THE EFFECT OF TECHNOLOGY ON THE PSYCHOLOGY OF DEATH AND DYING: AN EMPIRICAL PHENOMENOLOGICAL STUDY

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ABSTRACT

The Effect of Technology on the Psychology of Death and Dying: An Empirical Phenomenological Study

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This study explored the lived experience of death in the hospital intensive care unit (ICU) from the perspective of surviving family members. More specifically, attention was placed on the experience of withdrawing life-support for a loved one. A phenomenological approach was adopted, and a convenience sampling technique was employed with family members in a community in Southern California. Four (4) caregivers of dying patients were interviewed to explore the lived experience of removal of life-support for a loved one. The caregiver reactions were categorized into seven themes that were common to all four participants: (a) overall experience, (b) mental perspective, (c) ambivalence about care, (d) perceptions of technology, (e) the decision, (f) aftermath, and (g) suggestions for others. The themes were discovered through implementation of transcendental phenomenology in which the researcher's past experience was bracketed out from interpretations of the interviews. Thus, the participants' words were taken without preconception to the greatest extent possible. Even though the outcomes were identical—the death of the patient—the circumstances leading up to the decisions were each very different. Each circumstance had bioethical ramifications, including breaches in scope of practice, communication breakdown, and caregiver reactions. The results suggest several areas of improvement including those areas that were suggested by the participants themselves.

The intention of this research is to shed light on this experience for mental healthcare professionals, such as psychologists and social workers who provide care for the families before, during, and/or after the experience of a loved one’s death in the ICU. Moreover, it is hoped that this research will help mental health clinicians to better understand the needs of professional healthcare providers who are exposed to these untenable circumstances on a regular basis.

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I am indebted to the many individuals and families that have shared their lives and deaths with me throughout my career. Their generosity and teaching has inspired this work and will go on to inspire me throughout the rest of my life. In particular, I want to acknowledge the four women who sat with me to share their stories of loss. I am also very grateful to my committee members for their time, patience, and expertise.

Without my wife I would not have finished this project. Without her enthusiasm, curiosity, and ongoing love I would never have been able to maintain momentum. It is to her that I dedicate the lion’s share of acknowledgement for this project.

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[1] The style used throughout this dissertation is in accordance with the *Publication Manual of the American Psychological Association* (6th Edition, 2009), and *Pacifica Graduate Institute's Dissertation Handbook* (2014-2015).

Chapter 1
Introduction

Purpose Statement

This study explored the lived experience of death in the hospital intensive care unit (ICU) from the perspective of surviving family members. More specifically, attention was placed on the experience of withdrawing life-support for a loved one. A phenomenological approach was adopted, and a purposive sampling technique was employed with family members in a community in Southern California. The findings articulated and amplified the memories of these experiences as told by family members to elucidate the relationship that has developed between technology and death. The research was conducted to shed light on family members' experiences in order to help psychotherapists and mental health clinicians more effectively provide psychotherapy. In addition, it is hoped this research will assist healthcare providers such as doctors and nurses to help patients and families during end-of-life-care in the ICU and to find meaning in these experiences for themselves.

Historical Context

At the beginning of the 20th century, people lived and died in a different world than we do today. Unlike today, most people died at home or on the job, rather than in a hospital, and funeral rites and preparations were carried out at home (Ariès, 1981). People died most frequently of some form of infectious disease, such as pneumonia or tuberculosis, or during childbirth (Lerner, 1980; Linder & Grove, 1947). In the early 1900s, embalming was just gaining popularity and cremation was beginning to become more accepted (Ariès, 1974).

Van den Berg (1974) gave an example of a typical death ritual in his book, *Divided Existence and Complex Society: A Historical Approach.* This example dates back to the mid-19th century. At that time, when a family member died, the body would be displayed in the parlor usually up to three days. This allowed family and neighbors to visit and pay their last respects, and it was also an opportunity for them to support each other. Van den Berg's (1974) example involves a young boy who became frightened by the noises coming from the parlor where his grandmother's body was lying after her death. The young boy went to his mother and expressed his fear of the noise. His mother gently took him into the parlor where his grandmother's body lay and they investigated the noise together. As it turned out, the noise was emanating from the fluids dripping from his grandmother's decomposing body. There was an intimate interaction between the boy and his mother as she explained to him the source of the noise and thus enabled a healthy reaction to death for the cultural matrix of their time.

In contrast to death perceived as an intimate and even a community event as depicted above, by the turn of the century a psychological distance from death became more pervasive (Ariès, 1981; Callahan, 1993). Technology played a large part in this gradual distancing (Illich, 1974), which may have its roots as far back as the Renaissance when artists like Leonardo da Vinci studied cadavers to perfect their vision of the human form. Romanyshyn (1989) discussed the view of the corpse that developed during the Renaissance, as this view serves to distance the viewer from the reality of death itself by objectifying the corpse.

> To see the body as a corpse, or perhaps we should say, to transform the body into an object of vision, requires that we first eliminate the foul

> odors, and we have, it seems, succeeded quite well. We have deodorized and sanitized death. (p. 126)

This process of detachment had begun many years prior, possibly due to the findings of Copernicus (Romanyshyn, 1989). As the cosmos began to be seen as machine-like in its functioning, so the human body was also seen as mechanistic. Romanyshyn (1989) further wrote, “The heart is a pump, causing a mechanical rather than organic circulation of the blood, which aptly fits with the mechanically regulated circulation of the earth around the sun” (p. 136).

By the turn of the 20th century, the corpse became a specimen or an objectified other. At this time Freud's investigations into the unconscious psyche led to the analysis and exploration of the unconscious. Freud (1920/1962) took several years to incorporate the anticipation of death into his model of the psyche. Freud was inspired by earlier works, such as those of Spielrein (1912), to understand death as opposed to the pleasure-seeking or the sexual instinct: Eros juxtaposed with Thanatos (Ellenberger, 1970). The uniquely human ability to envision death has had a significant effect on the psyche. Rank (1929) pointed out that Freud himself was in denial of his own death as indicated by his relegating of our relationship to death as a mere instinct (Becker, 1973). Rank (1929) advocated that this uniquely human relationship to death be called what it is: death fear. Notably, Freud opted for physician-assisted suicide in the face of excruciatingly painful and terminal cancer (Gay, 1988).

Becker (1973) and Ariès (1981) have written extensively on the topic of death, and they highlight relatively recent changes in our ever-greater distanced relationship to death. Ariès (1981) wrote:

> In the course of the twentieth century, an absolutely new type of dying has made an appearance in some of the most industrialized, urbanized, and technologically advanced areas of the Western world—and this is probably only the first stage. (p. 560)

Technology has played a larger and larger role in this distancing as more and more people die in the hospital versus at home or at the scene of an accident.

Science and medicine have made miraculous improvements in our quality and length of life since the turn of the 20th century, as the average length of life increased from 49 years in 1900 to 79 years in 2006 (Shrestha, 2006). These changes were most dramatic at the beginning of the 20th century and can be traced to the advent of the germ theory and the use of sterile procedures (Preston & Haines, 1991; Shrestha, 2006).

Innovative technology has necessitated a whole new form of care in the hospital, and it has impacted popular views of health and dying (Illich, 1974). Medical technology and the associated expectation of recovery have resulted in more people dying in the hospital instead of at home (Ariès, 1981). Mellor and Shilling (1993) suggested that the modern experience of death has become sequestered and “privatized” (p. 411). In 1968 a noted physician (Elkinton, 1968) wrote:

> The doctor has always had to make decisions about his patient who is threatened with death. Until recently, such decisions have been less crucial because he has had relatively little power to bring to bear on the issue. Now, for at least some of his patients, new knowledge and its tools—antibiotics, potent drugs, intravenous fluids, resuscitation apparatus,

> artificial and transplanted organs—enter into the decisions that affect the time and nature of the act of dying. (p. 740)

The shift from death at home to death in the hospital began at the turn of the 20th century with the patient in mind, but it has devolved into a matter of convenience for the family (Ariès, 1974). The traditional and accepted form of death in the home has run headlong into our right to pursue longevity through technological means. Nuland (1993) described it this way: “We have created the method of modern dying. Modern dying takes place in the modern hospital, where it can be cleansed of organic blight, and finally packaged for modern burial” (p. *xv*). The modern act of death and dying has been taken over by specialists and removed from the everyday lived experience of the community (Field, 1996).

The notion of death has moved from an accepted social event to a dreaded lonely one (Ariès, 1974) that has come to be viewed as technical failure (Chapple, 2010; Illich, 1974). In contrast to van den Berg's (1974) cited example of a home death, the current state of technology has created a milieu in which resuscitation and rescue are the expected outcomes.

Contemporary Media Depictions

The frequent depiction of death and mourning in modern news media seems to be increasing our fear of death instead of familiarizing viewers with the reality of impending cessation of life (Dubied, Hanitzsch, Ashton, & Feasey, 2014; Gibson, 2007). Modern news media and films have perpetuated this distancing process by attempting to cash-in on the drama that accompanies modern death (Schultz & Huet, 2001; Walter, Littlewood, & Pickering, 1995). “Indeed, what we may be facing, and witnessing, is a widening gap and experiential differential between media/technological death culture and 'real life' contexts and temporalities of death and bereavement," (Gibson, 2007, p. 415). Popular media depictions of the relationship between technology and the human connection in medical care have become common sources of dramatic outlet within our culture. They are often inaccurate (Czarny, Faden, & Sugarman, 2010; Moeller, Moeler, Rahey, & Sadler, 2011) and, thereby, propagate the misconception of medical care, such that in real life resuscitation and rescue are expected (Chapple, 2010). The accuracy of these depictions is questionable, as was shown in a review of television programs depicting the outcomes of CPR in which the survival rate was much higher than that borne out in reality (Diem, Lantos, & Tulsky, 1996). A more recent study found more accurate success rates for CPR but, more importantly, found the outcomes of these "successes" to be misrepresented (Harris & Willoughby, 2009). This study showed that the outcomes of CPR were either a return to health or death, and this failed to depict the patients that live after CPR only to die soon after or those who live on with major physical debilitation. The authors of this study also note that "an elderly patient with metastatic cancer may believe that CPR is as likely to be successful for him or her as it was in a young road traffic accident victim" (p. 1277).

Recent news stories about the bioethical conundrums that have resulted from the intersection of technology and death have caught the attention of many people in 2014. The choice of sensational reporting has the effect of over representing certain types of events that are compelling to the viewer (McArthur, Magaña, Peek-Asa, & Kraus, 2001). News headlines such as: "Family seeks to have brain-death ruling overturned, girl declared alive" (DeBolt & Bender, 2014) and "Texas judge orders brain-dead pregnant woman off life support” (Johnson & Hadlock, 2014) caused much debate over the intellectual and ethical aspects of the cases, but the net effect of these portrayals is questionable.

To be more specific, the impact of technology on the psychology of death and dying is prominent in contemporary theatrical portrayals like *Grey's Anatomy* (Rimes, 2005), *Dexter* (Shill, 2013), and *Star Wars* (Kazanjian, & Marquand, 1983), to mention just a few. In the first nine seasons of *Grey's Anatomy*, which is about a hospital in Seattle, removal from life support in the ICU was depicted on seven different occasions. The first time was an episode that aired January 18, 2007. The family was given the choice, “You could keep him on life support and wait for nature to take its course, or you can—” The wife of the patient jumps in at that point and yells, “Pull the plug?” The doctor replies, “Yes.” The family decided to extubate and let him die, and the scene is depicted as being very peaceful with the doctor simply detaching him from the breathing machine and the heart monitor going to a flat line. This episode presents confusion between the course of nature and the imposition of artificial life-support, in addition to inaccurately portraying an extubation. A more helpful depiction would clarify for the viewer what they have to expect instead of using phrases like “let nature take its course” and “pull the plug.” In addition, the scene where the patient was extubated had little resemblance to reality. The makers of this television portrayal of death in the ICU failed to show the harsh reality including the reason that most doctors ask the family to step out of the room during removal of the ventilator (Faber-Langendoen & Lanken, 2000; Clinch, 2011). It is disturbing to watch a tube being pulled from the patient's trachea, and this image is likely to be registered in the family's memory forever.

Furthermore, after eight seasons, the climax of very popular television show *Dexter*, which ironically followed the exploits of a serial killer, used the removal from life-support in the ICU to sever the ties with the main character from his only living family member. He barged into the ICU and spectacularly pulled out his sister's breathing tube and her IVs. This action seems to link removal of life support with the actions of a serial killer, and the drama of this action served to sensationalize the climax of the television program.

Darth Vader from the popular science fiction movie series *Star Wars* is another depiction of technological life-support that has solidly become manifest in the collective psyche. As a young man Anakin Skywalker is severely burned; as a result, he wears a breathing machine. Thus, he becomes Darth Vader after becoming part human and part machine. The character Darth Vader is depicted as a servant of the "the dark side of the force," and the noise each breath makes is a large part of his ominous persona. Toward the end of *Return of the Jedi*, Luke Skywalker takes off the machine to reveal the humanity of his father who subsequently dies in his arms. It is not until his son is able to detach him from the machine that they are able to have any type of emotional connection, and Darth Vader is transformed back to the light side of the force as Luke's father.

The drama within popular cinema has depicted these circumstances in many ways that affect the psyche of the observing populous. The authors of popular media dramas have taken advantage of this juncture between technology and the psyche, and the result strengthens the disparity between reality and fantasy. This disparity between reality and fantasy engenders anger and disappointment when medical technology can do no more.

Personal Experience

I worked for 15 years as a hospital and hospice social worker and took part in many family meetings. I was always struck by the importance of these moments, and I was touched by the potential impact these events of death in the ICU would have on the families for the rest of their lives. I remember, at times, feeling like the hospital staff was treating families as if they did not have the capacity to make a rational decision, and it seemed they were being treated as inferiors. In such cases the intention of the hospital staff was to quickly move the dying patient out of the ICU to make room for another. I remember walking away from some of those meetings feeling the family was forced into a decision to remove life-support for the patient, even if I agreed that it was the right direction for the patient.

