the health team indicated that their loved one was either suffering, never going to recover, or experiencing poor life quality and this determined whether or not life support was withdrawn. Similarly, the participants in my study, waited for the lead of health professionals’ conversations to know that death was imminent, namely, physicians; to tell them that their loved one’s life was ending, thus supporting Tilden, Tolle, Garland, and Nelson’s (1995) findings.

Francke and Willems (2005) described awareness of impending death in the realm of terminal illness. Terminal illness is much different than unexpected critical illness. Francke and Willems (2005) described how some patients with terminal illness displayed unawareness until their death got much closer in time. On the contrary, some of the patients in this study had a near death awareness and their deaths were unexpected. My study described how temporary improvements in the patient’s condition can often appear to mean that the patient is getting better. These changes or slight improvements distort their death awareness similar to how family members reported perceptual distortions in Francke and Willems (2005).

Patient's Near Death Awareness

Nearing death awareness was not originally conceptualized in this process. This study supported, extended, and refuted extant literature on nearing death awareness. First, the findings extend existing literature on near death experiences, which are often confused with nearing death awareness. Near death experiences happen suddenly. Individuals experiencing a near death experience may feel clinically dead or sense they are dead, such as in the case of a tragic accident or drowning. Conversely, nearing death awareness happens slowly over time. Those experiencing a nearing death awareness feel as though they are going to die, such as in the case of cancer or chronic disease (Sanders, 2007).

Authors Callanan and Kelly (1992/2012) described “nearing death awareness” as a dying phase often mistaken as restlessness or delirium of the patient by family members and health professionals. Those nearing death often exhibit behaviors related to taking care of personal business, speaking or envisioning those already dead, and change or travel, to name a few. Nearing death awareness can happen in any setting, including the adult critical care environment (Callanan & Kelly, 1992/2012). A person experiencing nearing death awareness is said to have a “special knowledge about--sometimes a control over--the process of dying” by telling others what is needed for them to die peacefully (Callanan & Kelley, 1992/2012, p. 21).

A CINAHL literature search was conducted and revealed numerous studies on near death experiences and very few on nearing death awareness (Francke & Willems, 2005; Greyson, 2003; Seale, Addington-Hall, McCarthy, 1997; Simpson, 2001; Van Lommel, Wees, Meyers, & Elfferich, 2001; Yates & Stetz, 1999). Nearing death awareness tends to be studied from the dying person perspective rather than surrounding family members and mentioned primarily in

terminal illness cases and within the realm of palliative and hospice care rather than adult critical care.

Second, the dying in this study delivered several messages to their family members. Messages from the dying are either “attempts at describing what someone is experiencing while dying” or “requests for something that a person needs to die peacefully” (Callanan & Kelley, 1992/2012, p. 22). The messages from the dying in this study occurred either directly before their admission into the adult critical care or while in their hospital bed in the adult critical care. Experts on this topic mention how this phenomenon can occur in any setting. Family members in this study were asked to describe their loved one’s death as expected or unexpected. A high percentage of the deaths in this study were unexpected (11 out of 14 or 78.6%) as compared to expected (3 out of 14 or 21.4%) with a nearing death awareness that was prevalent. This study extends literature on the topic in that no other study has described nearing death awareness in the context of adult critical care and no other study has assessed the trajectory of an illness in relation to nearing death awareness. More research is needed to assess the illness trajectory in relation to the presence of nearing death awareness. My study supported nearing death awareness as not being context dependent.

Francke and Willems (2005) conducted a qualitative study on terminal patients’ near death awareness. The Francke and Willems (2005) study focused on nearing death from the perspective of the patient. These authors mentioned that a limitation of their study was that the awareness of relatives was not described. My study discovered the process of death imminence awareness from the perspective of the family member; revealed a patient self-awareness of impending death communicated to family members.

Yates and Stetz (1999) discussed that the development of awareness of dying being a vital process for bereaved adult family caregivers to include the following five categories: being uncertain, agonizing, hoping, pretending, and preparing. My study assessed family members of patients in adult critical care that are not necessarily the caregivers of the patient and hope was viewed differently. According to Yates and Stetz (1999), family members develop awareness of dying by hoping, pretending, and preparing for death. In my study, the presence of hope still meant a chance that the patient might have a chance at survival. It wasn't until all hope was lost before family members in this study understood that death was imminent.

Contrary to Fridh, Forsberg, and Bergbom, 2009, family members in this study faced death during the active dying process and not upon patient expiration. Fridh, Forsberg, and Bergbom (2009) described how family members faced death by seeing the expired person. In my study, family members are facing death much sooner during the active dying phase as described as *Dying Right in Front of Me*.

Dying Right in Front of Me

The strongest theme in this study was the family member's ability to sense their loved one's impending death. This study supported and extended literature on the topic. Meeker and Jezewski (2008) qualitative metasynthesis theme of "reframing reality" (p. 165) entailed family members looking for cues from the patient and their observations and interpretations of the clinicians in grasping the reality of the situation that their loved one might die. Limerick (2005) described how family members weigh their options and gather information in surrogate decision-making by visualizing their loved one's poor health condition. However, Limerick (2005) did not share the details or specifics of their visualizations (or patient's physical signs of decline) as my study has done. My study provided detailed descriptions of family members' sensory and

temporal cues when a loved one is dying in adult critical care. Nurses are in a unique position to help family members to discuss their perceptions directly at the bedside to facilitate their death imminence awareness, since nurses spend the most time with family.

In Chambers-Evans and Carnevale (2005), “coming to terms” (p. 36) in the dawning awareness surrogate decision-making process, participants provided descriptions similar to my study’s participants’ physical descriptions of their ill loved ones. Other research studies have labeled a similar theme with a different title. Swigart, Lidz, Butterworth, and Arnold (1996) refer “understanding and reframing the critical illness” (p. 486) phase in the surrogate decision to forego (let go) life support to mean something similar to *Dying Right in Front of Me*. The participant quotes are similar to quotes described by participants in my study.

Eggenberger and Nelms (2007) described the physical space that family members occupy as their “lived space” (p. 1622). In this space, families listened to and observed what was happening to and with their loved one. Tilden, Tolle, Nelson, Thompson, and Eggman (1999) referred to “recognition of futility” (p. 431) to contain cues from the clinicians and not from the patient. In my study, the participants observed cues primarily from their loved one, but from observations of the health team, too. Agard and Harder (2007) discussed how family members form personal cues as a way of adapting to the experience of having a critical ill loved one. Person cues were described as the intense observations of family members of the clinicians and patient. However, the exact descriptions of what they saw were not reported as they are in my study.

My study is unique in that no other study has mentioned an intuitive knowledge about family member death imminence awareness labeled as *Dying Right in Front of Me* with a sub-category of *Family Foreknowledge of Impending Death*, thus extending literature on the topic.

Several participants in this study had an intuition that their loved one was dying. In Tilden, Tolle, Nelson, Thompson, and Eggman (1999), a family member stated, “We just knew it was time,” (p. 436), however, this study didn’t actually describe their findings a phase in the process of death imminence awareness. In other words, no other study has examined the process for their death imminence awareness. This theme extended the most amongst extant literature. This study provided detailed and extensive information about what family members see, hear, and intuitively seem to sense that their loved one is dying in the context of adult critical care.

Turning Points in the Patient’s Condition

In this study, family members understood that turning points for the worse meant their loved one was dying. They understood this because nothing more could be done save their loved one’s life. To them, it felt like their loved one was already gone. Running out of time was just another indication that their loved one was dying. Tilden, Tolle, Nelson, Thompson, and Eggman (1999) used the term “facing the question,” (p. 436) as to when family members decide to withdraw life support measures. My study provided more information on the actual process for their thinking, a true examination of their awareness as compared to previous studies that have sought decision-making processes. Other studies have looked at themes from the perspective of decision-making whereas this study sought to examine their process of death imminence awareness. Family members are reluctant to remove life saving measures until they are absolutely certain that nothing more can be done to save their loved one’s life, because no one wants to live with the guilt that they caused their loved one’s death (Meeker & Jezewski, 2008).

Hayes (2003) described how family members seek time with their loved ones. Temporal factors were prevalent in my study. Family members were very time or temporally focused. They could remember how many seconds passed since the patient’s last breathe or how many grasps

of air before their final last breath or the exact time the patient died or time that life support was removed. Family members have an impeccable memory for temporal elements as noted by underlined quotes from the participants in chapter 4 and Appendix H. Hayes (2003) described that time was needed for family members to make surrogate decisions as well as in relation to the timing of events. Kaufman (2005) goes into great detail about how death is timed and orchestrated in American hospitals. One family member in my study discussed how her loved one's death would be at a specific time (5:00 p.m.), because friends of the family couldn't get off work until this specific time, so this is when life support was going to be withdrawn. Therefore, my study supports what resonates in the literature regarding how death is timed. It is timed not only from the perspective of health professionals, but from family members, too. Family members may connect time with the reality of their loved one still living. Time may denote living and not dying. Family members want more time, just as the dying typically desire more time, thus, connecting them in a world of living, rather than dying.

In this study, *Running Out of Time* meant that the patient was running out of time to live, which was different than other studies sense and meaning of time. Many other studies were written from the perspective of vigil time or time that family members had to wait around. My study described how time was associated with death imminence awareness. Family members understood that time left for living for the dying was shortened if they were called to come back into the hospital, or if hospice was being suggested, or if the health team was telling the family member to call in other family members to say their goodbyes to the dying patient. Family members in this study could recall the exact time the patient last spoke, or how many years they were married, or for how long the loved one spent time in adult critical care. Running out of time, in my study, also meant that death was imminent. Kaufman (2005) discussed time in

relation to death being carefully constructed and designed by health professionals; so again, time did not have the same meaning. Health professionals are always trying to move things along in a timely efficient manner according to Kaufman (2005). Temporal factors in this study did not carry the same exact meaning and also meant that family members, besides health professionals, were involved in orchestrating death around their own schedules.