As a bereavement counselor, I hear stories recounted in detail. People speak about feeling like the whole experience was surreal, like it was happening to someone else. They question their decision to remove life-support and sometimes they need to recount it over again and again. Sometimes symptoms of post-traumatic stress disorder (PTSD) are demonstrated, and sometimes treatment for depression is necessary.

As a hospice social worker, I witnessed hundreds of deaths in the home, where the dying person was surrounded by loved ones who felt in control and had as much information as they needed to provide care. I like to think that hospice is the reason the statistical trend is moving in the direction toward death taking place out of the hospital (see below). I know this is part of the reason, but money also plays a large part. Nursing homes are a major industry that is now capable of catering to patients on ventilators, which, until recently, were only available in the ICU.

My mother-in-law died in the ICU. She had chronic lung disease and required hospitalization for prolonged stays about once a year. After her last hospitalization, she was sent to a nursing home where she developed a fungus in her lungs that drastically affected her breathing. She was taken back to the hospital and was transferred to the ICU. The attending physicians were unable to successfully treat this infection, and she remained in the ICU for several weeks. Eventually, she developed ICU psychosis and became confused, disoriented, and unable to make decisions for herself. ICU psychosis is thought to be a result of not experiencing the change of night and day (Misak, 2005). My wife and I received a phone call at 2:00 a.m., and we rushed to the hospital. The doctor explained that her breathing had become significantly worse, and he recommended she be put on a breathing machine. She had an advanced directive that stated she did not want to live on a ventilator, but the doctor explained that it would just be for 3 days to give her lungs a rest and then he would remove the ventilator. We agreed. I remember thinking how different and unsettling it was to experience the decision as a family member, rather than vicariously as a social worker. After three days, she was taken off the ventilator and died very soon thereafter.

This experience gave me a whole new understanding of dying in the ICU, a deeper compassion for those involved, and a realistic approach to my own death. I am not cynical about medical care, but I am cautious. Therefore, I seek to study this phenomenon in a way that will shed light on the impact that technology has on the experience of death and dying in the ICU.

Clinical Relevance

Clinicians must be aware of the huge impact on their clients who have witnessed the death of a loved one in the ICU. Although bereavement is a normal adjustment process that almost everyone will face (James & Friedman, 1998), it can also be a significant trigger for psychiatric illness (Prigerson et al., 1997). It is important for all mental health professionals to become aware of the relatively new pressures and unintended consequences brought on by medical technology (Caldwell & Freeman, 2009; Kastenbaum, 2004). The stress related to the anticipation of life connected to a machine leads to confusion, ambivalence, and fear (Chapple, 2010; Green, 2008) and increases risk of psychological distress such as depression and PTSD for bereaved family members (Anderson, Arnold, Angus, & Bryce, 2008; Gries et al., 2010; Kross et al., 2011; Wright et al., 2010).

Chapter 2
Literature Review

While contemplating our new relationship to death, Hardwig (2009) wrote, “Up until recently, most people died quickly and too soon. Now, with many illnesses curable or held at bay, many die very slowly and too late—sometimes many years too late. It’s time to rethink dying” (p. 37). Almost 50 years ago, the seminal work by Glaser and Strauss (1965) revealed the new relationship between technology and death and dying:

> Dying away from home, and from chronic disease, will become more common during the next decades, making the problem of “awareness” even more salient to everyone concerned. Hospitals are scientific establishments and staff members are expected to make competent judgments about what is wrong with patients and to assess their prospects for recovering—or not recovering. For this very reason more and more terminal patients will persist in asking questions, and in expecting explicit, detailed answers, about the nature of their illness, how long the hospitalization will last, and why, and in what shape they will leave for home. Inevitably, more of them will discover, or be told, the truth. (The widespread improvement in educational level will strengthen these trends.) And so it is predictable that the problem of awareness will become more and more central to what happens as people pass from life to death in American hospitals. (p. 7)

The anticipation of death has far-reaching spiritual, economic, and personal ramifications (Kastenbaum, 2004). Ariès (1974) noted that death was so "omnipresent"

(p. 85) in the past that it became normalized and disempowered. However, more recently, the fear of death has become so powerful that the prohibition against facing it has replaced sex as the main cultural taboo (Gorer, 1955). The fear of death has become so universal that it is the underpinning of many of our unconscious thoughts and actions (Becker, 1973). Kubler-Ross (1969) wrote a seminal book called *On Death and Dying* that documented the process by which her subjects coped with a terminal illness. She noted five distinct commonalities among the people she studied: denial, anger, bargaining, depression, and acceptance. Two of these stages are defensive coping strategies (denial and bargaining), whereas anger and depression represent emotional reactions. The sequence is a process toward acceptance of the inevitable end—death (Kubler-Ross, 1969). *On Death and Dying* (Kubler-Ross, 1969) was a best seller, and it started the conversation about a subject that has engendered anxiety and fear—anticipation of death (Wong & Tomer, 2011).

The new relationship to death has occurred largely due to the new technology of rescue, for instance cardiopulmonary resuscitation (CPR) and defibrillation (Chapple, 2010). “In a way, fear of death animated the production of medical technology, which has resulted in a shift in the cultural frame through which we envision and imagine death” (Bishop, Brothers, Perry, & Ahmad, 2010, p. 9). For most people, the image of spending the last days of life in a hospital connected to life-support technology inspires denial, dissociation, and dread.

Trends in Cause of Death

At the turn of the 20th century, the leading three causes of death were infectious diseases, influenza, and tuberculosis (Wrightson, 1998), which were controlled through the medical innovations of vaccines and antibiotics (Shrestha, 2006). Currently, the leading causes of death are chronic heart disease and cancer (Wrightson, 1998), which require prolonged treatment and often lead to several ICU admissions prior to death (Rady & Johnson, 2004). This trend has impacted our relationship to death through both the increase in the average life span, up 30 years from 1900 (Shrestha, 2006), and the length of time it now takes from diagnosis to death (Freeman, Brim, & Williams, 1970).

Where People Die

Most people express a preference to die at home (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005; Grunier et al., 2007). However, most people die either in the hospital or in a nursing home (National Center for Health Statistics, 2011). One study found that 1 in 5 (20%) people died in the ICU in 1999 (Angus et al., 2004). However, the trend seems to be shifting toward an increase in deaths outside of the acute care setting, even though the authors of one study found that both minorities and those with lower levels of education were more likely to die in the hospital versus at home (Grunier et al., 2007).

The National Center for Health Statistics (2011) has tracked where people die since 1989 and found that over an almost 20-year period, the shift has gone from one-sixth to one-quarter of people dying outside of the hospital, with an increase in people dying in nursing homes and long-term care facilities. In 1989, 49% of Americans died in the hospital, in 2007 36% did (National Center for Health Statistics, 2011). In no way does this suggest a radical change from mechanistic to holistic means of facing death, since critically ill patients transferred from hospitals into nursing homes only serves to improve hospital mortality statistics (Kahn, Kramer, & Rubenfeld, 2007). Yet a greater number of patients who die in the hospital are dying in the ICU (McDermid & Bagshaw, 2009) and this, coupled with public perception of recovery, presents an inevitable tension between reality and expectation (Chapple, 2010). A significant amount of this tension is due to the ambiguous nature of death itself when families face the dissonance of being told a loved one is dead, yet the patient's body is maintained by medical technology (Wiegand, 2008).

Definition of Death

Even the definition of death has become a source of debate due to the fact that technology has clouded what used to be a very clear distinction—either one was alive or one was dead (Caldwell & Freeman, 2009; Shah & Miller, 2010; Shewmon, 2010; Youngner & Arnold, 2001). Before the widespread advent of medical technology, the definition of death was simple: irreversible cessation of the lungs and heart (Youngner & Arnold, 2001). After 1970, with the implementation of mechanical ventilation (artificial breathing assistance), it became necessary to be more specific about the definition of death because lung and heart functions could now persist mechanically (Green, 2008). Thus, medical advances have practically nullified the previous definition of death. For the first time in history, we are in the godlike position of deciding to turn off life—support to finalize death (Browning, 2013; Seymour, 2001; Youngner & Arnold, 2001).

The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1981) established the definition of death as, "An individual who has sustained either (1) irreversible cessation of circulatory and respiratory functions, or (2) irreversible cessation of all functions of the entire brain, including the brain stem, is dead" (p. 73). This definition emphasizes the centrality of the brain as the locus of control and, thus, the organ central to life (Chiong, 2005). Shewmon (2010) referred to brain death as the “mainstream position” (p. 257), which has been further defined as “the permanent cessation of functioning of the organism as a whole” (Bernat, Culver, & Gert, 1981, p. 391).

A focus on brain death as synonymous with the death of the organism may seem simple enough, but there are some compelling arguments against it (Shewmon, 2010). For instance, “Why is a patient with a destroyed brain considered dead rather than moribund and irreversibly comatose?” (Shewmon, 2009, p. 1). The brain death definition has, as its base, the contention that the human organism is a series of unified parts and that the brain is the unifier; thus, when the unifier is not functioning, the unification no longer exists and, thereby, the human organism is dead. However, what of the situation where the brain is no longer functioning, yet regulatory functions continue (e.g., thermo regulation or hormonal secretion)? In response to such ambiguity, Chiong (2005) suggested a contextual perspective that did not impose necessary criterion fashioned a priori that may not lend themselves to a given situation:

> The right way to argue for a given criterion of death is not to argue that it fits some singular “definition” of life or death that results from any conceptual analysis of these terms. Rather, we ought to seek some alternate model that can make sense of our best intuitive response to real-life cases. (p. 25)

Advances in medical technology brought a renewed need to be sensitive to families' dissonance between what they were told by doctors and what they might be seeing in the patient (Caldwell & Freeman, 2009). For instance, a person may hear of her or his loved one's terminal prognosis but see the chest raising and lowering (due to mechanical ventilation) and spontaneous movements or jerks. The news of impending death does not fit with the lived experience of seeing the patient's overt signs of life. It is not uncommon for the news of impending death to be completely denied by family members (Buck, 2013; Morse, 2011; Zimmermann, 2007).

Technology and Death in the ICU

The place where technology and death most closely interface is in the hospital ICU (Cook et al., 2003). By the late 1960s most hospitals in the United States had an ICU and by 2007, critical care beds numbered 67,357 (Carr, Addyson, & Kahn, 2010). The ICU has become an essential tool in the complement of care provided by hospitals across the United States and the world (Luce & White, 2009). ICU patients fall into two categories: those who have an acute or sudden illness or injury and those who have acute exacerbations of chronic illnesses (Miller, Forbes & Boyle, 2001). The ICU is set up to provide 24-hour intensive monitoring of vital signs and artificial life-sustaining interventions such as ventilators to maintain respiration, medications to maintain blood pressure, and dialysis to maintain kidney function (Vincent, 2013).

According to Vincent (2013), the advent of the ICU in the United States in the 1950s is most closely associated with the invention of mechanical ventilation for patients who cannot breathe on their own. The ICU was established to address acute injuries and illnesses and restore the patient's medical stability and quality of life (Truog et al., 2008). In order to accomplish this, the ICU contains an extensive amount of medical technology and a 2:1 patient-to-nurse ratio (Miracle, 2006).

Although the ICU is crucial to the lives of thousands of people each year, profound unintended consequences accompany these advances (Callahan, 2003; Chapple, 2010; McDermid & Bagshaw, 2009; Pavlovic, Lehmann, & Wendt, 2009). Prolongation of life is sometimes at the expense of quality of life (Callahan, 2003). The ICU itself can induce fear, prompting conditions such as myocardial infarction (Illich, 1995). The families of patients who die in the ICU experience an increased incidence of psychiatric distress than would be expected otherwise (Kross et al., 2011; Lemiale et al., 2010). "Technological advancements in aggressive medical management at the end of life have led more Americans to fear how they die rather than death itself" (Tilden, 1999, p. 162).

The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT, 1995) found that most doctors were unaware of their patients' treatment preferences (i.e., the wish to pursue or avoid resuscitation through CPR and/or mechanical breathing) and that 50% of patients had moderate to severe pain in the last three days of life. This study suggested that medical staff were not trained to provide end-of-life care, especially in the ICU.

The intensity and delivery of end-of-life care in the ICU varies drastically throughout the United States. A study sponsored by the Dartmouth Institute (Goodman, Esty, Fisher, & Chang, 2011) showed great variation in the concentration of services provided to Medicare beneficiaries with chronic illnesses. The authors pointed out that, even though the number of patients who die in the hospital has decreased, the number of days spent in the ICU during the last 6 months of life, the amount of physician time spent with these patients, and number of specialists attending to these patients has all increased drastically between 2003 and 2007 (Goodman, Esty, Fisher, & Chang, 2011). The authors emphasized a trend they labeled "supply-sensitive care" (p. 3) in which areas where more ICU beds were available also showed higher intensity care at the end of life. The study suggested there was not a consequent increase in the quality of care accompanying the higher intensity care. "Yet greater use of the hospital or ICU as a site of care does not lead to better outcomes on average" (p. 3).

Teno et al. (2005) divided hospitals into two groups according to higher or lower ICU admittance rates, length of stay, and provision of aggressive end-of-life services. The researchers sought to find out if any difference in end-of-life care existed between hospitals with high and low ICU intensity of care. Quality of care was determined according to symptom control, provision of information, respectful treatment, and shared decision-making. The hospitals with the lower-intensity patterns of practice provided higher-quality end-of-life care. Patients from the higher-use ICUs "received more-aggressive care at the end of life; they were more likely to have been transferred to an institution or across institutions and were more likely to die in an ICU" (Teno et al., 2005, p. 1908). Similar findings were reported in another study comparing high- and low-intensity end-of-life care in the ICU (Barnato, Tate, Rodriguez, Zickmund, & Arnold, 2012). These researchers found that the hospitals with a history of low-intensity end-of-life care tended to practice time-limited life-sustaining interventions, whereas hospitals with a history of high-intensity end-of-life care tended to practice "open-ended use of life-sustaining treatments" (p. 1). These findings suggest great variation in the intensity of end-of-life care and that the rush toward high technology and aggressive interventions accompanied with unbridled expectation for recovery may be counterproductive to quality end-of-life-care.