No Longer the Person I Once Knew

Family members in this study described how seeing their loved one in the critical care reminded them of the differences in their loved one before and after the critical illness or event. In their hearts, they knew that their loved one was no longer the same person and would never be the same person as they knew before the illness. Limerick (2007) referred to something similar in his grounded theory study. Family members' evaluate their loved one's past and future quality of life in the personal domain of surrogate decision-making.

Family members brought to the bedside of deceased loved ones often don't recognize their loved one after death, due to significant changes in their physical appearance. This is described by Fridh, Forsberg, and Bergbom (2009) as "facing death" (p. 115). Yet, this study did not fully describe family member's sensory cues of death imminence. My study expounded beyond changes in their physical appearance, since it also meant to participants in my study, the differences in the person, too. Family members in my study longed for the person they once knew, because they remembered their likes and dislikes, recalled their eating habits, hobbies, or activity levels from a long time ago. These changes in the dying person were so drastic as well as unacceptable to the dying patient that all hope was gone and movement toward *Doing Right by Them* was necessary.

McKiernan and McCarthy (2010) described a theme of “making sense of it all” (p. 258) as family members’ need to reconcile their idea about their loved one now as compared to the life they lead prior to the critical illness. In my study, not being the same as before meant a stark difference in the current person as compared to the past with a significant loss in their quality of life. In other words, family members in my study did more than reconcile or settle in their ideas and thoughts about differences in the dying person from before and after the critical illness. Family members in my study moved forward in a death imminence awareness process, toward accepting that their loved one was dying and would never be the same as the person they once knew, therefore, it became a time to let go or allow their loved one to die.

Doing Right by Them

Hayes (2003) described the “representation of others” (p. 95) to mean something similar to *Doing Right by Them*. Family members desire that health professionals remember the patient as a person and the life they led as well as their health preferences to manage decisions. Hayes (2003) mentioned that our connection with others tends to cause conflict. My study had several participants that mentioned internal family conflict or family discord. In fact, Swigart, Lidz, Butterworth, and Arnold (1996) described how “maintaining family roles and relationships” (p. 489) were a priority for families, so that family relationships were not destroyed as a result of the critical illness. In my study, maintaining family roles and relationships wasn’t voiced by the participants. Instead, family discord was present in some of the family members’ description of events. No family member mentioned anything about preserving relationships.

Limerick (2007) described how family members could not progress in their surrogate decision-making until they heard a confirmed terminal nature of their loved one’s illness from the health professionals several times. Family members in my study also relied on candid

conversations with health professionals, however, came to the conclusion themselves through strong sensory and temporal mechanisms as well as compiling health information to convey that their loved one was never going to recover or be the same ever again. Most all of the participants in this study were surrogate decision makers, therefore, the pressure to manage their loved one's health decisions may have been a catalyst in the process of death imminence awareness.

The theme of “standing with” (p. 211) the ill family member in Meeker's (2004) study, described family as the primary source of information about their loved one's health wishes. Family members in my study were also the primary source of information about their ill family member, especially in cases where the patient was too ill or unable to speak. Standing with the patient meant voicing preferences about end-of-life preferences just as the family members did in my study.

Tilden, Tolle, Garland, and Nelson's (1995) theme of “reasoning about the decision” (p. 635) to withdraw life support by family members, was due to their knowing that their loved one would not want life prolonged by machines. In my study, family members couldn't envision their loved one living in the condition, described as *Cannot See Them Living Like That*, therefore, moved to let go of their loved one from this world, but before doing so, needed to tell them that they would be okay and that they would be okay, too, giving them permission to go (die).

Time to Let Go

The concept of “letting go” tends to mean having to withdraw life support in the context of adult critical care literature. Since 86% of this sample population had to withdraw life support, it's reasonable to believe that their idea of letting go supported literature on the topic. My study is unique, since no other literature on the topic included the permission for the patient to go (die). Family members in this study gave themselves and the patient permission to let go (die). Letting

go in this study entailed the physical aspect of a person's being, but not their spiritual being. Family members in my study would let go of their loved one's physical body, but still sensed a presence and connection with their deceased loved one. This study offers both spiritual and temporal elements of letting go that was not described in literature pertaining to this concept.

Limerick (2007) described how surrogates make the decision to withhold or withdraw life support and then communicated these wishes as well as said their goodbyes to the patient. In my study, family members iteratively moved through the process of death imminence awareness until they came to a point of letting go of their loved one and this happened once they gave themselves and their loved one the permission. Swigart, Lidz, Butterworth, and Arnold (1996) discovered in the cognitive and emotional domain of reframing the critical illness, families understand that death is imminent once all hope is lost, due to a deterioration of the patient's health that could not be halted. Tilden, Tolle, Garland, and Nelson (1995) described something similar; families became more imminently aware that death is expected, once all hope is gone. Hope may be a way that family members cope with the devastation and disruption in the family system, however, at the same time hope appeared to be a deterrent in understanding that death was imminent. Parse (1999) posits that a hope-no hope worth is always present. Typically, hope implies moving forward, living in the present, and/or taking pleasure in what time is left to live with loved ones (Johnson, 2007; Parse, 1999).

There were several similarities and differences between this study and Lowey's (2008) concept analysis of letting go by the family caregiver in the context of end-of-life care. The definition of letting go in the concept analysis involved clinicians caring for families and patients with terminal illness to mean that a lack of acceptance that death was foreseeable. My study

extended this concept analysis to include the family member's perspective and meaning of letting go.

One of the antecedents of letting go in Lowey's (2008) research was that nothing else could be done to save their loved one's life and that everything possible had already been done. My study reflected something similar. A *Turning Point in the Patient's Condition* preceded a *Time to Let Go*, congruent with Lowey's (2008) concept analysis. Another antecedent that was unveiled in Lowey's (2008) concept analysis was that life for the family member would never be the same as it was before. In my study, family members realized that the person was someone they no longer knew and that the patient's life would never be the same as it was before, thus, the focus of my study being on the patient and not the family member prior to letting go. My study extended the concept of letting go, since family members in my study granted permission for their loved one to go, after telling their loved one that everyone would be okay. Permission to go (die) was not an attribute of letting go in the concept analysis by Lowey (2008) as it was discovered in this grounded theory study (Appendix H).

Several of the attributes of letting go in the concept analysis follow this middle range theory. The attributes of letting go described by Lowey (2008), included: (a) crucial turning points, (b) all hope for recovery was lost and everything had been done to save the patient, (c) acknowledgment of loss (emotional and physical) with death, and (d) the decision not to prolong or impede an inevitable death. My middle-range theory found that *Turning Points in the Patient's Condition* preceded a *Time to Let Go*, similar to items (a), (b), and (d) above.

Summary of Integration with the Literature

By returning to the literature, I realized that my grounded study was describing a process completely different than the surrogate decision making studies yet contained many similar

themes. The surrogate decision making processes contained similar themes to this study, but this would make sense since awareness precedes decision making. My study assessed the phases that family members go through in gaining death imminence awareness. The largest contributions of this grounded study are the following key categories: *Patient's Near Death Awareness*, *Dying Right in Front of Me*, and *Time to Let Go*. This study, like others, found the process to be non-linear in nature with iterative movement between phases (Hayes, 2003; Limerick, 2007). This study contained similar themes as studies concerning the process of surrogate-decision making. Death imminence awareness is likely a part of surrogate decision-making. Contrary to popular belief, family members may be managing end-of-life health decisions for their loved one's before death imminence awareness is fully present or with very little health education. The results of this study stands out among surrogate decision making studies related to the fact that nearing death awareness and strong sensory and temporal cues are initially very important early phases in the process of death imminence awareness. Family members in this study refused to let go until they were certain that all hope was gone and nothing more could be done to save their loved one's life, which gave them permission to let go. One participant mentioned that her father was unable to die, because she believed that the dying can sense when the living are trying to keep them alive.

Refinement of Conceptual Framework

The middle range theory on the process of death imminence awareness by family members of patients in adult critical care was more fully described than the originally proposed conceptual framework used to guide this research study. The originally proposed framework was broad, abstract, and unrefined as compared to the middle range theory grounded in the data.

There were numerous similarities and differences between the conceptual framework and study results.

The concept of family member active presence was too logical. The vast majority of family members in this study were not restricted from spending time with their loved one. The original conceptual framework assumed family member active presence as part of the process in gaining death imminence awareness. The concept of knowing the patient as a family member in the conceptual framework evolved into knowing the patient as a person to no longer the person I once knew, due to data findings. Family members knew the patient as both a family member and person, but also knew that the dying person was no longer someone they once knew, raising their death imminence awareness.

The concept of death awareness evolved to contain both concepts on how death awareness is gained, but also included surrogate decision making processes. This isn't too surprising, understanding that the majority of family members in adult critical care are surrogate decision makers, especially in this study. Some level of death imminence awareness is required to manage surrogate health decisions. Originally, this was proposed as family member end-of-life knowing. After analysis and evaluation of the core categories of this middle range theory, the process that was discovered is family members' death imminence awareness to mean something more specific than their end-of-life knowing.

Integration with Philosophical Perspective

My interactive-integrative philosophical perspective drove the interest and inquiry for this study. This study described the reciprocal nature between the patient and their family as well as the patient and family and the adult critical care environment. Death imminence awareness is a higher level of consciousness that evolves through these various reciprocal interactions.

Numerous antecedents described how family members gained death imminence awareness. The process of death imminence awareness by family members of adult critical care patients is not a linear process. The participant perspectives and stories were unique. These perspectives formed the core categories and relationships between the core categories that were linked using Glaserian approach grounded theory to generate a human health experience theory in the context of adult critical care. Glaserian methodology follows the tenets of this philosophical perspective, since this type of grounded theory approach embraced more objectivity as compared to other types of grounded theory. This study supported a holistic nursing approach in the care of patients and their families at end-of-life.

Study Strengths

This study had several strengths. First, this study was from the perspective of family members of patients in adult critical care and not clinicians. Few studies have attempted to establish death imminence awareness in family members of dying patients rather than patients. Second, the investigator has numerous years of experience working with family members of patients in adult critical. The critical care area is a highly technological and complex area that requires analytic skills. Analytical skills are imperative to grounded theory methodology. Third, this study incorporated secondary sources of data to support the emerging theory besides participant interviews. Fourth, this study had three sources of recruitment to obtain participants. Fifth, this study had a large enough sample to obtain theoretical saturation without any difficulties. Sixth, this study utilized a verbal informed consent allowing for interviews to commence immediately. Seventh, the investigator maintained theoretical sensitivity not to overlook subtleties in the data. *Patient's Near Death Awareness* emerged early in the constant comparative method and could have been overlooked if it weren't for noticing it resurface

several more times in my data. Eighth, the investigator was keenly attentive to changes needed during the study as they arose, such as the potential for a sampling bias by interviewing a health professional and related family member of the same deceased patient.

Study Limitations

This study had several limitations. First, the investigator did not have a demographic question concerning whether or not the decedent had an affirmative advance directive. Second, most of the participants were Caucasian, female, and surrogate decision makers. A more diversified sample population would enhance the transferability of the findings as well as provide additional information on death and dying practices, rituals, and traditions in specific ethnicities and cultures. Third, the study was conducted retrospectively to spare those actively grieving the potential for psychological damage. Death imminence awareness might yield richer findings if they were conducted at the time of the event. Perhaps this could be done from the perspective of a nurse at the time of dying. Fourth, the context of adult critical care is somewhat narrow. Future studies may want to explore death imminence awareness across various contexts or in broader perspective. Death imminence awareness may vary depending upon expected verses unexpected health events. More unexpected deaths occurred in the context of adult critical care. Fourth, this study was unable to report the percentage of patients admitted into the adult critical care that expired due a faulty hospital database. Ten to 29% of adults die in adult critical care (Society of Critical Care Medicine, 2012). A comparison between the percentage of patients admitted into the adult critical care in this study and percentage of adults that die in the adult critical care would have been an interesting finding to compare. Unfortunately, the investigator discovered interviewing the participants that several of the deaths were across one of the three

hospitals within one hospital system; therefore, it would have been too difficult to obtain an accurate statistic for comparison.

Unexpected Findings

There were several surprises about the results of this study. First, the investigator did not expect to discover a near death awareness, since 78.6% of the deaths in this study were unexpected. Critical illness or injury is usually sudden or abrupt in nature. Patients in the critical care are typically too ill to speak or unable to speak due to an advanced airway being present. Yet, time remained for family members to gain death imminence awareness.

Second, advanced technologies in the adult critical care do not seem to mean very much for watching family members. Family members were unable to interpret or pay much attention to the technologies yet were irritated by them at the actual time of death. Family members were also unappreciative of technology being turned off upon the death of their loved one with them still being present in the patient's room.

Third, family members were dissatisfied in their interactions with the physicians. Family members viewed physicians as the authority of health information about the patient, despite the increasing presence of primary care practitioners in adult critical care practicing today (Appendix P). Family members desire honest and straightforward communication. They wanted to be told when their loved one was dying. Family members did not appreciate being rushed in conversations or lack of face-to-face contact with physicians. Family members should be educated on the on the role and expertise available through other primary care practitioners, such as Doctors of Nursing Practice, now entering the acute care practice setting. Critical care nurses at the bedside influence the process of *Death Imminence Awareness* by allowing family members

proximity to the entire health team and their loved one as well as facilitate honest communications among all team members.

Fourth, health illiteracy of family members was found in this study. Efforts ought to be placed in providing better health education to both patients and their families.

Fifth, after over twenty years of research supporting family presence, it was surprising to hear that just a few family members were still not being allowed to visit their loved one without some restriction. Most of the family members in this study were able to visit without any restriction; however, there were just a few that were restricted.

Sixth, every person grieves differently and at different paces. One family member lost his loved one almost five years ago and spoke about the death as though it had happened yesterday.

Seventh, elements of the final theme surprised me because it addressed how family members never completely let go of their dying family member. They let go of them physically after telling them that they will be okay and the dying person it's okay to die, yet hold on to this individual in non-physical ways.

Eighth, it was surprising to learn that family members are quite temporally sensitive. Health professionals should know that family members will remember time elements in the delivery of end-of-life care. Nurses can facilitate death awareness by communicating the number of days the patient has been in the critical care unit or had been on mechanical ventilation, if significant. Also, nurses should educate family members that dying persons breathing patterns change during active dying. Family members in this study could recall the seconds or minutes before their final breathe. Family members may also remember how many hours they waited to hear from a physician or other primary care practitioner concerning their dying family member's

declining health status or diagnostic medical test result. This information could be assessed on hospital follow-up satisfaction surveys.

Implications for Nursing Education

This study has several implications for nursing education. First, this study generated some theoretical ideas that can inform practice in terms of how to interact with family members and facilitate their knowledge about a dying patient. Also, the findings need continued critical thinking by students and practicing nurses. Theories can inform nursing practice to provide quality end-of-life care. Second, this study conveys the importance in care of the entire family and not just the patient. Family members are just as vulnerable as the critically ill. Third, death in the context of adult critical care looks much different than death in any other area of the hospital. Undergraduate nursing students don't always experience end-of-life until their critical care rotation. Students at this level respond to the adult critical care environment much like the family members in this study. Students require death imminence preparation for what they might see, hear, and know about end-of-life in this context. Higher level nursing education may want to consider the list of death and dying media as an instructional strategy and integration of the arts and humanities to teach about death and dying with lower level students (Appendix I).

Implications for Nursing Practice

The process of death imminence awareness by family members of adult critical care patients described a theory to guide nursing practice. The family members in this study were asked how nurses could have better supported them through their experience with a loved one dying in the adult critical care. Family members offered specific recommendations for nurses (Table 6). A nursing practice concern exists related to family member interactions with other

health professionals based upon statements from the participants in this study (Appendix N). A recommendation about this issue is made in the implications for research section of this paper.

The early confirmation of an advance directive and code status is of utmost importance for practicing nurses. A code status is a term used by health professionals to describe what treatments or procedures can be implemented should a patient's heart or breathing cease. Family members often confuse living wills for advance directives, yet living wills are not recognized in every state and are not legally binding. Many family members believe that a will, in general, is a healthcare will. There is durable power of attorney for health care and a durable power of attorney of finances; therefore, family members need to be educated on all of these documents, since my experiential knowledge supports this confusion among family members. Nurses should ask family members to bring in their documentation upon admission. Nurses in the adult critical care ought to ensure that conversations about code status are undertaken before a patient's condition turns for the worse. Over 75% of adults in America do not have an advance directive (Byock, 2012). An advance directive is a legal document that is recognized in every state concerning health preferences in the case of serious illness when persons are unable to make decisions for themselves. Every living person should have an advance directive and this completed copy must be given to their primary care practitioner. A copy of the advance directive should be given to hospital staff upon admission. There are numerous online resources that offer information on establishing an advance directive, such as the *My Five Wishes*.

The study findings address a need of the dying, which is permission for their death. Critical care nurses ought to convey this important need of the dying with family members. Nurses are in a pivotal position to educate and facilitate communications on dying as well as provide a comfortable, dignified, and peaceful death for individuals and their families.

Implications for Nursing Research

The theory of death imminence awareness by family members of patients in adult critical care has several implications for nursing research. First, the theory itself identified potential mediators and moderators in the process that could be tested. Second, research pertaining to *Death Imminence Awareness* should be explored across various contexts to determine whether or not death imminence awareness is similar or different. Third, research may want to assess the competency of family members as surrogate decision makers. This study cast additional light on family member vulnerability as surrogate decision makers based upon the lack of health education combined with family member reactions (emotional, behavioral, and physical) to having a dying loved one. A shift from *patient* incapacity or incompetence decision making to *surrogate decision-maker* incapacity or incompetence may need to be explored. Fourth, additional research may need to focus on the effect of family discord on death imminence awareness. Family members of this study confirmed family discord to be a hindrance on their understanding the seriousness of the situation. Fifth, the extent of death imminence awareness should be studied in the future in relation to surrogate decision-making. Sixth, future research should address recommendations for *all* of the health team members, based upon the statements made by these participants concerning their interactions with other health professionals besides nurses. Seventh, future research may investigate the effect of the adult critical care physical environment on family member's death imminence awareness or the lack thereof. Eighth, due to lack of a diverse sample population in this study, a future research focus may be on the death and dying practices, traditions, and rituals of specific ethnicities and cultures as well as their death imminence awareness processes.

Conclusion

This chapter discussed the findings of this study in relation to extant literature and original conceptualizations on the topic. The middle range theory on *The Process of Death Imminence Awareness by Family Members in Adult Critical Care* offers new nursing knowledge and implications for nursing practice, education, and additional research. Death imminence awareness was defined and related to extant literature to determine areas of refute, support, and extension on the topic. Nursing care that is sensitive to quality and cost at the end-of-life in the context of adult critical care can be improved through studies such as this one so that life is not being impeded or prolonged in futile cases, despite life quality.