This emphasis on technology has caused people to fear the period just before death more than dying itself (Hardwig, 2009; Palladino, 2004; Tilden, 1999; Valente, 2004). Seymour (2001) described these unintended consequences:

> the use of an armoury of scientific and technological advances to try and pull dying people back from the very brink of death has, it might be argued, leapt ahead of our ability to deal with the professional, social, ethical, and financial consequences thrown up by its use. (p. 1)

Confusion and distrust have resulted from the mix of ICU cultures (Gauntlett & Laws, 2008; Lind, Lorem, Nortvedt, & Hevrøy, 2012), the expectation for rescue (Chapple, 2010; Ferrell, 2006; McDermid & Bagshaw, 2009), and miscommunication (Mack & Smith, 2012; White, Engelberg, Wenrich, M., Lo, & Curtis, 2010) in the end-of-life decision-making process. "Many people dying in institutions have unmet needs for symptom amelioration, physician communication, emotional support, and being treated with respect" (Teno et al., 2004, p. 88).

ICU culture. A historical view of the ICU environment and its stressors is important in painting a complete picture of the relation between technology and the process of dying. As early as the 1970s, healthcare professionals have been aware of the ICU's unique stressors (Hay & Oken, 1972), especially in regard to the potential for medical mistakes in such an environment. The authors saw the stress in the ICU as adaptive on one level due to the need for nurses and doctors to remain alert and responsive; however, maladaptive responses such as emotional depersonalization, distancing from certain patients, communication difficulties, and tension among the ICU staff were also noted (Hay & Oken, 1972). Twenty-three years later, a similar study found a relation between the use of medical technology and burnout in the ICU (Schaufeli, Keijsers, & Miranda, 1995). The authors noted that ICUs that had higher use of medical technology also had a higher rate of nurse burnout (Schaufeli et al., 1995). They speculated that nurses caring for a mechanically ventilated patient may see that patient as simply an extension of the equipment, which would increase job burnout. Schaufeli et al. (1995) also found that higher use of medical technology in the ICU also had a negative relation to nurses' subjective evaluations of job performance.

The ICU is a high-stress environment in which conflict is common among healthcare practitioners, family members, and patients. The ICU is suffused with confusing contraptions and distracting devices (Chapple, 2010). In his book, *Deathwatch: American Film, Technology, and the End of Life*, Combs makes the connection between the movie screen and the EKG monitoring the heart rate. He wrote:

> Just as films visualize a mobile death sign for spectators, so, too, the monitors in intensive-care units register the flowing waves of the heart's vitality and their gradual weakening and the slide to "flatline." Both these moving images "confirm." The EKG has become so user-friendly, so self-evident, that it competes with the dying body for our attention during a death watch. (p. 10)

Thus, the ICU environment is full of distraction and competition of and for attention from both healthcare providers and family members. This scenario is packed with potential for misunderstanding and conflict.

A cross-sectional survey of 7,498 staff members from 323 international ICUs showed 72% of respondents indicated a conflict within the previous week, and 53% of those reported the conflict was severe or even dangerous in intensity (Azoulay et al., 2009). High work volume and lack of emotional support for grief contributed to this stress (Azoulay et al., 2009). Chapple (2010) suggested that a hospital is not an appropriate place to die, due to an overreliance on technology and a rescue mentality that has created a culture that does not lend itself well to end-of-life care. Buchman, Cassell, Ray, and Wax (2002) contend that physicians confuse the meaning of the Hippocratic Oath with the need to keep the patient alive at all costs. In other words, there is a process of denial at play in the ICU even when a patient is clearly beyond rescue. Van den Berg (1978) also referred to the Hippocratic Oath, but he points out the frequency by which it refers to the “patient’s interest” (p. 8). The patient's interest becomes clear when advice from Hippocrates is heeded: “Treat the patient, not the illness” (van den Berg, 1978, p. 8).

Death is a commonplace occurrence in the ICU after withholding or withdrawing life support (Kuschner, Gruenewald, Clum, Beal, & Ezeji-Okoye, 2009). ICU staff cope with patient death in various ways (Hinderer, 2012). Acknowledgement of grief is antithetical to the culture within the ICU (Brosche, 2007), thereby compounding the stress death has on ICU personnel and negatively impacting the quality of care they provide (Brosche, 2003; Stayt, 2009). Approximately one-third of 2,392 ICU nurses surveyed in a French study reported symptoms of occupational burnout (Poncet et al., 2007). Both the fast pace of the ICU and the tendency for staff to avoid formal forms of support (Shorter & Stayt, 2010; Weir, 2005) make for a culture that is rarely in harmony with the needs of dying patients and their families (Chapple, 2010). Wiegand and Funk (2012) surveyed 204 critical care nurses, and found half had experienced moral distress on the job. The nurses reported that the majority of distress was related to end-of-life care, and it caused “anger, depression, sadness, frustration, and helplessness” in the nurses (Wiegand & Funk, 2012, p. 484).

“Burnout” and “compassion fatigue” are common psychological effects of the high-intensity ICU culture. Leiter and Maslach (2009) define burnout as “a psychological syndrome that involves a prolonged response to chronic interpersonal stressors on the job” (p. 332), while Coetzee and Klopper (2010) see compassion fatigue as resulting from prolonged exposure to emotional stress, where the ineffectual attempts to rectify or ameliorate an undesirable situation leads to hopelessness and a progressive depletion of nurturing ability. The onset of compassion fatigue is progressive and cumulative, leading to “accident proneness, the emotional effects of breakdown, apathy, and a desire to quit, the social effects of unresponsiveness, callousness, and indifference towards patients, the spiritual effects of poor judgment and disinterest in introspection, and the intellectual effect of disorderliness” (Coetzee & Klopper, 2010, p. 239).

Shorter and Stayt (2010) found that ICU nurses tended to distance themselves from dying patients as a coping strategy. The researchers conducted a phenomenological study among ICU nurses through in-depth interviews and found that they were hesitant to develop close relationships to their dying patients and their families. This coping strategy was seen as emotional dissociation: “Throughout the data there was evidence that participants coped by emotionally disassociating themselves from the situation” (Shorter & Stayt, 2010, p. 164). The nurses tended to justify and normalize this practice as a means for them to continue the work. However, this emotional dissociation, along with exhaustion and feelings of inefficacy, is a symptom of occupational burnout (Maslach, Schaufeli, & Leiter, 2001) and may possibly explain why many families of dying patients report a lack of support and communication from medical staff (Kirchhoff et al., 2002).

Nurses have also reported moral distress over procedures that were perceived to be unnecessary for the dying patient (Ferrell, 2006; Wiegand & Funk, 2012). The definition of “moral distress” most often cited is from Jameton (1984): “Moral distress arises when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action” (p. 6). A frequently cited example of moral distress among nurses is the experience of witnessing aggressive life-prolonging care that seemed to cause suffering and prevent patients from receiving palliative care that would focus the intervention toward a comfortable end of life (Ferrell, 2006). The perception of futile and aggressive care in the face of terminal illness is perhaps seen as an affront to the Hippocratic Oath, “do no harm” (Mohammed & Peter, 2009).

Nurses who attempt to advocate for their patients are sometimes rebuffed by the physician, and this causes them frustration and moral distress (Sundin-Huard & Fahy, 1999). Sundin-Huard and Fahy (1999) focused on confrontations with physicians surrounding end-of-life care as reported by ICU nurses during interviews. The nurses reported that failures in multiple attempts to advocate for appropriate end-of-life care for their patients caused them emotional distress and outrage. “In some cases, the distress that nurses feel, and the recurrence of ethical dilemmas, leads them to burnout” (p. 13).

Intuition, however, would suggest that nurses who feel empowered and participate in family meetings also would report lower levels and frequency of moral distress. This contention was supported by a survey of 277 critical care nurses that measured both the frequency and degree of intensity of moral distress (Browning, 2013). The nurses reported few incidents of moral distress, but the intensity associated with the incidents that were reported was very high. Older nurses reported the highest levels of intensity in moral distress, and this was usually concerning the areas of personal responsibility and participation in procedures that were not seen to be in the patient’s best interest (such as those that would forestall a patient’s death). In addition, the same study found that nurses who received extended critical care training also reported more intense and more frequent levels of moral distress surrounding care that was perceived as not in the patient's interest (futile care). The author speculated that the nurse's age and extended end-of-life care training might influence the dissonance between the care patients received and what the nurses had learned to be appropriate and compassionate (Browning, 2013).

Stress is also common with ICU physicians, and it has been correlated with job burnout (Mehta & Lyckholm, 2008) and depression (Embriaco et al., 2012).

> We become doctors because our ability to cure gives us power over death of which we are so afraid, and loss of that power poses such a significant threat that we must turn away from it, and therefore from the patient who personifies our weakness. (Nuland, 1993, p. 258)

Kearney, Weininger, Vachon, Harrison, and Mount (2009) have noted that physicians working in end-of-life care are particularly susceptible to compassion fatigue and burnout. These unresolved responses to stress and grief have been shown to lead to harm, both to the physician's health and to the quality of patient care that he or she provides (Christakis, 2009).

A possible contributing factor to compassion fatigue and burnout among physicians may be the intense sense of responsibility for medical outcomes, both good and bad, that they typically take on (Buchman et al., 2002). "The surgeon's heroic optimism unfortunately predisposes to the creation of barriers to communication with his or her patient, particularly when the news is unfavorable or (worse) that the rescue attempt has failed" (Buchman et al., 2002, p. 666). The heroic stance that physicians have been known to take (Katz, 2006) is willingly perpetuated by patients and their families who want and need to trust that the physician will care for them at the very least and save them at best (Nuland, 1993). In support of this notion, it is interesting to note that emergency life-sustaining therapies such as CPR are commonly referred to as heroic measures (Maddi, 1996). Thus, it is difficult for a physician to face the death of his or her patient because it is both seen as a failure and a breach of that sacred trust between them (Buchman et al., 2002).

The results of a recent study (Shanafelt et al., 2012) of occupational burnout among physicians in the US seems to confirm this by showing that physicians reported more frequent and more intense levels of burnout than those in other American occupations. More to the point, the authors also divided the results by medical specialty. Emergency department and critical care (ICU) physicians reported significantly more frequent symptoms of burnout than any other medical specialties. The doctors who were most exposed to death and dying in the hospital were most likely to report loss of enthusiasm for work, cynical feelings, and a decreased sense of accomplishment, all of which the authors of this study suggested were consistent with burnout (Shanafelt et al., 2012).

A significant aspect of physician burnout is the tendency to second guess or question the care they provided to their patients (Yeoman & Sleator, 1995). To investigate this potential source of distress, Ruopp et al. (2005) conducted in-depth qualitative interviews with 75 attending, resident, and intern physicians. The authors found that a significant number of physicians questioned the care they had provided to their patients who had died (Ruopp et al., 2005). Physicians were especially troubled by issues of miscommunication, appropriateness of routine treatments, and the ambiguity of responsibility. The majority expressed sadness and frustration, and some expressed guilt and anger. Communication issues were most often cited as physicians reflected back on why the death had been less than ideal, a finding that is consistent with those of other studies (e.g., Sutcliffe, Lewton, & Rosenthal, 2004). “The culture of medicine shapes the stories physicians tell and their affective responses to patient deaths” (Ruopp et al., 2005, p. 517).

Communication. The International Consensus Conference in Critical Care (Carlet et al., 2004) found that communication was one of the major reasons for systemic problems with the care provided to patients dying in the ICU. The authors cited the terminology used by physicians as insensitive, ambiguous, and “emotionally laden” (p. 771), along with the consistent finding that families rate the lack of accurate and timely information about their loved ones as their most vehement complaint (Carlet et al., 2004).

It has been demonstrated that ICU physicians tend to feel that families unrealistically expect certainty in predictions of disease course (Christakis & Iwashyna, 1998; McDermid & Bagshaw, 2009), and at the same time, family members have consistently reported a breakdown in communications from the medical team regarding alternatives to aggressive end-of-life care (e.g., Fried & O’Leary, 2013; Levin, Moreno, Silvester, & Kissane, 2010). One study found that the vast majority (93%) of surrogate decision-makers in the ICU felt open and honest communication with the physician about terminal illness would have been most beneficial to help prepare them for the patient's death (Apatira et al., 2008).

White et al. (2010) studied the process by which physicians communicated prognosis to families. They found that, of the 51 audio-taped conferences between physician and families, a wide variation in language usage existed; only a small percentage of physicians checked if the family understood what they had said, and in only one of the 51 conferences was it ascertained that the family was ready to hear prognostic information before it was delivered (White et al., 2010). Two-way miscommunication, physician misunderstanding of the patient/family wishes, and the patient/family not understanding the physician’s prognosis and alternatives are not uncommon, suggesting the importance of viewing the patient and family as integral members of the ICU culture (Sorensen & Iedema, 2011).

Miscommunication has sometimes put medical professionals in the position of feeling forced to provide non-effective medical care at the behest of family members (Mohamed & Peter, 2009) and put some patients and family members in the position of not having enough information to make fully informed decisions (Rady & Johnson, 2004). Family members have even expressed distress due to feeling forced or coerced by physicians into having procedures (e.g., surgical insertion of a feeding tube) for older adults nearing end-of-life (Teno et al., 2011). Conflict and ethical dilemmas are inevitable in the ICU; however, Edelstein, DeRenzo, Waetzig, Zelizer, and Mokwunye (2009) suggested that ICU staff are not trained and do not have the skills to manage conflict resolution to maximize patient-centered care and the establishment of shared goals.

To further explore these points, Almerud, Alapack, Fridlund, and Ekebergh (2007) studied communication in the ICU by interviewing patients who had been admitted to the ICU for life-threatening illness or injury. Patients were interviewed just after discharge from the ICU, and phenomenological analyses of the results were conducted. Patients reported finding security in trusting the care and expertise of the medical team, while simultaneously feeling highly vulnerable. Patients expressed concerns about potential death, the confusing and frightening environment, the experience of “forced dependence” (p. 155), and feeling invisible amidst the medical technology (Almerud et al., 2007). The participants communicated they felt secondary to the technology that demanded the attention of the nurses and doctors, and the researchers emphasized the dissonance between the act of technical curing and the art of caring.

Similarly, Cox et al. (2009) focused on surrogate decision-makers for patients who had significant “chronic critical illness” (p. 1) that required mechanical ventilation in the ICU. In order to evaluate the clarity of communication about treatment planning and prognosis, the authors interviewed surrogates and the physicians. Almost three-quarters of surrogates indicated that physicians did not discuss treatment outcomes with them. Although less than 10% of the patients were alive and functionally independent at the one-year follow-up, almost all the surrogates initially reported strong expectations for the patient's full recovery, while less than half of the physicians later reported they initially shared these high expectations. This prospective study demonstrated the expectation gap between patients’ families and attending physicians (Cox et al., 2009).

Gaps in communication may be complicated and even facilitated by people's tendency to focus on positive information and disregard negative information. The tendency to acknowledge information that fits already formed positive expectations, coupled with the tendency to disregard factual information that challenges these expectations, is known as the optimism bias, and it influences every aspect of our lives (Sharot, Riccardi, Raio, & Phelps, 2007). The tendency to disregard or minimize negative prognoses is likely to be active during a family meeting with the physician. The influence of miscommunication within the ICU environment was demonstrated by an experimental study (Zier, Sottile, Hong, Weissfield, & White, 2012) that investigated surrogate decision-makers' interpretation of a list of hypothetical prognostic statements. Subjects were surrogates in the waiting rooms of several hospital ICUs. Researchers clearly stated this study had nothing to do with their loved ones in the ICU. Participants were divided into two groups: those who received positive or hopeful prognostic statements and those who received a list of more negative or grim prognostic statements. The participants were then asked to rate the survival potential with a numerical percentage. The researchers found "Participants' interpretations of prognostic statements expressing a low risk for death were relatively accurate, but interpretations of statements conveying a high risk for death were more optimistic than the actual meaning" (Zier et al., 2012, p. 360). This study revealed a consistent pattern of overly optimistic evaluations of poor prognostic information, and this tendency may partly explain miscommunications in the ICU. "We identified cognitive and psychological factors affecting how surrogates *process* risk information that may contribute to their overly optimistic expectations" (p. 365). The researchers interviewed some of the participants afterward and found their justifications for their optimistic biases included their need to express optimism as well as their doubts about the physician's ability to provide an accurate prognosis (Zier et al., 2012).

Miscommunication in the ICU is related to physicians' hesitance to convey accurate information regarding survival estimates of patients with terminal illness (Gordon & Daugherty, 2003). To investigate this, researchers contacted more than 500 physicians after their patients had been admitted to hospice (Lamont & Christakis, 2001). The study revealed that more than 60% of physicians either did not give estimates or knowingly gave inaccurate estimates of length of life. Reasons for these patterns in communication (or lack thereof) have been studied by other researchers (Mack & Smith, 2012). Physicians provided justifications such as, “It will make people depressed” or “It will take away hope” (Mack & Smith, 2012, p. 1). The authors suggested that physicians prefer to continue trying interventions, no matter how unlikely the positive outcome, until there is nothing more to try. Mack and Smith (2012) summarized their findings with the following:

> Patients and families want prognostic information, and it supports their ability to make decisions that are right for them. Given this, and the lack of evidence that discussing prognosis causes depression, shortens life, or takes away hope, it is hard to argue against honest communication of a poor prognosis. (p. 2716)

Based on the literature presented in this section, it seems clear that the ICU is an integral part of modern death and dying (Chapple, 2010), that the environment of the ICU has not evolved to meet the needs of the dying patient (Hardwig, 2009; Palladino, 2004;

Tilden, 1999), and that medical staff are sometimes at odds with each other, with patients, and with families regarding end-of-life care decisions (Ferrell, 2006; Wiegand & Funk, 2012). The ICU environment and advanced life-support technology are components of a situation where patients, families, and medical staff do not seem to have compatible agendas and procedures to the benefit of anyone involved, especially the dying patient (Seymour, 2001).

Technology has provided life-saving interventions; however, when these interventions become futile and death is imminent, they become a distraction from caring human interactions (Almerud et al., 2007). Communication between patient or family members and physicians has become mutually bifurcated into hoping for cure and preparing for death, and an important opportunity for discussing both is frequently missed (Back, Arnold, & Quill, 2003). Attention to an evolving process of understanding, emotional support, and honest and sensitive communication is vital for informed decision-making in the ICU.

End-of-Life Decision-Making

Since the advent of contemporary medical technology, relatives are frequently required to make life-and-death decisions in the ICU for their incapacitated loved ones (Chapple, 2010; Ditto, 2006; Prendergast, & Puntillo, 2002; Winzelberg, Hanson, & Tulsky, 2005; Whitmer, Hughes, Hurst, & Young, 2005). These decisions often involve whether or not to stop life support (i.e., breathing machine, artificial feeding and hydration, blood pressure medications) (Kamisar, 2012). The authors of one study found that, over the period of one year, 16% of patients admitted to the ICU died there, and 87% of those were removed from life support (Verkade, Epker, Nieuwenhoff, Bakker, &

Kompanje, 2012). The ventilator, which provides mechanical breathing assistance, is the most frequently removed life support (Bartels & Faber-Langendoen, 2001).

The oversight of care for another person is stressful (Schenker, Tiver, Hong, & White, 2012). Wendler and Rid (2011) conducted a systematic study of more than 40 research projects in an effort to evaluate the effect this responsibility had on decision-makers. A large proportion of the studied population experienced significant distress. "Our evaluation of more than 2,800 surrogates indicates that this practice places emotional stress and burden on at least one third of surrogates, which is often substantial and lasts months or, in some cases, years" (Wendler & Rid, 2011, p. 344). The most common sources of stress were found to be uncertainty of patients' wishes, uncertain prognosis, the hospital environment, and poor communication. Additional stressors were found in a qualitative study of 30 surrogate decision-makers in the ICU (Schenker et al., 2012). Interviews were conducted and specific themes emerged concerning the decision-making process such as "1) not wanting to feel responsible for a loved one's death, 2) a desire to pursue any chance of recovery, and 3) the need to preserve family well-being" (p. 1657).

Ideally, the decision of whether or not to start or withdraw life support hinges on certain milestones of decline, such as multiple organ failure (Henig, Faul, & Raffin, 2001). However, Garland and Connors (2007) in a study that focused on ICU patients and their physicians from one hospital between 2002 and 2005 found a different relationship. The researchers found that "comorbid conditions, acute diagnostic category, and the source of ICU admission" were not most predictive of these decisions (Garland & Connors, 2007, p. 1298). The physician was the variable most predictive of removal of life support. The authors noted that physicians influence these decisions to a great degree through how or if end-of-life options (e.g., hospice or palliative care) are brought up with the patient or family (Garland & Connors, 2007).

The decision of whether to withhold or withdraw life support is relatively recent and coincides with the advent of life-support technology and a movement toward shared decision-making between patients/families and physicians (Callahan, 1993; Mohammed & Peter, 2009; Seymour, 2001; Truog et al, 2008). These decisions have ethical ramifications and are wrought with moral struggle (Coustasse, Quiroz, & Lurie, 2008; Ditto, 2006). The relatively recent advances in life support technology and the resulting impact on end-of-life decisions have caused the medical, legal, and lay communities to pause in an attempt to gain bioethical grounding (Henig, Faul, & Raffin, 2001; Jansen, 2006).

Bioethics. Bioethics as a discipline developed concurrently with the advances in life support technology in the early 1970s (Veatch, 2010). It became an integral part of medical decision-making as a result of the ethical dilemmas that accompany these technologies, organ transplantation, dialysis, and oversight of medical experiments (Coustasse, Quiroz, & Lurie, 2008; Jonsen, 1997; Sherwin, 2011).

The first time the issue of withdrawal of life support was legally and ethically considered was in the case of Karen Ann Quinlan (Jonsen, 1993). In 1975 Quinlan's father requested that life support be removed from his daughter (Jonsen, 1993). She had overdosed, her brain had been deprived of oxygen for approximately 15 minutes on two separate occasions, and she was kept alive by mechanical ventilation. Several months passed, and she did not seem to have any chance of recovery. Her family felt the mechanical life support was prolonging her death, so they requested its removal (McGowan, 2011). The hospital and attending physician refused their request because they felt this act would have them actively killing their patient. The case was taken up by the state supreme court, which ruled in favor of the family (Veatch, 2009). The decision was accomplished through consultations with an ad hoc bioethics committee (Veatch, 2009).

Bioethics committees became common as a consultative body within hospitals in the 1970s just about the same time ICUs were becoming standard complements of hospitals across the United States (Jonsen, 1993). In an attempt to gain a moral foothold within a technological moving ground (Callahan, 2003), bioethics adopted four fundamental guiding principles: beneficence (do good), non-malfeasance (do no harm), autonomy (self-determination), and justice (equality for all) (Beauchamp & Childress, 2001; Henig, Faul, & Raffin, 2001). The application of these four principles provided a rational process for decision-making in an often chaotic and confusing medical, technological, and ethical environment (Henig, Faul, & Raffin, 2001).

Although each of the four bioethical principles is important, autonomy is the most controversial and arguably the most relevant to end-of-life care (Meyers, 2004; Winzelberg, Hanson, & Tulsky, 2005). To a great extent, bioethics began in response to disregard of the patient's wishes, and patient self-determination became a rallying point (Childress & Fletcher, 1994). The notion of autonomy has “self-rule” (Beauchamp & Childress, 2001; p. 58) at its base of meaning. Beauchamp and Childress (2001) define autonomy as being the combination of two guiding conditions: “(1) *liberty* (independence from controlling influences) and (2) *agency* (capacity for intentional action)” (p. 58).

Thus, to achieve the principle of autonomy requires a level of honesty, understanding, and collaboration between the physician and his or her patient. These virtues have not always been at the forefront of the doctor/patient relationship.

Oken (1961) documented the paternalistic behavior of oncologists who revealed the extent to which they told the truth to their cancer patients. Through questionnaires and interviews, Oken (1961) found that 90% of participating oncologists favored withholding the diagnosis from their patients. The physicians defended this practice by citing their clinical experience and the potential harm such information might cause, though the researcher could find no evidence of this harm. Instead, evaluation of the data suggested that feelings of impotence and fear were the physicians' true motivators. Oken (1961) was quick to point out how the omission limited clinical options and interfered with potential treatments.

In the ensuing decades, the principle of patient autonomy has become more central to the practice of medicine (Schneiderman, Jecker, & Jonsen, 1990). Patient autonomy was at the heart of the Patient Self-Determination Act enacted by the United States Congress in 1990 (1994), which mandated that healthcare providers inform patients of their right to accept or refuse treatments, standardized implementation of informed consent practices, and emphasized the need for completion of advanced directives and the assignment of a healthcare surrogate in the case of unresponsiveness (Patient Self Determination Act of 1990, 1994).

The question of how successfully the medical community has adjusted to this mandate has been the impetus for a significant amount of scholarly work (e.g., Brudney, 2009; Johnson, Cook, Giacomini, & Willms, 2000; Meyers, 2004; Miyaji, 1993; Stirrat &

Gill, 2005). For instance, Miyaji (1993) interviewed 32 physicians about their communication with their terminally ill patients. He found that, although information regarding the diagnosis was not withheld, the physicians reported significant hesitance to disclose the prognosis of terminal illness to their patients. The physicians assumed the lack of questions from a patient indicated complete understanding. "The absence of questioning is interpreted as a sign of patients' unwillingness to know as well as of their understanding" (Miyaji, 1993, p. 257). When patients did ask questions, their physicians used hopeful euphemisms and vague language to skirt around the finality of impending death indicated by a terminal prognosis. Physicians were much more comfortable talking to patients about potential treatments, even in the face of a terminal illness. The author characterized this habitual style of communication and justification as simply another form of paternalism. Miyaji (1993) suggested the physicians might be holding onto the information about end-of-life alternatives because of the power this affords them. These findings are similar to those already cited (e.g., Lamont & Christakis, 2001; Mack & Smith, 2012), but Miyaji (1993) also pointed out that a rigid adherence to the principle of autonomy may damage the relationship between patient and doctor in some circumstances. Miyaji (1993) wrote:

> It is clear that the old, god-like role of the doctor is no longer acceptable, but the doctor cannot be just an ordinary fallible human being. Most patients and their family members still expect physicians not only to fulfill legal obligations to respect patients' rights, but also to devote themselves to caring for patients compassionately. (p. 261)

Problems were also revealed in another study of patient-physician communication (Gordon & Daugherty, 2003). Through interviews with the authors, 14 oncologists described themselves as “reluctant” to provide prognostic information to their patients with advanced cancer (Gordon & Daugherty, 2003, p. 153). The oncologists were able to inform patients of the terminal nature of the cancer, but they reported difficulties in providing prognostic information. These difficulties are consistent with physicians’ insistence on maintaining hope and optimism. Oncologists relied on violent metaphors to explain their reluctance: “hit someone in the face with it” or “force it down their throat” or “you can't beat people over the head with that” (Gordon & Daugherty, 2003, p. 155). The physicians frequently used the word “push” (p. 156) to represent the patient's desire to know more information, and this seems to reflect the pressure felt by the oncologists. This reversal from physician's action toward patient to patient’s action toward physician demonstrates the impetus for the patients to be their own advocates. The researchers pointed out that these metaphors represent the physician's perception of adversarial relationship with their patients (Gordon & Daugherty, 2003).