APPENDIX A:

THE UNIVERSITY OF ARIZONA HSPP CORRESPONDENCE FORM

Human Subjects
Protection Program

1618 E. Helen St.
P.O. Box 245137
Tucson, AZ 85724-5137
Tel: (520) 626-6721
<http://orcr.arizona.edu/hspp>

HSPP Correspondence Form

Investigator: Nancy Baumhover, Doctoral Candidate

Department: Nursing

Advisor: Pamela Reed, PhD

Project No./Title: 13-0354 The Process of Family Member Knowing that End-of-Life is Imminent in Adult Critical Care

Expiration Date: N/A

IRB Committee Information

Administrative Action

FWA Number: FWA00004218

Administrative Review – New Project

Documents Reviewed Concurrently

F200 (signed 2013-04-01; revised 2013-06-06)

Consenting Instruments:

Oral (version 2013-05-31)

F107 (version 2013-05-10)

Site Authorizations:

Scottsdale Healthcare

Recruitment Materials:

Script

Data Collection Instruments:

Interview

Questionnaire

Participant Materials:

Mental Health

Other (define):

CV Baumhover

Determination

Approved as submitted effective as of the signature date below

Regulatory Determination(s)

Exempt Approval 45 CFR 46.101(b)(2): Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior.

Reminders: No changes to a project may be made prior to IRB approval except to eliminate apparent immediate hazard to subjects.

Arizona's First University – Since 1885

T106: HSPP Correspondence Form
Form version: 02-11-2013

Nancy Baumhover, Doctoral Candidate

13-0354

Page 2

Digitally signed by
Thomas Park
DN: cn=Thomas Park,
o=University of Arizona
IRB, ou=Co-Chair, IRB2,
email=tpark@email.arizo
na.edu, c=US
Date: 2013.06.11
15:42:46 -07'00'

Thomas K. Park, PhD
Co-Chair, University of Arizona IRB

Date

TKP: cb

cc: Scientific/Scholarly Reviewer

-
- No changes to a project may be made prior to IRB approval except to eliminate apparent immediate hazard to subjects.

APPENDIX B:
SCOTTSDALE HEALTHCARE RESEARCH INSTITUTE INSTITUTIONAL REVIEW
BOARD APPROVAL

June 27, 2013

Nancy Baumhover, PhD
1340 E Harrison Street
Gilbert, AZ 85295

RE: **SHC IRB #2013-030**: Your application dated 6/13/2013 regarding The Process of Family Member Knowing that End-of-Life is Imminent in Adult Critical Care (None)

Dear Dr. Baumhover:

I have reviewed your request for expedited approval of the new study listed above. Your study is eligible for expedited review under FDA and DHHS (OHRP) Category 7. Research on Individual or group characteristics or behavior designation.

This is to confirm that as of 6/20/2013 I have approved your application. The protocol is approved through version dated 3/28/2013. You must obtain informed consent from all subjects; however, signed written consent is not required. Verbal consent form version 3/28/2013 has been approved at this time.

The following documents were taken into consideration during the review of this study:

Initial expedited review-Category 7
Expedited Application signed 5/22/2013
Waiver of Authorization of HIPAA- 5/13/2013
Fee Waiver signed 5/13/2013
Protocol 3/28/2013-includes appendices- Recruitment Script; Verbal Informed Consent; Participant Demographic Questionnaire; Semi-Structured Interview Guide; Mental Health Referral Services

You are granted permission to conduct your study as described in your application effective immediately. The study is subject to continuing review before the expiration date of 6/19/2014, unless closed before that date.

Please note that any changes to the study as approved must be promptly reported and approved. Some changes may be approved by expedited review; others require full board review. Contact Kituria V. Gaines (480-323-3071; fax 480-323-3208; email: Kgaines@SHC.org) if you have any questions or require further information.

Sincerely,

A handwritten signature in black ink that reads 'Robert A. Marlow MD'.

Robert Marlow, MD-IRB Chair

SHC IRB 2013-030 Initial Review-Approved

PRINCIPAL INVESTIGATOR RESPONSIBILITIES

As Principal Investigator for a study involving human participants, you assume certain responsibilities. These include; but are not limited to, reporting adverse events, requesting renewal of approval in a timely manner, and notifying the IRB of modifications to the protocol.

Below is a list of your responsibilities related to your human subjects research project:

Conduct the study in accordance with the relevant, current protocol and only make changes in the protocol after notifying the IRB, except when necessary to protect the safety, rights or welfare of subjects.

Record and track number of subjects accrued as well as information regarding study drop-outs or withdrawals. You will need to report this and other information in a Periodic Progress Report to the IRB at time intervals established by the IRB. You are responsible for tracking those submission deadlines.

Provide brief updates on the changing scientific literature as that literature pertains to the efficacy and safety of the specific procedure or intervention under study.

Report any complaints from subjects as well as any and all serious or unexpected adverse events related to this study to the IRB.

Maintain and use copies of the currently approved consent document related to this project (if applicable.)

Maintain a file of the consent documents bearing the signature of the subjects enrolled in this study, and include a copy of the signed consent document in the patient's Scottsdale Healthcare medical record (if applicable.)

APPENDIX C:
RECRUITMENT SCRIPT FOR STUDY

This recruitment script is to be read to potential participants who meet the inclusion criteria and may be interested in participating in this study by the hospital resource person or principal investigator.

Title of Project: The Process of Family Member Knowing the End-of-Life is Imminent in Adult Critical Care

“You are being invited to voluntarily participate in the above-titled research study. The purpose of this study is to better understand how family members come to know that a hospitalized family member is nearing the end-of-life in the adult critical care.

If you agree to participate, your participation will involve one in-person or by telephone audio-taped interview lasting approximately one hour in length. Participants may desire more or less time, dependent upon your needs and desire to share your story of events. In-person interviews will be at a conducted in a private location of your choosing or you may choose to be interviewed by telephone rather than in-person, if this is more convenient. A follow-up interview may be necessary to clarify any misconceptions, but will not exceed one hour in time.

Your anonymity and confidentiality will be maintained at all times. Only the principal investigator and hospital resource person will have access to your name. You may choose not to answer some or all of the questions. Your name and person information will not appear or be linked to the audio-tape or any other documents. Please know that you may withdraw from this study at any time with repercussion. In order to maintain your confidentiality, your name will not be revealed in any reports that result from this project.

There are no direct benefits from your participation in this study. However, there is some relief and psychological benefit in sharing your story about your loved one’s death. There is no cost to you, except for your time. There are no known risks from your participation. However, due to the emotional nature of this study, information regarding mental health facilities available in your community will be provided to you if needed, at the time of interview.

If you are interested in participating in this study, please contact the principal investigator, Nancy Baumhover at 480-510-8515, or you may give permission to contact the principal investigator? If you have any other questions about participation in this study, please contact the principal investigator.

Thank you for your interest in this study.”

APPENDIX D:
VERBAL INFORMED CONSENT

Study Title

Family Member Knowing that End-of-life is Imminent in Adult Critical Care

Principal Investigator

Nancy Baumhover, MSN, RN, CCRN, CNE

Doctoral Candidate at The University of Arizona

The purpose of this study is to describe how family members come to know that a hospitalized family member is nearing the end-of-life in the adult critical care.

Approximately, 20 to 30 participants will be enrolled in this study.

You will first be asked to complete a questionnaire about basic descriptive information, such as your age and relationship to the patient. You will then be asked to participate in an interview with the principal investigator about your experience with a dying family member in adult critical care. A sample interview question is: How did you first come to know or realize that your loved one's life was approaching the end? The interview will be conducted so that it is convenient for you. This may be by phone, your home, or preferred meeting place and it will be audio-taped. The interview will take approximately 1 to 3 hours of your total time, including a second interview if needed to follow up on any questions.

Every effort will be taken to keep your name anonymous and keep your study-related information confidential.

Your participation is completely voluntary. You may refuse to participate in this study at any time. If you decide to take part in the study, you may leave the study at any time without any recourse or penalty.

There is a small risk of psychological distress due to the emotional nature of the topic. If you become too exhausted, upset, or find the interview questions disturbing, you can stop the interview. You can continue the interview after a short break, at another time or you may withdraw from the study immediately. You will be referred to grief counseling services. In the event of a research-related injury, you may contact the principal investigator, Nancy Baumhover. The principal investigator is required by law to report any signs or reports of abuse. Any signs or reports of abuse will be reported to the appropriate law enforcement agency.

There are no direct benefits to you. However, you may gain some satisfaction in knowing that by participating in this study, you have contributed to knowledge-concerning how families deal with a family member in critical care at end of life.

There is a 1 to 3 hour time commitment to participate in this study. Yet, there are no costs or payments for participating in this study.

For questions, concerns, or complaints about the study you may contact the principal investigator, **Nancy Baumhover at 480-510-8515.**

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the **Human Subjects Protection Program at 520-626-6721 or online at <http://orcr.arizona.edu/hspp>**.

An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

You are aware that you are being asked to participate in a research study. You have had the opportunity to ask questions and have had them answered to your satisfaction. You voluntarily agree to participate in this study and indicate this agreement by participating in the interview. You will be U.S. mailed a copy of this informed consent.

Thank you for your participation in this study.