Gordon and Daugherty (2003) concluded with an acknowledgement that the principle of autonomy was fashioned with an "ideal" patient in mind. These oncologists' real life experience was with people who do not necessarily fall into the category of ideal. For instance, a patient who was not able to make decisions and a family that was not unified regarding choices (Brudney, 2009), or a patient who was ambivalent about foregoing treatment (Ohnsorge, Keller, Widdershoven, & Rehmann-Sutter, 2012) would not be ideal scenarios. Thus, Gordon and Daugherty (2003) further pointed out that these physicians might be practicing two of the other bioethical principles, those of beneficence and non-malfeasance. “Consequently, oncologists vary the amount of prognostic information given to patients depending on patients’ level of hope, the presence of unrealistic expectations, and responses to earlier efforts to disclose prognostic information” (Gordon & Daugherty, 2003, p. 165). These findings are consistent with a more recent survey of oncologists (Daugherty & Hlubocky, 2008) regarding their practice of prognostic disclosure, but, in addition, this study revealed that physicians reported they would want detailed prognostic information including time estimates for their own terminal illness.

The principle of beneficence seems, on the surface, to be relatively obvious and uncomplicated; however, just as with most medical concerns, the principle of beneficence can be deceivingly complex. Beauchamp and Childress (2001) outline two aspects that go along with the principle of beneficence: “*Positive beneficence* requires agents to provide benefits. *Utility* requires that agents balance benefits and drawbacks to produce the best overall results” (p. 165). For example, the provision of a medical treatment may or may not be viewed as beneficent based on a ratio of the potential for positive and negative outcome. This cost versus benefits calculation is often encountered in the ICU when life support is considered (Beauchamp & Childress, 2001).

The consensus statement from the American College of Critical Care Medicine (Truog et al., 2008) outlined two ethical principles directly pertaining to death in the ICU. For instance, the act of withholding versus withdrawing life support is seemingly different. Withholding life support is a passive act, while withdrawing a ventilator or blood pressure medications is active. The commission, however, determined that there is no bioethical difference between withholding and withdrawing life support from a terminally ill or injured patient (Truog et al., 2008). In other words, the decision to withhold life support for a patient admitted to the emergency department is not ethically different form the decision to withdraw life support from a patient in the ICU.

The second ethical principle outlined in their position statement (Truog et al., 2008) also has to do with the removal of life support. This principle makes the distinction between actively killing versus allowing a patient to die. For instance, the authors used the example of Karen Ann Quinlan because the court decided a patient's family has the right to refuse treatment even in the case where the patient would die without the treatment (Truog et al., 2008). In this case, Quinlan's family was not killing her by withdrawing life support, they were merely allowing her to die. The authors wrote, “Therefore, the withdrawal of life-sustaining treatments is not legally considered a killing, and the actions of clinicians in this regard are described as 'allowing the patient to die' from the underlying illness” (Truog et al., 2008, p. 956).

The ethical tension brought on by life support technology is most often encountered in the ICU (Faber-Langendoen & Lanken, 2000; Gallagher & Holmes, 2011; Seymour, 2001). Physicians may view a patient's admission to the ICU as a “therapeutic trial,” and if the treatment goes well, the patient will be discharged to the less acute floors of the hospital or sent home (Truog et al., 2008, p. 953). However, if the trial does not go well and the patient does not show signs of recovery, then the goals are reassessed and the possibility of palliative or comfort care should be considered in place of the vain hope of recovery that is perpetuated by all-out application of medical technology (Truog et al., 2008). Within the ICU, if life-sustaining treatment is deemed incompatible with the patient's goals and wellbeing, the physician has no moral or legal responsibility to initiate or continue it (Davis, 2008). In this case, physicians are adhering to their own bioethical autonomy (Stirrat, & Gill, 2005). Because of this tension, the term “medically futile care” was coined and since has been imbued in an ongoing bioethical debate (Callahan, 1991).

Futile care. Recent advances in medical technology have led to an increased expectation for recovery among the public at large (Choong et al., 2010; McDermid & Bagshaw, 2009) and increased conflicts between patients/families and physicians (Callahan, 1991). For an ethical dilemma to arise, there must first be tension between two choices, such as the choice to act or not act, or to withdraw or maintain life-sustaining interventions (Callahan, 2003). Within these decisions, there is a tension between the principle of autonomy and the principle of beneficence and non-malfeasance (Schneiderman et al., 1990). For instance, if the patient expresses a desire to continue treatment, and the physician deems this treatment harmful or ineffective, the physician may be adhering to the principle of patient autonomy by acquiescing, but the physician may be going against the principles of doing the right thing (beneficence) and doing no harm (non-malfeasance) (Gallagher & Holmes, 2011). However, a physician who refuses to pursue further curative or life-sustaining interventions for a terminally ill patient may invoke the term *medically futile care* to indicate the inappropriate initiation or continuation of life-sustaining treatments (Baily, 2011). Christakis (1999) wrote about the term:

> Futility is based on a prognosis not only that the patient is unlikely to recover spontaneously, but also that any intervention will likely be ineffective. As the avoidance of futile treatment has assumed increasing

> prominence, for reasons of justice, beneficence, or economy, prognostication—which is, after all the fundamental and essential basis for the determination of futility—has increased importance. (p. 14)

Based on the confusion surrounding the imposition of care that may be deemed futile, Schneiderman (2011) proposed a definition of futility to be weaved into medical policies and procedures given the cost and suffering that are inherent in these circumstances. If a procedure has demonstrated no clinical benefit in the last 100 attempts, then it is likely to continue to be of no clinical benefit in the future (Schneiderman, 2011). More importantly, Schneiderman et al. (1990) posited a qualitative definition of medical futility that relates more to a person's quality of life. If the realistically achievable goals of a particular intervention do not include a person existing outside dependence on life-support technology and potential for socially meaningful interactions, then Schneiderman et al (1990) suggests the physician has no duty to offer such an intervention.

A group of physicians who took part in a study to estimate the amount of futile care provided in the ICU (Huynh et al., 2013) decided that futility can be assigned under the following circumstances: "burdens grossly outweigh benefits, patient will never survive outside an ICU, patient is permanently unconscious, treatment cannot achieve the patient's goals, or death is imminent" (p. E2). Over a period of three months, the authors found that approximately one-tenth of patients in the ICU are receiving futile care. The most common example of futile care was when the burdens grossly outweighed the benefits. The second most common example of futile care was when treatment did not coincide with the patient's goals; however, several patients evidenced all four criteria simultaneously (Huynh, et al., 2013). The practice of providing futile care has also been the source of moral distress and impaired communication among ICU staff, and this has directly correlated with emotional exhaustion (Meltzer & Huckabay, 2004).

The legal case of Helga Wanglie brought these issues to public attention (Miles, 1991). Wanglie's husband and adult children insisted she be kept alive in the ICU by mechanical ventilation (Miles, 1991). They demanded this even though her doctor was adamant that the treatment was inappropriate due to her vegetative condition (Angell, 1991). Because there was no compelling evidence of Wanglie's wishes, the case went to court, the judge ruled on the side of the family, and Wanglie was kept on mechanical ventilation (Angell, 1991). On the face of it, this case seems to be the opposite of the Quinlan's situation, in which her father was attempting to remove her from mechanical ventilation, and the court ruled in his favor (Jonsen, 1993). However, both rulings are similar in that they simply allowed the patients' families to decide (Angell, 1991). Of additional interest in the Wanglie case was the doctor's contention that her life was not worth prolonging (Ackerman, 1991). Ackerman posited:

> The parties to the dispute do not disagree about whether maintaining Mrs. Wanglie on a respirator is likely to prolong her life; they disagree about whether her life is worth prolonging. This is not a medical question, but a question of values. Hence the term “medically inappropriate,” with its implication of the relevance of technical medical expertise, is itself inappropriate in this context. (p. 28)

The Wanglie case demonstrated the emotional and confusing position families often face regarding end-of-life care (Miles, 1991; Ackerman, 1991). Hardwig (2005) noted that the medical industry, through its consistent imposition of hopeful statements throughout the course of a chronic disease, is partly to blame for this confusion. When it comes time to make end-of-life preparations, the family is conditioned to expect miracles (Chapple, 2010), and this expectation is supported by the media and entertainment industry (Diem, Lantos, & Tulsky, 1996). Furthermore, a physician's terminal prognosis is not immune from error (Christakis, 1999). However, Schneiderman (2011) points out that the diligent adherence to a futility policy will provide some level of clarity and understanding if applied with clear and compassionate communication, utilization of the multidisciplinary treatment team, and provision of aide to the patient and families in finding care somewhere else if treatment continues to be demanded.

Quality of End-of-Life Care in the ICU

Several studies focused on the family's rating of the dying experience in the ICU (e.g., Mularski, Heine, Osborne, Ganzini, & Curtis, 2005; Teno et al., 2004), finding that most people were dissatisfied with the quality of care their family members received. Families reported that pain was not controlled in the majority of patients, and other symptoms of distress were not addressed, such as agitation and breathing difficulties (Mularski et al., 2005). Kirchhoff et al. (2002) employed a qualitative focus group format to investigate families' experiences with the death of a loved one in the ICU. Families expressed some common themes such as overwhelming uncertainty, dilemma, and responsibility to protect. Participants indicated that better communication with healthcare professionals would have alleviated much dissatisfaction (Kirchhoff et al., 2002). In contrast, the authors of a cross-sectional quantitative study found the majority of families to have been satisfied with the quality and quantity of end-of-life care in the

ICU (Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003). These two studies had significant methodological differences, which may account for their contrary findings. For instance, the second study (Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003) was conducted by the hospital itself, and the questionnaire was accompanied by a letter signed by the hospital CEO. The first study was held outside of the hospital and procedures to neutralize the interview experience were adhered, thereby promoting participant openness and honesty (Kirchhoff et al., 2002). Certainly an honest and open discussion about quality end-of-life care in the ICU would benefit all involved and facilitate increased quality, which would promote the survivors' subsequent healthy bereavement.

Bereavement and Grief

Recovery from the loss of a loved one can be the most challenging situation a person can face (Holmes & Rahe, 1967; Muller & Thompson, 2003). Grief can be so intense that one may become susceptible to illness, and it may take some time to re-engage with life (Bondi & Picardi, 1996; Nolen-Hoeksema & Larson, 1999). Although a return to normal functioning does evade a small percentage of those who have suffered a loss (Neria & Litz, 2004), the vast majority of people adjust to the loss and regain some form of normality in their lives (James & Friedman, 1998).

To be clear, bereavement is the event of a person’s death to whom one is emotionally attached, while grief is the distress that accompanies that event (Zhang, El-Jawahri, & Prigerson, 2006). Kastenbaum (2004) provided this definition: “Grief is a response to bereavement; it is how the survivor feels. It is how the survivor thinks, eats, sleeps, and makes it through the day” (p. 350). Bowlby (1980) described grief this way:

> Loss of a loved person is one of the most intensely painful experiences any human being can suffer. And not only is it painful to experience but it is also painful to witness, if only because we are so impotent to help. To the bereaved nothing but the return of the lost person can bring true comfort; should what we provide fall short of that it is felt almost as an insult. (pp. 7–8)

The process of grief is idiosyncratic, owing its course to a number of factors such as gender, relationship, age, and previous history of loss (Kastenbaum, 2004). These contributing factors span the width and breadth of the experience from the point in time prior to the loss (Coombs, 2010; Reynolds & Botha, 2006) to some degree throughout the survivor's life (Bowlby, 1980). For instance, care-giving for patients in a vegetative state showed that grief responses, and even depression for some, began well before the patient's death (Chiambretto, Moroni, Guarnerio, Bertolotti, & Prigerson, 2010). This phenomenon is known as anticipatory grief, which is the acknowledgement of an impending death and initial adjustment to life without the person in question (Gilliland & Fleming, 1998). Zhang, El-Jawahri, and Prigerson (2006) studied the length of time grief is salient and found subjects reported relatively high levels of yearning (for the deceased) two years after the loss. Shah et al. (2013) found that expectation and anticipation of death plays a role in the survivor's bereavement. For instance, unexpected and unanticipated deaths led to a heighted risk or mortality in survivors versus those deaths that were anticipated. Preparation or anticipatory grief may play a buffering role in the adjustment to loss (Shah et al., 2013).

The increase in morbidity and mortality among surviving spouses is another sign of the risk to those in bereavement (Bowlby, 1980; Kastenbaum, 2004; Williams, 2005). Research has suggested a higher risk of mortality for widowed spouses as compared to married subjects who have not suffered the death of their spouse (Elwert & Christakis, 2008; Kaprio, Koskenvuo, & Rita, 1987; Martikainen & Valkonen, 1996), but these findings have not been completely consistent. The researchers of one study (Elwert & Christakis, 2008) found that, over a 9-year period after the death of a spouse, women have a 16% higher risk of death and men have a 18% higher risk of death (than the general population), but these findings varied significantly by the cause of death. The author of another large longitudinal study found an initial risk, but also found the risk of death to diminish after six months (Bowling, 2009). Stroebe, Schut, and Stroebe (2007) reviewed 16 longitudinal studies published between 1993 and 2006 and found relatively strong consistency for increased risk of mortality and morbidity among bereaved spouses. Similarly, this “widowhood effect” was studied by Moon, Kondo, Glymour, and Subramanian (2011, p. 1) through meta-analysis (15 prospective cohort studies) of the risk of death after becoming a widow. Evidence for an increased risk was documented, but the risk significantly diminished after 6 months. Furthermore, the researchers found no evidence for a difference in gender or age (Moon et al., 2011). King et al. (2013) conducted a 4-year longitudinal study comparing the mortality of those who experienced the death of a cohabiter to those who were cohabiting but had not been exposed to a death. The researchers did not find an increase in mortality among those exposed to death, though the latter group reported a higher incidence of new prescriptions for antidepressant medication, which indicated a higher rate of depression.

Clinical depression is said to be a risk factor in the health of bereaved people, whether they are spouses (Zisook, Paulus, Schucter, & Judd, 1997) or parents (Cohen-Mansfield et al., 2013). This has been directly addressed in past versions of the *Diagnostic and Statistical Manual of Mental Disorders* (3rd ed., rev., *DSM-III-R*; American Psychiatric Association, 1987; 4th ed., *DSM-IV*; American Psychiatric Association, 1994) in which a diagnosis of depression was excluded if it was related to bereavement. Because depression-like symptoms are to be expected after the death of a loved one, the diagnosis of a major depressive episode was considered to be excessive. The text from the *DSM-IV* bereavement exclusion criteria read that a diagnosis of Major Depressive Episode (MDE) should not be made if: “The symptoms are not better accounted for by Bereavement, i.e., after the loss of a loved one” (4th ed., *DSM–IV*, American Psychiatric Association, 1994, p. 327). The authors of the *DSM-IV* simply placed bereavement within the section titled “Other Conditions That May Be a Focus of Clinical Attention” (p. 684) and described bereavement and Major Depressive Episode as two distinct conditions (Corruble, Chouinard, Letierce, Gorwood, & Chouinard, 2009). Of course, it is true that most people do not experience clinical depression as a result of bereavement, and the spirit behind the bereavement exclusion was to avoid labeling normal responses to life events, such as the death of a loved one, as pathological (Maj, 2008). Due to more recent research (Corruble et al., 2009; Zisook, Shear, & Kendler, 2007) bereavement is no longer an exclusion in the newest version of the *DSM* (5th ed.; *DSM-5*; American Psychiatric Association, 2013). While considering the change, it was noted that “Bereavement remained the only life-event that excludes the diagnosis of MDE and MDE is the only psychiatric disorder superseded by bereavement” (Zisook et al., 2012, p. 427). The *DSM-5* made the distinction between normal grief and MDE because some people had the normal experience of grief in addition to MDE and, under the old criteria (*DSM-IV*), they were not considered for treatment. Thus, after one month of persistent symptoms of depression following the loss of a loved one, a person can be considered to be clinically depressed. The authors of *DSM-5* made the distinction that the dysphoria associated with grief is usually due to yearning for the deceased loved one "rather than the self-critical or pessimistic ruminations seen in MDE" (5th ed.; *DSM–5*, American Psychiatric Association, 2013).

Most of the research on grief has been conducted using quantitative methods (Muller & Thompson, 2003). Several studies recently have employed a phenomenological approach (e.g., Gerow et al., 2010; Hornjatkevyc & Alderson, 2011; Seah & Wilson, 2011), which takes into account both the subject and context and provides a clearer description of how a phenomenon is experienced by the individual (Creswell, Hanson, Plano, & Morales, 2007). The phenomenological approach is also consistent with and sensitive to a bereaved person's construction of meaning which can allow for adaptation and even growth (Neimeyer, Prigerson, & Davies, 2002).

Hornjatkevyc and Alderson (2011) conducted interviews with eight gay men who had lost their partners. Analysis of the interviews revealed several descriptive themes common among them: "(a) relationship with him, (b) losing him, (c) living without him, (d) connections with other people, (e) moving through loss, (f) future romantic relationships, and (g) continuing to live with and without him" (p. 807). The main themes emphasized the relationship with their deceased partner, indicating the central meaning the connection had had in their lives. Hornjatkevyc and Alderson (2011) emphasized the utility of phenomenological methodology over that of quantitative methodologies to tease out the nuanced differences and similarities common to the experience of bereavement and grief. Ghesquiere (2013) used phenomenological methods to study "complicated grief" among older adults. Complicated grief (CG) affects approximately 7% of bereaved people (Kersting, Brähler, Glaesmer, & Wagner, 2011), and it is defined by an increased intensity and prolonged duration of distress symptoms (Ghesquiere, 2013). Ghesquiere (2013) identified several common themes through interviews of eight subjects:

> observing that grief was causing a great deal of distress and impairment; grief not meeting expectations of what grief "should be"; an important influence of social relationships on support-seeking; lack of effectiveness of grief support groups and/or care from mental health professionals prior to study enrollment; and strong reactions to the label of CG. (p. 1)

The results of the research cited indicates that the bereavement process is by no means uniform, simple, or even thoroughly understood. Many variables play a part in the adjustment from loss. The loss of a loved one exacts a significant toll on some people, but by far the vast majority of people adjust without prolonged distress. It would be beyond the scope of this research to provide an exhaustive exploration of the factors and circumstances that lead to adjusted or maladjusted bereavement, thus the ICU setting and its relationship to bereavement will be the main focus of the remaining section.

Bereavement and the ICU

During the withdrawal of life support in the ICU, patients' families benefit most when communication about end-of-life treatment planning is clear, understandable, and consistent **(**Bartels & Faber-Langendoen**,** 2001). Families reported their wellbeing was tightly entwined with the patient's care and comfort (Bartels & Faber-Langendoen, 2001), and when a patient dies in the ICU, a correlation with subsequent risk of psychiatric illness among the patients' survivors has been well documented (Anderson et al., 2008; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008). Wiegand (2008) studied families during the process of withdrawing life support in the ICU. The author conducted interviews with 19 families throughout their decision-making process for patients who could not decide for themselves and who had previously been relatively healthy (Wiegand, 2008). The author grouped the findings from the interviews into categories:

> this happens to other families; time to understand the illness or injury; time to see if health would be restored; riding a roller coaster; family readiness: willing to consider LST (life-sustaining treatment) as an option; one step at a time; family readiness: time to make a decision; family will go on; waiting for a miracle. (p. 1119)

These narrative themes reflect the process undergone by families, beginning with shock and disbelief and ending with the decision to withdraw life support.

Wright et al. (2010) conducted a longitudinal study that followed the caregivers of cancer patients. The authors compared mental health of caregivers for patients who died in the ICU versus at home and found caregivers of patients who died in the ICU experienced higher incidence of psychiatric illness (e.g., PTSD) than caregivers of patients who died at home (Wright et al., 2010). Another study showed a high rate of psychiatric difficulties experienced 90 days after the patients had been discharged from the ICU (Lemiale et al., 2010). Lemiale et al. (2010) followed 284 survivors of patients who died in one of 21 participating French ICUs. The results of the 3-month follow-up indicated that family members did not have a significant number of physical difficulties after the death of their loved one, but they did report substantial psychological distress (e.g., PTSD and depression). More than a third of the respondents reported prescription antidepressant use following the death (Lemiale et al., 2010).

Researchers found symptoms of PTSD through investigations into families' response to the ICU (Anderson et al., 2008; Gries et al., 2010; Kross et al., 2011). According the DSM-5 (5th ed.; DSM–5; American Psychiatric Association, 2013), the definition of PTSD involves exposure to a trauma, whether in person or hearing the details, intrusive memories and/or dreams having to do with the trauma, avoidance of stimuli reminiscent of the trauma, some form of cognitive disturbance, along with hyper vigilance or irritability, all lasting longer than one month. These studies have shown that those who experience the death of a loved one in the ICU are at greater risk of PTSD than people who experience the loss of a loved one elsewhere. For instance, longitudinal research conducted by Anderson et al. (2008) attempted to establish the relationship between family characteristics and psychiatric symptoms among families of patients in the ICU. They evaluated 50 subjects at initial contact, one month, and again six months later. Self-reported symptoms of anxiety and depression decreased at each evaluation point; however, at the 6 month point a significant number of subjects (35%) reported symptoms of PTSD. There was no difference between family members for whom the patient died and family members for whom the patient was still living (Anderson et al., 2008). In other words, the cause of PTSD was not shown to be due to the death of a loved one, and the authors suggested it might be the ICU experience itself that was the cause of the PTSD.

Azoulay et al. (2005) conducted a cross-sectional study and found relationships between families' reports of clinically significant PTSD symptoms after the experience of being in the ICU with a loved one. They conducted phone interviews with family members 90 days after the patient's discharge or death. The authors made the distinction between posttraumatic reaction and PTSD, and posttraumatic reactions were predictive of the subsequent development of PTSD (Azoulay et al., 2005). The authors found that half of those whose loved one died in the ICU (28 out of 56 respondents) reported symptoms of PTSD, compared to 28% of those whose loved one was discharged from the ICU alive (66 out of 228 respondents). Similarly, Gries et al. (2010) conducted a cross sectional study of the relationship between psychiatric symptoms among caregivers and the death of a loved one in the ICU. The researchers looked at PTSD and depressive symptoms 6 months (3 months later than Azoulay et al., 2005) after the death. They obtained these data through 226 questionnaires (response rate of 46%): 14% of respondents “met symptomatic criteria for PTSD,” (p. 283) and 18.4% for depression. The authors mentioned the disparity between their findings and that of Azoulay et al. (2005) and suggested that the difference may be attributable to the 90-day period post-death in Azoulay et al. (2005) versus 6 months in Gries et al. (2010). However, these findings are consistent with those of Tilden, Tolle, Nelson, and Fields (2001) who found high levels of stress in families 6 months after withdrawal of life support.

The setting and context of the ICU play a large part in a surrogate decision-maker's experience due to the sudden nature of decision-making and the dilemma of having to be responsible for whether or not to withdraw or withhold life-prolonging technology such as breathing machines, artificial feeding, or medications to sustain blood pressure (Kirchhoff et al., 2002). Families are sometimes faced with life-or-death decision-making for which they may have sustained guilt (Doka, 2005). If life-sustaining technology is withdrawn at the behest of a family member, they may feel they are killing their loved one regardless of the legal or bioethical positions to the contrary. If they decide to continue life-sustaining technology, they may later feel they prolonged suffering in a long drawn-out death process (Shah & Miller, 2010). These phenomena have a significant impact on the survivor's experience of bereavement and grief and subsequent health.

Summary

The breadth of experience and contributing factors surrounding death in the ICU following discontinuation of life support is the focus of this literature review. Medical discoveries and technology have paved the way for people to expect a long drawn-out death after a chronic illness (Hardwig, 2009). This new relationship to death and dying brought on by modern medical technology brings with it confusion and animosity (Chapple, 2010; Green, 2008). Van den Berg (1978) described the situation: "Medico-technical power, which has at its aim the restoration of health, is poorly suited to the approach of death. This power increasingly makes death a catastrophe" (p. 57). Because the ICU and all the accompanying medical technology hold out so much hope for cure, the perception of catastrophe in the aftermath of a death in the ICU leaves the family in chaos. Thus, the experience of death in the ICU leaves the family/caregiver in distress and psychological imbalance.

Chapter 3
Research Problem and Method

Awareness of the risk factors associated with the experience of removing life support for a family member is essential for clinicians. After a thorough examination of the topic, Lemiale et al. (2010) expressed the need in this way:

> We believe that our findings and those from earlier studies indicate an urgent need for creating multidisciplinary collaborative working groups and evaluating the impact of a proactive post-ICU management strategy on the long-term mental health burden in ICU relatives. This strategy could be driven by trained ICU clinicians (nurses and physicians) who would refer family members to psychologists and psychiatrists when symptoms of anxiety, depression, or stress are detected. Evidence that up to one third of ICU-patient relatives may develop mental health disorders after the ICU experience supports this approach. (p. 1135)

Psychologists' sensitivity to the nuanced feelings that arise after these experiences will make a significant positive difference for these clients. The study of the impact of medical technology on death and dying is important for creation of interventions to mitigate the potential for long-lasting distress on surviving family members. This research will focus on the lived experience of family members of people who have died in the ICU after the decision to withdraw life support.

Method

This research employed transcendental phenomenology (Moustakas, 1994) due to its emphasis on understanding the experience highlighted by common essences and communicated in a naturalistic, conversational fashion. Qualitative research methodology is appropriate for psychology because of its descriptive nature versus the deductive nature of empirical methodologies (Dilthey, 1884/1977). Qualitative research has the potential to reach greater depths of human experience because the researcher “enters the participants’ world to collect data and literally becomes the instrument when analyzing it” (Devers & Robinson, 2004, p. 241). This methodology is well suited for the investigation of meaning derived from a human experience (LeVasseur, 2003), such as the one proposed by this study. Given the maxim “method must serve topic and not the other way around” (Coppin & Nelson, 2005, p. 34), this research methodology was chosen due to the intensity, richness, and universal impact of the topic.

Philosophical Background of Transcendental Phenomenology

Transcendental Phenomenology is based on the philosophy of Edmund Husserl (1931/1962), who focused on the subjective nature of reality. Phenomenology grew out of the philosophical environment in Germany at the turn of the 19th century (Dowling, 2005). The source from which the term “phenomenology” sprang was the Greek word *phaenesthai*, which means to show itself or to appear (Moustakas, 1994). As a reaction to the exclusive emphasis on objective reality during the turn of the 19th century, Husserl expanded upon and formulated the philosophical movement that emphasized the lived experience of the object or the phenomena of what he called Transcendental Phenomenology (Heelan, 1987). It may seem contradictory that Husserl was a mathematician as well as one of the leading philosophical scholars of his day. His frustration with the empirical attempts to apply mathematical certainty to the lived experience drove him to expend much energy in the formulation of his Transcendental

Phenomenology (Smith, 2006). Husserl (1970) called the attempt to reduce the lived experience to mathematical certainties “naturalism” (p. 40), which has its roots in Descartes' emphasis on mental logic *cogito ergo sum* (Heelan, 1987). "This naturalistic attitude ‘reifies’ and it ‘absolutizes’ the world such that it is treated as taken-for-granted and ‘obvious,’" (Moran, 2008, p. 401).