Nancy Baumhover

APPENDIX E:
MENTAL HEALTH SERVICES IN PHOENIX, ARIZONA METROPOLITAN AREA

Mental Health Services in Phoenix, Arizona Metropolitan Area

There are numerous mental health services. Many mental health issues can be addressed by trained counselor and/or therapists. Call to learn the facility location and hours of operation. For an emergency, contact a facility that remains open 24 hours per day. Facilities may employ psychologists and/or psychiatrists. Psychiatrists can prescribe medications whereas psychologists conduct behavioral psychotherapy for various behavioral and mental health issues.

Terms that you should become familiar with include:

Psychiatrist - A type of medical doctor who specializes in the care of mental illnesses, such as schizophrenia; Psychiatrists have the ability to write prescriptions for medication unlike other types of mental healthcare providers.

Psychologist - Scientist that studies how the brain works and what problems can occur with thoughts and emotions; Some psychologists offer therapy and other services to help treat mental illnesses like depression.

Counselor - Mental health practitioner who uses talk therapy or conversations to help patients develop strategies to change behaviors and understand their thoughts and feelings

Inpatient - Mental health services that involve patients staying over night at a facility away from their homes; Psychiatric hospitals and rehabilitation facilities are common providers of inpatient care.

Outpatient - Mental health services where patients attend appointments for treatment with practitioners and then return to their own homes; Mental health clinics and private practices are common providers of outpatient care.

St. Luke's Behavioral Health Center-Central, South, or downtown valley area

1800 E. Van Buren Street

Phoenix, AZ 85006

602-251-8535

Banner Behavioral Health Hospital-East and north valley area

7575 E. Erll Drive

Scottsdale, AZ 85251

602-254-4357

Aurora Behavior Health System-west valley area

6015 W. Peoria Ave

Glendale, AZ 85302

623-344-4400

Magellan Health Services-west valley area

11361 N. 99Ave

Peoria, AZ 85345

623-523-6600

Retrieved from www.yellowpages.com

APPENDIX F:
PARTICIPANT DEMOGRAPHIC QUESTIONNAIRE

Participant Demographic Questionnaire

Please answer the following questions based on your situation at the time of your loved one's passing.

1. Which best describes your relationship to the deceased.

- ☐ Non-relative or friend
- ☐ Spouse or significant other
- ☐ Child or step-child
- ☐ Sibling
- ☐ Parent
- ☐ Grandparent
- ☐ Other relative (ex: aunt, uncle, or cousin)

2. Gender (mark one)

- ☐ Female
- ☐ Male

3. What is your age in years_____

4. Which best describes your family situation-spouse or partner? With or without children?

- ☐ Single (without children)
- ☐ Single (with children)
- ☐ Married/Remarried (without children)
- ☐ Married/Remarried (with children)
- ☐ Divorced or Widowed (without children)
- ☐ Divorced or Widowed (with children)

5. Which best describes your employment status.

- ☐ Unemployed
- ☐ Employed (part-time)
- ☐ Employed (full-time)

6. Are you employed in healthcare?

- ☐ Yes
- ☐ No

If yes, what type of employment as a health professional? (Physician, nurse, respiratory therapist, registered dietician, social work, etc.)

7. Which best describes your ethnicity?

- ☐ Arabic
- ☐ Asian
- ☐ African American
- ☐ Caucasian
- ☐ Hispanic/Latino
- ☐ Native American

8. Which best describes your highest level of education.

- ☐ Grade School or Junior High
☐ High School
☐ Community College or college or university coursework or degree
☐ College/university graduate degree

9. Please describe your religious affiliation_____.

a) Did you find that your religious or spiritual views were important in any way during your family member's illness?

10. What was the age of your loved one upon their death?**11. Were you present at the time of your loved one's death? (mark one)**

- ☐ Yes
☐ No

12. Please indicate the approximate length in time your loved one was a patient in the adult critical care area prior to their death in either days or weeks.

- ☐ days
☐ weeks

13. Please describe the nature of the patient's critical illness or injury. What caused the patient to be admitted to the adult critical care unit?**14. Did you make surrogate health decisions for your loved one? If so, please describe your role in the health decisions that were made for your loved one.****15. Have you had a previous experience with a death of a loved one, friend, or relative in the adult critical care before this loss? (mark one) If so, did it have any influence on this experience? Please explain.**

- ☐ Yes
☐ No

**Participants will be mailed a copy of the informed consent. This page will be kept separate from other data and removed and shredded upon study completion.*

 Participant Name

 Home address

 City, State, Zip code

 Phone number, including area code

 Email address

Check if in-person or phone interview:

*In-person interview*_____

*Phone interview*_____

Length of interview_____(minutes)

APPENDIX G:
SEMI-STRUCTURED INTERVIEW GUIDE

Semi-Structured Interview Guide

1. Please tell me about your loved one's illness.
2. How did you first come to know or realize that your loved one's life was approaching the end?
3. What events or situations contributed to your knowing that your loved one's life was near its end? (Prompts might include what helped or hindered their knowing.)
4. What were your experiences regarding any health decisions that you had to make? (Prompts might include what were their sources for information and what they found credible or trustworthy and/or what factors they considered when deciding who or what to listen to, did their knowing about the imminence of death play a role in this?).
5. What would you like for nurses to know that would have supported you best through the experience?

APPENDIX H:
ADDITIONAL STUDY FINDINGS

Patient's Near Death Awareness

(Patient) said that everything is set and in place, ready for her death.

He obviously knew this was something beyond what I thought. He sort of knew.

I remember saying something to him, some tender thing and um.....he just kinda shook his head and walked away. Other times, I'd catch him staring at me, you know these are really personal moments? I'd turn and look at him and say "What?" He would just shake his head and look away again. So, I think he knew.

Going Someplace Else

*[As each descending peak on the LCD took you a little farther away from me
Away from me]*

[I have no idea how quickly your soul left]

Graphic Physical Changes

I didn't recognize my mom. She looked like she aged so quickly. I knew the minute that I laid my eyes upon her that she wasn't going to make it.

He didn't look like himself.

I knew the minute that I saw her that I should have been there sooner. My mom had short term memory loss, she was losing her hair, and she had a rash. She couldn't keep anything down, she was throwing up.

Seeing her it became much more apparent that she wasn't doing well and wasn't going to make it

I could tell it was bleak from the moment I walked in the room.

She spent five weeks in critical care and couldn't get rid of the tube (endotracheal tube) to help her breathe.

She wasn't breathing right. She couldn't breathe and was turning blue.

She was weak and motionless. Her hands were puffy.

She was too weak to write.

I was very upset...I....I....I had a little breakdown. It was almost like shock...all those tubes in his throat.....and nose...and all those IVs hooked up. Whenever I did walk in and gasp or

whatever I did....there was a nurse in the ICU, it was a male nurse and he came running right over. He was great!

He was incoherent, extremely lethargic, and not speaking.

After 11:00 pm that night, she never spoke again.

He was not waking up and not responding. He couldn't open his eyes.

He was moving a lot slower and having a harder time getting to the bathroom.

His skin was turning yellow and he was losing weight.

She started to swell up. They (health professionals) couldn't figure out why she was bloating up.

I could tell the minute that I saw her, that she probably wasn't going to live through that. I couldn't even imagine her coming out of what I saw. The only thing that I cannot get out of my mind is the condition her body was in. She was jerking and jerking and jerking. There was absolutely no response and she just kept jerking. She lived like that for 11 days.

They immediately put him on a ventilator. His heart never quit, his heart was still beating under its own power. He did not have, I don't think, electro-stimulation to his chest. He had an EKG monitor on, but he didn't have anything to make his heartbeat. It was just his breathing. The machine was breathing for him.

His head was all big.

She got a nose bleed and it just kept bleeding and bleeding and wouldn't stop (on the drive to the hospital emergency room).

["Love is watching someone die"/So who's going to watch you die? (repeat chorus)]

[sleep eventuates to death]

[fat, swollen and sick]

[She is losing hair, cannot sleep, losing weight, coughing up bright red blood, and vomiting]

[her skin becomes yellow, flakey, she's too weak to fight]

[buzzers and alarms ringing]

[body mottles]

[your feet were turning so blue]

[unresponsive, unable to speak]

No Signs of Life

She just laid there with no life present.

The respiratory (the participant meant, mechanical ventilator) had him all pumped up. His brain was literally doing nothing.

And of course, it was like, they were giving a ton of oxygen and pumping him up making him look so good, but to me it was all so very artificial.

My dad did not have pain sensors and did not have certain reflexes that should have been there even in a coma.

[We saw the unchanging straight line on the monitor]

Body Losing Control and Shutting Down

There is just one thing that I will never, never forget. It's not a pleasant topic, but one day, I can remember I went in and she had a really bad bowel movement. I didn't suppose things would work like that. It was the smell of death. It was like dead body smell. I just knew that was just one more sign that she was dead inside. There was no medicine injected that could be that bad. The smell was so horrible. I had never smelled anything like it before. I can remember feeling like I was going to throw up just walking into the room. This is when I knew and told the nurses that she cannot go on any longer like this. I am not going to allow it. I was so angry.

You see the changes in people. He was throwing up on himself and filling his pants. It's like they totally start losing control over their body.

I walked in and picked her up and felt that she was wet. That's never a good sign, because your body relaxes and lets everything out.

They had all this fluid going in, but it was just seeping out of his skin. I remember one time, I tried to fluff his pillows, but pulled my hand out from under him and my hand was just soaked.

[lungs gather the last lungful of air and leave nothing]

Foreknowledge of Impending Death

It was a feeling in me, watching what they were doing that told me she wasn't going to make it.

In my heart, I knew that he was tired of fighting and he wasn't up to this challenge. I think he just kind of gave in.

I just knew he was in very bad shape.

I knew pretty much, that he was dead. I had a sensation that he probably was dead the moment he went limp in my arms but what I didn't know is that they were able to keep him alive, all the way to the hospital in the ambulance.

We had all agreed to disconnect the breathing and whatever happens, happens. It was a horrible thing, because we just knew she wasn't going to live.

He didn't want them (the grandchildren) to see him, because he was getting so bad. I knew the moment he went into the hospital the last time that that was the last time he would be home.

The first time they said they'd say they were going to try to get her off the ventilator, but this time there was absolutely no talk or mention of this happening, so I knew things were bad. I realized what was going to happen. They didn't seem very optimistic

I remember after his stroke in 2003, he could talk his head off. Once, his eyes were closed, it was not looking good. I knew then, I need to do what I need to do, because I didn't want to regret anything.

There really wasn't one minute that we thought she was going to make it.

[I have a question and I want a straight answer. Is my brother dying? I need a straight answer. The physicians ask her, "What do you think? We can say what we think, but what's your gut feeling or reaction?" The family member states, "My gut feeling is that there's not going to be a positive outcome here. My brother is not going to walk out of this hospital. "The physician states, "I think your right (name). I think that he's dying. We also have problems envisioning him walking out of the hospital too, because he has too many problems based on what Dr. (name) is telling me and based upon what we see in the ICU.]

Nothing More Can Be Done to Save Their Life

They were trying everything they could.

The last meeting that we had with the doctors, was that she would have to be moved. They wanted to take her to a place where they take near brain dead patients. We just thought, "WHAT FOR, what for (yelling)?" Then, that's when we said, (Name of patient's husband), you have to let her go and we cannot save her anymore. It would have been miserable for her and the kids. He was in such turmoil. He thought that he could bring her home and he and the kids would take care of her. The kids would have been scared to death to see her like that. Everything was just bizarre with his thinking. Of course, his thinking was bizarre because he was about to be widowed with 11 kids to raise and the youngest was only 9 months old.

We knew that there wasn't anything that could save his life.

The nurses were careful about what they said, but I could tell by their reactions or how they would make a facial expression or their hand gestures, such as there's nothing that we (health professionals) can do.

[I wish I had better news Matthew (husband of patient in The Descendants (2011): George Clooney). You and I agree. Her condition is deteriorating. She has no eye movement, no papillary responses, and no brain stem reflexes whatsoever. We could keep her alive, but her quality of life would be so poor. Basically, the way it is now. She'll never be the way she was Matt. Never. We know that now after 23 days. There's nothing more we can do.] –Also, supports the No Longer the Person I Once Knew theme, too.

[as we tried to revive his silenced heart]

[He had died...in spite of our prayers...in spite of our skills....in spite of our medicine/what more we could have done]

["there's no chance"/the doctor would say/no matter what we could do/we could not make you stay]

Running Out of Time

A few hours later, I went home. I was sitting at the bus stop trying to get home. I got a call telling me that I needed to come back.

The doctor had been in before this and said it was time to call hospice.

They told me that it was time to tell the other family members to come.

[I caught her last heartbeat]

[60-40-30 beats per minute]

[Soon we would be out of time]

[It was your time]

Already Gone

Most of those 12 hours, I remember saying to him, if you want to come back, if you're trying to come back, if you're fighting to come back, anything, any motion, a tear, a quiver, move a finger, anything! I just wanted to know if I was right with stopping when I stopped and not that he was working to get back. I never saw anything, no response.

He never opened his eyes again. To me, it seemed like he was already gone. That's when I called both of his sons. I called Fr. (priest name) and asked him to come quickly to get him baptized. The priest came the next day and was 20 minutes late.

She took it off (oxygen mask) to eat, and I don't know what happened, but she just wasn't... I looked up and she wasn't there anymore.

When she got there, she was pretty much already gone, dead. When I picked her up, she wasn't responding and she was wet. I think she was already gone here at home (crying, shaken voice).

The only thing keeping him alive was those machines. It was obvious when the tube was removed that he couldn't breathe on his own.

I was ready for anything, because they had said to me, all these things can happen and once you decide to take the tube out and shut it off, we can't turn it back on. I remember gripping the arms of the chair thinking this is going to be so horrible, but it wasn't, because he wasn't there, he was never there!

[The first two days he was listening to me. I would say, "(Patient name), if you can hear me, touch my hands." And he would, but now it's not happening like that anymore.]

[Whirling oxygen/And medicine around/Artificially to a body and mind/That didn't want to anymore]

[you were gone]

Not the Same as Before

I can remember when I was little, you know, younger, she was so very active. She was such a strong woman. She was always moving so fast, I used to tell her to slow down. She'd always walk so fast. I used to ask why she was running (laughing), but she was active, so it was difficult to see her this way.

I was told that he (patient) will never be able to open his eyes and speak to me again.

(Patient) was an active person. I knew him well and this did not sit well with him at all.

He couldn't walk anywhere by himself anymore. For the last month, he would only eat about 10% of his food. He just didn't have any appetite, whereas before, he was eating everything in sight.

They told us that she had a massive aneurysm and would never recover. They told me at the hospital that her bleeding in the brain was to such an extent that had she been there when it was happening they still wouldn't have been able to do anything like before. My mom used the treadmill 20-30 minutes a day, every day. She cooked, too.

The doctors told me that what I see in there (in the patient's room) is the way it's going to be. My husband loved life-always had a smile on his face. I told him (friend of the couple) that there was no quality of life left now.

The neuro doctor said she wasn't responding to the cold water placed in her ear test and that she'd never be the same and it would not be possible for her to come back. He said she was brain dead because her eyes didn't move.

[Ascites insulates pain and pallor enwraps what was my life]

[the urine burns]

[It's really hard to watch. He's 6'3, was 253 lbs. and now he's like 150 lbs.]
[you were the strongest man]

Cannot See Them Living Like That

I know that (patient) would have never wanted to be living in that condition. That was just totally not the way she wanted to live. I can remember things she told me back when her dad was sick and what she would want.

Over the course of being married for 18 years, we had endured together the death of his brother and dad and my mother. He'd say, don't let me linger. I would say, I won't. He'd say, don't leave me laying in bed with all sorts of things attached to me.

He told me more than once, he said, "I know you think that I should be happy that I'm still alive (after his stroke), but to me this isn't living."

She didn't want to be on a ventilator in a care center for the rest of her life. I definitely knew that she wanted nothing to do with care centers.

Honoring the Patient's Health Wishes

I knew exactly what he wanted and didn't want, because he told me.

She left everything in order, from years before. We did everything she wanted...to a "T"

She started to do this thing, moving her head to her mouth to out.....out. I couldn't figure it out. I kept asking her is it something you want, something to eat. I couldn't figure it out. Oh, but we (the participant and the patient) had discussed before that this is what our mother did when she wanted the tubes out.

She did have them write a "do not resuscitate" (DNR) order. She told me not to resuscitate her and not to keep her alive on artificial tubes.

[I do not want him to suffer anymore. I am suffering, but he is also. I cannot handle this anymore. I just hope that I make the right choice.]

[I know him, I know what he wants. Let me tell you, I don't want to see him suffering. You know? Now a day, he doesn't want to be bothered. Let me go, he says. He says this a lot. He's dying. I know what he wants, he told me. I know who he is and what he wants]

The nationally known Terri Schiavo case prompted a conversation that allowed one family member to know what to do for his father, because of a conversation between them about the Schiavo case years prior.

The brain wave test was the deciding factor for me, because he showed us what normal brain waves look like and how they would look in a coma. Another thing was what my dad told us he wanted when he heard about that Schiavo case.

Time to Let Go

She had so many tubes and she was so weak. Once we decided to let her go, I saw tears come out of her eyes.

He (physician) told us we had some decisions to make and whether or not we should let her go.

My son came in and said they were just waiting for me. In other words, to tell them when to do it (remove from ventilator). I said, oh this is really hard, he said, "It's time." I said, alright, because it's never going to get any easier.

There's a plan. There's a time. It might not be our time, but it's the right time. Let's let her die.

[Amongst the vending machines and year-old magazines in a place where we only say goodbye]

[I can't leave until I know that (husband) is okay. It's time to go now.]

[I believe that he managed to stay alive until he was sure that my baby boy and I were all right.]

[Stop the test we ordered; as hard as it was for us, we had to set him free]

Permission to Go

I can remember my sister going into his room and telling him that if he wanted to let go that it was okay.

I told him he'd be in a better place, without any hurt or suffering and nothing will hold him back and that he'll be able to go anyplace he'll want to go and that he'd be meeting those who already passed and his mother, whom he never had gotten the chance to meet. I told him its okay, I don't know what I am going to do without you, but I'll be okay until it's my time.

I also talked to her about mom and dad and how they are waiting for her. And, that I would be okay, if she went.

[I had to tell you it's ok to go/Say "hi" to loved ones waiting on the other side/I know some day; you'll be there when I take that ride.]

[I'm letting you go]

Let go, but Not Let Gone

[Look what I found in the driveway! In his hand was a beautiful live butterfly/within 15 minutes or so that our phone rang. / It was my mother calling from the hospital. Dad had died. Dad had visited me just after his death, as the butterfly, whispering that he was fine, and flying high.]

[I am not there, I did not die]

[A part of me will die, the day I'll let you go.] About a sister who will never truly let go her sister that died.