Husserl (1929/1960) focused on the subjective experience of the subject in conjunction with the object as the path toward perception of reality and, like Descartes, recognized that any objective reality is dependent on the subjective perception of that reality (Moustakas, 1994). For Husserl, the dualism of subject and object was bridged by the perception of the phenomena in the moment (Moran, 2008), and regarding this he wrote about the ordinary *natural attitude* that perpetuated the empirical and reductive view of the world (Husserl, 1927/1971):

> So when we are fully engaged in conscious activity, we focus exclusively on the specific thing, thoughts, values, goals, or means involved, but not on the psychical experience as such, in which these things are known as such. Only reflection reveals this to us. Through reflection, instead of grasping simply the matter straight-out—the values, goals, and instrumentalities—we grasp the corresponding subjective experiences in which we become “conscious” of them, in which (in the broadest sense) they “appear.” For this reason, they are called “phenomena,” and their most general essential character is to exist as the “consciousness-of” or “appearance-of” the specific things, thoughts (judged states of affairs, grounds, conclusions), plans, decisions, hopes, and so forth. (p. 3)

Husserl (1931/1962) further clarified these notions by using the term *noema* to indicate what is perceived, and *noesis* to mean the psychical act of experience of the phenomena. The bridge between subject and object lay in the fact that these two fundamental functions of consciousness are simultaneous. The intentional consciousness of a thing is a reflection automatically imbued with values, goals, and judgments. This level of perception refers to the experience of "thinking, feeling, remembering, and judging" (Moustakas, 1994, p. 69), thus, noema is that intentional perception of an object, not the object itself (Husserl, 1931/1962). This process is so automatic that the values and judgments that accompany any phenomena are "concealed and hidden from consciousness" (Moustakas, 1994, p. 69).

One could say the natural attitude is to remain unconscious until effort is put forth to doubt the world around and the normal perception of its objects (Moustakas, 1994). Noema is the attraction of attention drawing consciousness toward one phenomena versus another, and the experience of this phenomena can be seen to have been entirely internally conceived, or intentional (Husserl, 1931/1962). The automatic naturalistic tendency of our experience of the world around us is what Husserl (1935/1970) was responding to in his development of Transcendental Phenomenology as an attempt to address the conscious experience of the lived world that acknowledges categorization or conceptualization.

Husserl felt it was important to be aware of the tendency to place judgments and categorizations on the sensory input when attempting to look anew at phenomena (Moustakas, 1994). He proposed the process of bracketing, or what he called “Epoche,” to acknowledge and see beyond, to transcend, the preconditions that are habitually placed on the lived experience of the world around (LeVasseur, 2003). In other words, the automatic way of seeing the world is put aside in describing the phenomenon in question, and the phenomenon in question is put in brackets in order to be able to see it for what it is, not what we already think it is (Hamill & Sinclair, 2010).

Methodological Research Background

The practice of phenomenological research is called "attentive practice of thoughtfulness" (van Manen, 1984, p. 38). The transformation of the philosophy of Transcendental Phenomenology into a research methodology is intended to provide a concise and organized design that will bring to light the essence of the participant's experience (Moerer-Urdahl & Creswell, 2004). The researcher attempts to see the phenomenon in a fresh way through the lens of the participant by the practice of setting aside prejudgments and sympathy. To clear away predeterminations through contemplation and meditation helps to facilitate a focus on what the participants are actually conveying, instead of choosing evidence that conforms to predetermined conclusions (Moustakas, 1994). That is not to say that the researcher is a blank slate; the researcher brings a point of view that is not denied, but brought to consciousness and bracketed to see the phenomena from a fresh perspective (Hamill & Sinclair, 2010). “The challenge of the Epoche is to be transparent to ourselves to allow whatever is before us in consciousness to disclose itself so that we may see with new eyes in a naive and completely open manner” (Moustakas, 1994, p. 86). The point is to create some distance from the automatic subjective experience to open up a new way of seeing and hearing (Himanka, 2010).

Transcendental Phenomenology is not an explanatory or interpretive method of investigation. The focus lies instead on description of the source of attention (Husserl, 1927/1971; Lopez & Willis, 2004). After the researcher is prepared through the process of Epoche, the data is considered through the process of Phenomenological Reduction (Moustakas, 1994). Thus, Husserl (1927/1971) emphasized whatever is left over after the Epoche process is to be studied and described. He pointed out that there will be two perspectives, the one prior to Epoche, what he termed the naturalistic attitude, and the new transcendental attitude (Himanka, 2010). Himanka (2010) gave the example of two perspectives of seeing a group of apples; the arithmetic worldview would see three apples versus the alternative perspective of seeing the apples as something to eat (p. 620).

Another aspect of the Phenomenological Reduction is the acceptance of all horizons, as Husserl (1935/1970) put it, which means giving equal relevance to all that comes into consciousness while reflecting and remembering the phenomena. During the retrospection of the phenomenon in question, the researcher removes the redundancies and peripheries and the remaining horizons are grouped into themes as Moustakas (1994) wrote, “Organizing the horizons and themes into a coherent textural description of the phenomenon” (p. 97). Thus, the researcher looks for irrelevant and repetitive statements and removes them from the data set. After clustering the remaining statements into units of meaning, themes emerge from the data (Moustakas, 1994). For instance, in a study of the experience of falling out of romantic love, Sailor (2013) identified five themes from analysis of the interviews: “loss, emotional pain, negative sense of self, gradual decline, and pivotal moment of knowing” (p. 7). Another example of Phenomenological Reduction is the study of the “ripple effect” among youths participating in a leadership mentoring program (Moerer-Urdahl & Creswell, 2004). Moerer-Urdahl and Cresswell (2004) found that participants in a mentoring program tended to use common terms such as “the ripple effect,” which described the potential for their work to have long-lasting effects (p. 4). “Four themes emerged from this analysis about how participants experienced the ripple effect: investing and reinvesting in others, influencing others positively, giving and receiving, and establishing interconnectedness among relationships” (p. 14).

The ultimate goal of transcendental phenomenology is access to the attribution of meaning surrounding the phenomenon (Moustakas, 1994). Meaning is achieved through the imagination that opens the door to previously inaccessible aspects and connections during consideration of different perspectives and contexts. Moustakas (1994) called this "imaginative variation" such that studying the data will lead to enhanced groupings of the themes and enriched descriptions of the meaning conveyed by the research data. At this point in the analysis of the data, each participant's response, which had previously been dealt with separately, is grouped together in an attempt to synthesize them into the essence of what the subjects conveyed (Moerer-Urdahl & Creswell, 2004; Moustakas, 1994). It is this synthesis that provides the material for the phenomenological description.

Participants

Research participants had experienced the decision to remove life-support from a family member, had an interest in exploring this experience and its meaning, were able to engage in a lengthy interview process, and were willing to be tape recorded and have the results published (Moustakas, 1994). The researcher employed a convenience sampling technique with family members living in Southern California. Participants were contacted, and a brief description of the study was made available to them. Four participants were employed for this study, and an effort was made to vary the demographic background and relationship to the loved one that died in the ICU. No participant was eligible prior to one year after the date of the death. In addition, this study was limited to people with a primary relationship to the deceased, (e.g., spouses, parents, adult children).

Data Collection

In-depth in-person semi-structured interviews were conducted. Prior to the interviews, the researcher sat in meditation to facilitate the Epoche process. This helped to set aside preconceptions and biases to enable a fresh reception of the participant's experience. Moutstakas (1994) suggested that the Epoche process might need to be engaged during the interview also, not to disrupt the interview, but silently within the researcher.

The interviews took place at three locations: the researcher’s consultation office, the office of one of the participants, and the researcher's home. The locations were secure and free from interruption, as Moustakas (1994) stated: “The interviewer is responsible for creating a climate in which the research participant will feel comfortable and will respond honestly and comprehensively” (p. 114). The interviews were participant driven with one question presented at the beginning. This question was generated based on recommendations by Moustakas (1994): “What was your experience of the death in the ICU?” Each interview was left to unfold naturally, as there was no script. When prompts were necessary, they were presented spontaneously based on the unique situation. Interviews unfolded in the form of a discussion.

Data Analysis

The researcher created transcripts of the interviews, and the data was analyzed for basic themes to bring out meaning communicated by the participants. Significant statements were identified during the process of horizontalization (Moustakas, 1994). Then statements that were common among participants were clustered into categories or what Moustakas (1994) calls “invariant constituents” (p. 122).

The researcher considered textural aspects of the data by asking, "What did the participants experience through death in the ICU?" The structural descriptions of the experience were examined through details such as the relationship with the deceased, cause of the death, and the participants’ age. These textural and structural considerations of the data were further synthesized into the essence or themes of the participants’ experience of the phenomenon of death in the ICU. Moustakas (1994) called this stage “intuitive integration” (p. 100).

Ethical Considerations

Participants' recollection of the death is the primary area of ethical consideration. These memories may have triggered distress, and if the experience was traumatic, and had not been adequately processed prior to the interview, it may have required further therapeutic attention. Due to this potential, certain arrangements and procedures were followed. No person was eligible to participate in this study prior to one year after the death. Prior to the interview, the participant received by mail a brief description of the project along with an informed consent form. The researcher reviewed the project description and the consent form in person just prior to the interview to clearly communicate the nature of this study and the procedures that were involved. The participant was instructed that she or he may stop the interview at any point for any reason, and it was made clear that the researcher may also stop the interview for any reason during the process. Following the interview, a debriefing took place with all participants, and referrals to local psychotherapists were on hand. Participants had the phone numbers of the researcher and the dissertation chair to address any questions or concerns that may arise at a later date. Participants reviewed transcribed versions of their interview to assure accuracy. Confidentiality was maintained by following these procedures: the location of the interviews was secure and private; interviews were recorded in a digital format with no identifying personal information or labels; reference to the data was aggregate and specific examples were veiled so as not to be traced back to the individual; these data were kept in a locked cabinet; and any identifying information was not included in the research text.

Chapter 4
Findings

These data were analyzed with the methodology of transcendental phenomenology (Moustakas, 1994). The four participants are middle-aged, Caucasian, and female. Two of the participants were spouses of the deceased, two were daughters, and all of the deceased had been more than 70 years old at the time of death. Each of the four participants was in the position to make the decision to stop life-support because the patient had become nonresponsive. Three of the participants experienced their loved one's death just after removal from life support, and one participant experienced her mother's death 4 days later. It is important to note that long chronic illnesses preceded each of the deaths, and one of the deceased was placed on life support after a surgery that was expected to be successful.

I spent significant time reflecting upon these interviews with a priori values and judgments. Husserl described this as the “naturalistic attitude” (1927/1971, p. 6). This attitude reflects the academic book learning that influences perception by making certain aspects of the experience more salient than others. For instance, I was initially tempted to view these interviews from the perspective of pathology or symptoms of PTSD. It was not until I reviewed Husserl's work, and then reviewed the interviews, that a fresh perception of them was possible. I noticed the judgments and values that had caused an a priori interpretation of the interviews, and I was then able to set them aside to the greatest extent possible. I adopted a new way of seeing these experiences by bracketing out my preconceptions to the greatest extent possible to view these interviews from outside my typical cultural milieu. From this perspective, the themes became clear and the experiences the participants conveyed came to life.

Tracing one example of how these interviews came to life might clarify this process of reduction to invariant constituents (Moustakas, 1994). Upon transcribing these interviews and carrying these words with me throughout the days, I was able to look beyond the surface meanings to a deeper level of understanding of my relationship to these narratives. I noticed a tendency within myself to see the experiences of the participants through eyes of a healthcare professional. In this capacity, I have sat with countless people who have lost loved ones to death in the hospital. This perspective created a certain expectation that became evident, and it caused me to be more alert to some aspects of the interviews rather than others, which, in turn blinded me to other aspects of the related experiences. For instance, I had the perspective of a therapist as I was reflecting on the phenomenon related by each of these women. This caused me to pick out sections that were obvious to be revisited on our next session together, even though I was fully aware that I would not see these people again in this capacity. I was on the lookout for unconscious contradictions that may be a clue to an underlying problem. I had to bracket out my tendency to see these narratives as descriptions of problems to be solved. These people were not recounting problems, they were simply sharing their experience as they carried it at that moment we met. When I categorized their stories as problems, I missed out on a good proportion of what they were conveying.

It was only then that I was able to notice the level of ambivalence, for instance, that consistently ran throughout these interviews. As I reflected on these seemingly contradictory statements, it became clear to me that the experience was not either all good or all bad for these women. In other words, this experience was horrific and, in some cases, infuriating, but each of the participants was able to remember some good. Terror and fondness were not mutually exclusive for these women when recounting their experience, and this was not a problem. Thus, it became clear that *ambivalence about care* was one of the themes to be extracted from this investigation.

These themes reflected the lived experience of each of the participants in what they emphasized to a greater or lesser extent. Table 4.1 depicts seven themes common to each participant's reported experience: overall experience, mental perspective, ambivalence about care, perceptions of technology, the decision, the aftermath, and suggestions for others. These categories are by no means mutually exclusive; however, they provide a framework with which to better understand the lived experiences as expressed by these women.