APPENDIX I:
MEDIA AND FILM ON DEATH AND DYING

Media and Film on Death and Dying

1. *About Schmidt* (2002)-wife dies at home suddenly due to brain clot
2. *Afterlife* (1998)-woman dies at scene of car accident and wakes up in the mortuary
3. *Beaches* (1988)-Hillary dies on beach
4. *Big Fish* (2003)-father of tales dies in hospital (not ICU) bed
5. *Brian's Song* (1971)-Brian dies in hospital bed, not ICU
6. *City of Angels* (1998)- A city with immortal angels walking amongst living. An angel falls in love with a heart surgeon who attempts to save a patient, but the patient dies in the operating room on the operating table.
7. *Defending Your Life* (1991)-no deaths in ICU. People who have died show heir worth to a court in the afterlife.
8. *Dying Young* (1991)-dies of leukemia, but doesn't die in the movie
9. *Flatliners* (1990)-medical students conduct near-death experiences, but not in ICU
10. *Ghost* (1990)-Sam Wheat is murdered and becomes a ghost that visits his fiancé.
11. *Harold and Maude* (1971)-Maude dies due to over-does of sleeping pills. Maude is rushed to the hospital. Considered "dark humor" film. Harold dies by driving his car off a seaside cliff, but shows him above the car crash scene looking down calmly over the car crash site.
12. *Jacob's Ladder* (1990)-military movie with soldiers dying in battle in the field.
13. *Love Story* (1970)-Oliver and Jenny marry. Jenny suffers from leukemia. Jenny dies in the hospital bed with Oliver by her side (not in the ICU).
14. *My Life* (1993)-dies at home surrounded by family with hospice nurse present
15. *On Golden Pond* (1981)-classic on aging, and death and dying. Norman and Ethel Thayer --- Norman does not die in the film.
- 16. PBS Frontline: Facing Death Documentary-met specifications, see chapter 4**
17. *Premonition* (2007)-husband killed in a car accident at the scene, but his wife has premonitions about the event before the event
18. *Rabbit Hole* (2010)-4 year-old child dies
- 19. Steel Magnolia's (1989)-met specifications, see chapter 4**
20. *Terms of Endearment* (1983)-Emma visits the doctor for a flu vaccine. The doctor discovers two lumps in Emma's right armpit while administering a flu vaccine. Emma is diagnosed with cancer. Emma dies in hospital bed (not ICU).
21. *The Bucket List* (2007)-death not in ICU
- 22. The Descendants (2011)-met specifications, see chapter 4**
23. *The Five People You Meet in Heaven* (2004)-Eddie, carnival maintenance dies when trying to save a young girl when a ride malfunctions.
24. *The Fountain* (2006)-cast die, but not in the ICU—this movie is a science-fiction
25. *The Lion King* (1994)-animated
26. *The Lovely Bones* (2009)-14 year-old girl is murdered
27. *The Notebook* (2004)-husband and wife die together in hospital or appears to be a long-term care bed.
28. *Tuesdays with Morrie* (1999)-college professor and young man exchange life stories every Tuesday, but professor does not die at the end
29. *TV series: ER-* critical care area, but not ICU-*not the same context*
30. *TV series: Gray's Anatomy---*critical care area, but not ICU-*not the same context*

31. *Up* (2009)-animated
32. *What Dreams May Come* (1998)-family dies in car accident and then father of family dies in motor vehicle accident (MVA) –he dies at scene of accident
33. *Wit* (2001)-woman dying of ovarian cancer—she does not die in ICU
34. *Whose Life Is It Anyway?* (1981)-car accident leaves a man paralyzed who is fighting for his right to die. His wishes are granted. He is hospitalized in preparation for stopping dialysis and other treatments, but is not shown dying or dead at the end of the movie.

APPENDIX J:
LYRICS TO “WHAT SARAH SAID”

Lyrics to “What Sarah Said”

And it came to me then that every plan is a tiny prayer to *father time*

As I stared at my shoes in the ICU that reeked of piss and 409

And I rationed my breaths as I said to myself that I'd already taken too much today

As each descending peak on the LCD took you a little farther away from me

Away from me

*Amongst the vending machines and year-old magazines in a place where we only say
goodbye*

It stung like a violent wind that our memories depend on a faulty camera in our minds

But I knew that you were a truth I would rather lose than to have never lain beside at all

And I looked around at all the eyes on the ground as the TV entertained itself

'Cause there's no comfort in the waiting room

Just nervous pacers bracing for bad news

And then the nurse comes round and everyone will lift their heads

But I'm thinking of what Sarah said that *"Love is watching someone die"*

So who's going to *watch you die?*.. (repeat chorus)

APPENDIX K:

PBS FRONTLINE: FACING DEATH – PHYSICIANS’ STATEMENTS

PBS Frontline: Facing Death – Physicians’ Statements

- There is always something else that can be done to put off the inevitable
- Sometimes doing nothing is a very important consideration
- ***The adult ICU is at the apex of life and death.*** A tremendous amount of technologies that prolong life, but ultimately cannot overcome the patient’s illness in most cases. Their diseases are life-shortening.
- The history of critical care is that patient’s get admitted, respond to the treatment, and get better. Now, Americans are coming to ICUs to die. Modern medicine is now doing what twenty years ago was science fiction.
- Almost every body system can be supported by life saving technology. Patient’s can be kept breathing and their heart beating, the patient’s could stay in a “suspended animated” state virtually forever. Decisions at end-of-life have become much more complicated and most individuals who are admitted to an ICU have never discussed their health preferences with their loved ones who will make their health decisions (surrogates).
- Proxies make life and death decisions for someone else. The decisions are life and death and if the patient is to live, will the patient be in the same condition as before the illness or injury.
- Stopping treatment usually is an acknowledgement that death is near.
- Everyone wants the best possible care and no one wants to die badly or alone
- The uncertainty in surrogate decision making is the most disturbing for family and the availabilities of therapies has given the illusion that we can fix everything, which is not true. This creates a situation where we are choosing life or death and this is not the reason for these advanced technologies.
- The only hope is a “good death” and comfort at the end
- More people die in hospitals than they do at home

APPENDIX L:
SUMMARY OF “STEEL MAGNOLIA’S” FILM (1989)

Summary of “Steel Magnolia’s” Film (1989)

In *Steel Magnolia’s* (1989), actress Julia Roberts plays “Shelby,” a brittle Type I Diabetic that requires hemodialysis early in life following a pregnancy. The story entails her getting married and starting a family, but having a child causes Shelby’s health condition to worsen. Shelby requires the insertion of an arterial-venous fistula and hemodialysis due to kidney failure. Shelby is placed on a kidney transplant list, but her mother is an acceptable donor and offers to donate one of her kidneys to her daughter. Before Shelby receives the transplant, she collapses at home into a coma and never awakes. Shelby is placed in adult critical care where she has a feeding tube and is intubated on mechanical ventilation. Her mother visits her, performs range of motion while she lie in a coma. Actress, Sally Field, who plays Shelby’s mother, brings pictures of Shelby and her young son. This speaks to a supportive nursing action regarded as personification, a widely known concept in critical care, which will be discussed in supportive nursing behaviors and actions section of this paper. Shelby’s mother becomes very upset, because Shelby is unresponsive and cannot open her eyes. The patient’s unresponsiveness and inability to open her eyes supported the *Dying Right in Front of Me* key category.

The mother and family maintain vigilance at the bedside. The mother is self-neglectful, not getting a proper dinner in days and refusing to leave the bedside in the event that Shelby were to awake and the mother not be there. Self-neglect is a common family member reaction, which will be discussed in the family member reactions section of this paper. They show the husband signing paperwork and life support (mechanical ventilation) being turned off and removed, because she never awakes supporting the *Time to Let Go* key category. Shelby’s electrocardiogram slows to a heart rate of 36. The family remains at the patient’s beside until her heart no longer beats. The family watching her heart rate lower supported the *Dying Right in Front of Me* key category.

APPENDIX M:
SUMMARY OF “THE DESCENDANT’S” FILM (2011)

Summary of “The Descendant’s” Film (2011)

The Descendants (2011) is a movie about a husband whose wife is connected to life support (mechanical ventilation) in an adult critical care due to a power boating accident in which she suffered a traumatic brain injury (TBI). In patient’s room there are personal knick knacks, such as a blanket from home, framed pictures, stuffed animal, figurines, and framed school diploma supporting the concept of personification. The pictures are of the patient as a young girl and young woman. The patient is in an unconscious state the entire movie and the decision by the husband to withdraw life-support is looming. The patient had been in the adult critical care for 23 days in a coma with a tracheostomy. Actor George Clooney plays “Matthew” in the movie. He discusses how his past 23 days have been no paradise even though he and his family live in the state of Hawaii, known to be a paradise to many. Life to Matthew became nothing but a paradise with “IV’s, urine bags, and tracheal tubes” surrounding him.

For the first several days, “Matthew” decides she’s not dying, but just not doing well (state of denial-observed by many). Matthew is frequently filmed waiting in the hospital waiting room or at the patient’s bedside. The statement reflecting his disbelief in how critical her situation was, “Elizabeth” (his wife-the patient) is going to make it out. She’ll wake up. Ok. I know it. It’s not her time.” To me, this state of denial was also supported in my interviews with the participants of this study. The physician meets privately with Matthew and tells him,

I wish I had better news Matthew. You and I agree. Her condition is deteriorating. She has no eye movement, no papillary responses, and no brain stem reflexes whatsoever. We could keep her alive, but her quality of life would be so poor. Basically, the way it is now. She’ll never be the way she was Matt. Never. We know that now after 23 days. There’s nothing more we can do.

Matthew and Elizabeth have two daughters: 10 and 17 years-old. The younger daughter mentions how her mother was “sleeping and going to wake up.” Matthew returns to the family waiting room telling family/friends that “he’s still hoping for the best.” Matthew’s oldest daughter who is away at college returns home. Matthew tells her, “It’s time to let her go, because the doctors told me that she’s never going to wake up” and their mother “Would have wanted it this way.” Matthew referred to their mother being “gone and not there” anymore. Matthew invites family and friends to his home for a gathering to explain that everyone should say goodbye, because life support was going to be withdrawn per his wife’s wishes and everyone deserves the opportunity to say goodbye. Matthew shows Elizabeth’s father her advance directive. The father responds by saying, “Elizabeth was always a strong, thoughtful, good girl” and he is not surprised that she had an advance directive. Matt finally decides it’s time to let go. The wife (patient) is withdrawn from the mechanical ventilator and her tracheostomy is removed at the end of the movie. Conversations from this movie film supported all of the key categories in the middle range theory, except *Patient’s Near Death Awareness*.

APPENDIX N:
PARTICIPANTS' HEALTH INFORMATION STATEMENTS

Participants' Health Information Statements

I don't get what's a good oxygen level versus what's a bad oxygen level. Or, like, I don't know what a good heart rate to have when you're in a coma or what a bad heart rate to have is.

No brain waves on the electric machine. (Meaning: electroencephalography (EEG) machine)

I didn't know that the brain gave off waves. I didn't know that existed.

The explanation that I got was that his blood pressure was so low because of his breathing problems that by the time the blood got down to his kidneys, there wasn't enough. I'm not a medical person, so this is how I understood it and this is how it was explained.

One participant thought a "do not resuscitate" (DNR) order meant a "resuscitate" order as follows:

He had a resuscitate order (this patient was resuscitated, yet had a DNR status)

My dad was laying there with a catheter because the waste builds up in his system (urine catheters facilitate the elimination of urine)

I still thought that she could go on her own (after being asked if she thought patient could pass on her own, despite technologies)

Respirator or breathing machine or intubator (to mean mechanical ventilation)

Investigator: *I remember you said at one time he was on 100% oxygen. Tell me what this meant to you?*

Participant: *I remember at one time he was down to 40% and hoped they'd get him off of it. I wanted to be able to talk to him again. (Note: 100% is the highest fraction of inspired oxygen on mechanical ventilation that can be provided. This means that patient was seriously compromised.)*

I don't know, I don't know (laughing). They did one test, where they took the fluid and tested it. Ah, and she was diagnosed with cancer.

He did not have, I don't think, electro-stimulation to his chest. He had an EKG monitor on, but he didn't have anything to make his heart beat. (Meaning; some type of electrical therapy; the three types include-pacing, defibrillation, or synchronized cardioversion. The family member probably meant pacemaking.)

APPENDIX O:
PARTICIPANTS' FAMILY DISCORD STATEMENTS

Participants' Family Discord Statements

My step-mom, who is not legally married to my dad, also hindered my ability to figure it out.

My dad's girlfriend was going crazy. She would not shut up or stop crying and we finally had to ask her to leave the room, because I just wanted to spend time with my dad. My dad's girlfriend kept telling everyone that she was his wife and could the decisions.

I have tried and tried and tried to tell her husband (patient's husband), that she (patient) cannot live like this. It's not a life.

I told him that there was a lot of confusion within my family about whether or not he was a do not resuscitate or resuscitate. I guess that one of my sisters, before she had left, told one of the nurses that he was supposed to be resuscitate, resuscitated...BUT, he was actually a "do not resuscitate." It was written in his directive, so there was confusion and so he was resuscitated this particular night. This would have probably been the night that he passed away, but this happened and he was resuscitated. After he was resuscitated, that's when they rushed him over to the ICU at the hospital

The icing on the cake was my brother. I can remember calling me brother to tell him that our dad passed away and asked him if he wanted to come, he said no because he had said his goodbyes a few days before. This was horrible for me. I just knew at this point, I was going to have to handle everything. I haven't talk to him but once since my dad has passed away."

After his death, I went to stay with family in (state). That was a disaster. Now, I am staying with a friend, because my family was such a nut case. I never expected it. No one could have told me that my family would do the things they did, but they did. They asked me to come live with them after he died. I think they thought that he left me a lot of money. Everyone was seeing dollar signs. I had no idea how much death changes people.

APPENDIX P:
PARTICIPANTS' EMOTIONAL, PHYSICAL AND BEHAVIORAL REACTIONS

Participants' Emotional, Physical and Behavioral Reactions

Two family members described their experience as feeling as though they were on an emotional roller coaster:

I was on such an emotional roller coaster

I really felt like I was on a roller coaster and others needed to help me keep things into perspective

Other descriptive words used by family members to describe their behavioral, emotional, or physical well-being include:

Numb

I had a lot on my shoulders

I felt sort of guilty for how long it took, before I did let them take him off the ventilator.

I was really upset about it and reported this nurse (another nurse being rough with patient).

I was very upset...II...I have a little breakdown

It was a hopeless situation

I was so angry

Exhausted

It would have been nice to talk to her (patient) one last time (crying)

The doctor completely ignored my child who had been living this situation for over a year. This was so upsetting to me. (The child asked the physician a question about the patient)

We got a second opinion. I just wanted to be sure that there wasn't anything else we could do.

I was really tired and had been up there all day. I didn't get any sleep. I don't remember what I heard half of the time.

We just kept hanging on to hope. Hope was all we had.

Two statements indicative of family member self-neglect:

We weren't there to treat ourselves. We just wanted (patient name) to get well.

I didn't want to leave. I didn't want to eat. I wasn't hungry. I didn't care about any of that, I just wanted to sit next to him and spend time with him.

One family member's response to my question about what might have hindered her ability to know how serious matters were was:

Well....(laughing) denial, but nothing that they did.

APPENDIX Q:
PARTICIPANTS' STATEMENTS ABOUT THEIR INTERACTIONS WITH PHYSICIANS

Participants' Statements About Their Interactions With Physicians

I don't ever remember seeing one doctor.

I felt like all we ever got from the doctors were just the facts. I never felt like her doctors were ever really telling us to stop and consider anything. It was more like they just presented the facts and nothing but the facts. I felt like the nurses were more caring than the doctors. The doctors were so busy and have so many patients.

We did some investigating and it almost seems like an extra zero got added on to her prescription or maybe she was just taking too many of those pills. We mentioned what we thought and knew from our own searches about the medicine, but no one seemed too interested in checking on what was going on with her medicine until it was too late.

What hindered (the participant's ability to know that death was imminent) at the same time is that they (physicians) "beat around the bush." They (physicians) would always say that there was always the chance that this could happen or that could happen. I got tired of hearing the rate of success or failure of tests. I know that they cannot always tell you concrete answers, but if they were more sympathetic and could give more concrete answers. I wish that I could have just gotten more "yes or no's." I wanted their professional opinion without the wishy-washiness of it. They won't tell you their professional opinion; they give you the statistics about it, instead. I wished that I could have just signed some waiver to take away any liability on their part. I asked them if they had to make the decision, what they would think, but they never really came right out and said what they would do. They'd say that they can't answer it. I think they say this, so that they don't get sued.

The doctors would just come in and tell me about results, but would never ask me how I was doing or anything. He didn't really care about me as the patient's family. The nurses made me feel like I was human. We aren't sick like the patients, we're just sad. I think that it would have been more helpful if the nurses intervened between us and the doctors to get more clear information.

They (nurses) always said they didn't know or just couldn't tell us with certainty what would happen. I know that cannot disclose the situation, because of the doctors.

I called the doctor to get that information, but he never returned my call due to patient-physician confidentiality. The doctor just wanted to run tests. He ran tests that made no sense, like an agility and strength test (on patient dying from terminal cancer). The biggest thing in the hospital is that they need to change protocol. I feel like when family asks about something and it's not a life or death answer, then a nurse is better to present this information than a doctor. I can understand life/death decisions coming from the doctor, but if it's just a question about something not that important. I don't appreciate doctors who are out playing golf all day long

and show up after eight hours or at the end of the day, when I've been waiting for the answers to my questions. Family should get answers right away, like within an hour. Just like knowing when a procedure is going to happen or not or what the procedure is all about, why can't the nurse tell you information about stuff. Some talk and others don't, but this is just pathetic. This isn't fair. I can remember a time that my son who is 12 y/or was a little upset and asked the doctor a question, he didn't even turn his head and acknowledge my son. The doctor completely ignored my child who had been living this situation for over a year. This was so upsetting to me.

I don't even know if they explained it to him (consent for procedure-patient may have been incompetent to sign due to previous stroke). You see that's the problem, the doctors at (hospital) never availed themselves to me. It was hard for me to say what their thinking was, because I was never able to talk with them.

Sometimes, the doctors just didn't come around very much. I understand that they are busy, but why can't they come around more often. I wish they could have checked on her more often. They just seem all business and have things to do

*I said my husband would kill me; I'm not signing it (consent for surgery). I knew that it meant he'd have a (ostomy) bag. My husband would hate me. And, Doctor (name), like I said he's such a close friend, he looked at me and said, he was going to die if I didn't sign for it. **He said to me if you don't sign it, I'll sign it and you can tell him, it was me.** I did what I had to do...he had all these doctors in there that I trust, fully, so **I went ahead and signed the permission.** When they took him (the patient) out to the operating room and he said to me, **"What have you done?" That was the last thing that he could ever say to me.** I called the nurse who called the doctor, but when the doctor saw him, he didn't know anything about my husband. He never saw his records or anything. In fact, at one point he asked if he had prostate surgery and I said (laughing)...No....No.....he never knew anything about my husband. I just hated to leave him there.*

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