(Table 4.1) *Table of Common Themes Evoked from Removal of Life-Support*

Themes	Examples
Overall Experience	- It was so painful. - Traumatic - It was life changing. - It probably was the worst experience. - It probably was the best it could have been. - I'd never want to do it again. - It shook me to do this. - It really affected me.
Mental Perspective	- There was this sense of detachment. - It seemed like it was weeks but it was not. - I think that it's hard to say there's no hope. - I just didn't want to lose her. - The experience of being responsible for someone's death. - That all of this was happening did have a kind of dream-like quality to it.
Ambivalence About Care	- The doctor was very... she was very sympathetic, she was very kind, she said, “Oh I'm sorry that you have to go through this and make this decision.” - So I was really disappointed in their treatment. - They were a little distant, and in their mind they were probably giving us privacy. - They gave us the time to spend with her. - But they were so compassionate in ICU. - I never had any nurse that made me angry. I only had nurses that weren't informative.
Perceptions of Technology	- She was intubated at that time, she was in ICU. - And then we watched the monitor and everything slowed down. - Not just when you see that ventilator come off, then you see the whole person, the whole thing. - Without all that machinery on him, it's like he can't be dead. - It's the worst to see somebody in ICU. They can't communicate. - I regret that I didn't see him with everything taken off. - We actually went out of the room and asked them to turn them off.

(Table 4.1) *Table of Common Themes Evoked from Removal of Life-Support*

Themes	Examples
The Decision	- They didn't offer a lot of alternatives or choices or anything. - There was no way that I would even think of continuing the ventilator or doing any of that stuff. - I never questioned the idea that he was dying. - I had pretty much given up hope by then myself. - They never told me that he was going to die. - “It's you and your family’s decision to take him off life support.” - I had decided because the nurse said to me, “He's in a lot of pain.” - Well, she’s brain dead, why are we doing all this? - Oh my God, did we make the wrong decision? - We might have made a different decision had we known she really wasn't brain dead. - What if we make that decision and she does live, and she’s on tube feedings the rest of her life, and she's in diapers and in a wheelchair. - It's a passive thing to say, “Do not resuscitate” because it’s something in the future, it’s a hypothetical, but then to actually, you know, have to...
Aftermath	- And then it was quiet. - I was dazed, I was in a stupor. - The anger didn't really come until like a year later. - I'll never forget him. - I stuck in that anger for a really long time. - I know it's her body, but you still feel like she’s left in there alone. - I remember the kind of lost feeling. - I guess it’s just something I'm going to have to live with for the rest of my life, wondering if I made the right decision. - I still have nightmares about it. - It still haunts me. - I live with that guilt. - We’ve tried to, I guess, kind of rationalize it.
Suggestions for Others	- I think the hospital should have asked, “Well, does she have a DNR?” - I think that it would always be preferable if people could die at home. - I definitely feel people should have advanced directives. - When you're having the family make these difficult decisions on what to do and what to honor in the power of attorney, you really need to give them accurate information because it's already an emotionally charged moment.

Overall Experience

All four participants depicted the overall experience with words that reflected the monumental nature of the event. The interview began with the question: “What was your experience of the death in the ICU?” One participant reflected, “Well, it was... traumatic, life changing, um... poignant, almost surreal. I think those are the main adjectives I'd say to describe what it felt like.” Participants made statements exemplifying attempts to make sense of the overall experience: “It was probably the best it could have been.” This statement was in contrast to a statement from the same participant: “It was the worst experience.” Another participant said, “It felt like my whole world fell apart.”

A common aspect of the overall experience reported by the participants was feelings of guilt. Guilt was expressed either overtly or covertly throughout the interview. Statements such as, “Now we're feeling totally guilty, still to this day... that maybe we made the wrong decision,” was how one participant related feelings of guilt. Another participant expressed a more covert example of the lived experience, “So I said I'm going to leave, ’cause I can’t be here.” Another expressed her experience in this way, “And then, you know, that anger and rejection, you know... and then the intubation and having to take her off of it and then her not dying.”

Mental Perspective

The individual’s mental perspective acted as a filter through which each participant took in the experience. One participant aptly summed up her mental perspective in this situation by saying, “It's kinda weird what you think when these things happen.” Examples of mental perspective often involved some sort of dissociation

(Nijenhuis & Van der Hart, 2011) from the experience in the ICU. For instance, “Because it was so surreal, and it felt like I was a displaced person. I felt displaced. I felt out of sorts—sort of an out-of-body experience.” Each of the participants had some degree of time distortion, and this influenced their perspective. One participant said, “So there wasn't a lot of time to get used to anything,” and another said, “It seemed like it was weeks but it was not.”

All participants, to some degree, experienced the mental perspective of clinging. One participant expressed this most directly by stating, "You don't want to let go of the person." It meant a lot to one of the participants that her mother seemed to acknowledge her when she entered the room in the ICU. She expressed the experience this way, "I thought she was trying to communicate something to me. But, I mean, they... the doctors and nurses said, 'Oh that's just a bodily response.' But that's not how it resonated with me."

Finally, the weight of this experience was clear with each of the participants, and this was a significant aspect of their mental perspective. Statements that included phrases such as, “Being responsible for someone else’s death,” and another participant who reported hearing from the doctor, “It's you and your family's decision to take him off life support” reflected the intensity of this situation for these people.

Ambivalence About Care

Ambivalence characterized the interface between participants and the healthcare provided. Participants consistently both praised and criticized the care their loved ones received in the ICU. One participant’s interpretation of the care she and her family received in the ICU was expressed this way: “The ICU nurses were a little distant. In their mind, they were probably giving us privacy." The angry reaction to her mother being revived in spite of having an advanced directive stipulating otherwise is a good example of this dissonance expressed by another participant. Subsequently, the participant had to advocate for her mother to be removed from life support. Despite her anger, the participant described her interaction with the physician by saying, "The doctor was very... she was very sympathetic. She was very kind. She said, 'Oh, I'm sorry that you have to go through this and make this decision.' " Because her husband had been transported to an alternative hospital's ICU, another participant commented on the differences in locations where her husband received care by saying, "it was like night and day."

Moreover, ambivalence was also a primary response to the level of communication in the ICU. One participant said, "I never had any nurse that made me angry. I only had nurses that weren't informative." Participants mentioned ambivalence surrounding questions about scope of practice demonstrated by the medical team. The most glaring scope of practice breach was a nurse who prematurely announced to a participant and her family that the patient was brain dead. The participant described it this way, "When the doctor came in to talk to us the next morning, I said, 'Well, the nurse said she was brain dead.' He said, 'I never said she was brain dead!' "" The discrepancy in information between the nurse and the doctor communicated at different times to the family caused significant distress to the participant and her family. Another participant said, "And I'll tell you, I wished I could remember that one gal that said to me, 'cause I didn't know it until that day. She said, 'He's still in pain. He's in horrible pain.' I was so glad she told me." This participant was recounting what a nurse said to her, which made this participant hasten her husband's removal from life-support. This could be seen as another example of scope of practice confusion, as this information is ordinarily conveyed by the attending physician. It is important to note that participants frequently expressed complimentary phrases in these interviews: “But they were so compassionate in the ICU,” and “They just made it comfortable.”

Perceptions of Technology

The presence and influence of technology significantly impacted participants throughout their experience in the ICU. The life support machines impaired communication and intimacy at the end of life. The monitoring devices became hypnotic as participants sat in the room with their loved ones. “And then we watched the monitor and everything slowed down,” said one participant. Another participant said, “We actually went out of the room and asked them to turn them off.” The monitoring devices became key in the perception of life and death: “Watching the numbers and everything... we could see everything was... flat.”

The discrepancy between how they knew their loved one to be and what they were experiencing in the ICU was a common topic brought up. “Without all that machinery on him, it’s like he can't be dead” was how one participant put it. Another participant said, “Because when I said goodbye to him, I couldn't even get close to him. There was so much around the bed that I couldn't even kiss him on the cheek.” And finally, another reflected upon the experience this way, “I think that technology is distancing us from our humanness in general, but certainly in what should be the most intimate moments in one's life: birth and death.”

The Decision

The decision to remove life support was the nexus of the experience in the ICU for these people. With this decision came varying degrees of contemplation and lamentation, which was impacted most directly both by how it was presented by the physician and by the participant's relationship to hope.

Even though the decision to remove life support was shared by the four participants, how this decision became manifest was different for each of them. For instance, one participant said, “They didn't say, you know, they didn't ask me, ‘What do you want to do?’ or anything like that.” The same participant went on to say, “They just said, you know, basically that he was dying. They didn't offer a lot of alternatives or choices or anything.” Her relationship to hope was exemplified by this statement, “I had been watching for two weeks this process, this evolution. And I saw, you know, the... deterioration and the, um, I mean I was, I had pretty much given up hope by then myself.”

In contrast, a physician said to another participant, “It's you and your family's decision to take him off life support.” The participant said, “I was just kind of going along hoping that he maybe was still going to survive, and until that... that's when the doctor, he kind of said to me, ‘Ya know, he may or may not survive after this.’ ” This participant framed her decision this way, “And then when the nurse told me that ‘Yes, he was in pain,’ ...the doctor made me realize that I was going to have to take him off life support. And the nurse made me realize I had to do it sooner than trying to see if he was going to respond.” This participant decided to take her husband off life-support based on the ICU nurse's statement.

The third participant decided to forgo surgery for her mother, and ultimately to take her off life-support based on misinformation provided by the ICU nurse. “We might have made a different decision had we known she really wasn't brain dead” was how this participant framed the dilemma. This participant was very clear about consideration of implications surrounding this decision: “On the flip side, you don't want to prolong something, and it's going to be harder later to unplug the ventilator or something. Now we know for sure that's not what she wanted, you know.” She went on to say, “What if we make that decision and she does live, and she's on tube feedings the rest of her life, and she's in diapers and in a wheelchair?”

The final participant remembered her mother being resuscitated and placed on life-support in spite of an advanced directive that stipulated against it. This participant said she resented having to make the decision to remove life-support because of a mistake the assisted living facility made in not honoring her mother's advanced directive. She said, “I just didn't feel very comfortable with that at all.” In addition, she said, “I really wouldn't want anyone else to have to put up with that; to have to go through that experience because... I don't like the idea of having control over somebody's life.” As she sat in reflection of this experience, she said, “It's a passive thing to say ‘do not resuscitate’ because it’s something in the future. It’s a hypothetical; but then to actually, you know, have to...” Her voice trailed off as she became overwhelmed by emotion.

Aftermath

Each participant reflected on the residual effects of this experience. The lived experience of these memories present themselves on a regular basis for these people, and the grief has lasting ramifications. The lived experience was present in the room for the women throughout the interviews, as reflected by these statements: “I was dazed; I was in a stupor,” “I remember the kind of lost feeling,” and “I'll never forget him.”

Each participant was able to describe her initial experience just after life-support was removed and the subsequent death of her loved one. One participant described the time just after her mother died this way: “Nobody is there to direct you, I remember this kind of lost feeling.” Another participant described it this way: “I didn't get to stay with him very long. They asked me to leave, and I said I wanted to follow the body to the morgue, and they wouldn't let me. I thought that was really nasty.” Another participant related her feelings about not being present when her husband died, “But personally, I wish I would have been able to see him alive before he passed.”

The most common reaction in the aftermath of this experience was anger in combination with the realization of the evolving nature of this experience. For instance, one participant described the evolving nature of her loss experience this way: “Actually, I wasn't angry at all at first. The anger came later when I began to understand what actually happened.” Another participant seemed to take responsibility for her anger: “I think it’s more my fault than anybody else’s because I don't think in the ICU that they want to tell you that they’re not going to live.” Later on in the interview she said, “I was stuck in that anger for a really long time.”

Guilt was also common in the aftermath for each of the participants although to differing degrees. One participant expressed guilt surrounding her relationship to the memory of her husband: “There’s a rare moment when I feel guilty, like I'm not observing the memory well enough.” Another participant reflected on her family’s decision to remove life-support: “Now we're feeling totally guilty, still to this day all three of us feel guilty, um, that maybe we made the wrong decision." Furthermore, a participant who was not present at the moment of her loved one's death said, "I think people made me feel kind of guilty, and not purposely, it was my own guilt because so many of them were so glad that they were there."

Each of these people expressed ways they were able to adapt to living with this experience. For instance, one of the participants said, "(I have) perspective and some compassion... for the fact that they just don't know everything." She was referring to the physicians and medical staff whom she perceived to be so frustrating at the beginning of her experience. Attempts to live with the residual feelings and memories were described by another participant this way: "We've tried to, I guess, kind of rationalize it." Along those lines, another said, "I seriously think as sick as he was and the way that I handled things, it was probably the best case scenario."

Suggestions for Others

One of the ways each of the participants adapted to this experience was to think about suggestions for what could have gone better. These were presented in this context in hopes of alleviating the distress of others in similar circumstances. For instance, one participant commented on her mother having been put on life-support against her wishes:

> I think certainly first of all the initial putting her... intubating her... that is really, I don't know, it seems, that seems unprofessional on both the part of the assisted living, and I think the hospital should have asked, "Well, does she have a DNR?"

Later in the interview she went on to say:

> I think it would have been nicer to have her in a, you know, in a... in a room in a setting where she would have felt comfortable. Even if she wasn't aware of where she is I think that her soul would (be) aware of where it is, and... Yeah, I think that it would always be preferable if people could die at home.

Similarly, another participant commented:

> I definitely feel people should have advanced directives. Um, I don't understand how it went from a DNR to just jump on him and intubated him. It wasn't even, they didn't look at me and say should we do this. It was just done. That was in the ER. Um, I think people need to make it known. I mean I was kind of going, “Well he wouldn't want this, and—” I think that needs to be addressed right from the beginning.

Another participant commented on the level of communication that is necessary to be able to make an informed decision:

> When you're having the family make these difficult decisions on what to do and what to honor in the power of attorney, you really need to give them accurate information because it's already an emotionally charged moment. You just got this news, and you're trying to do the right thing.

Chapter 5
Discussion

The findings of the present study offer a view into the lived experience of removing life-support for a loved one in the ICU. Participants were clear in their descriptions of what they experienced during this process. These interviews took place after a significant amount of time had elapsed since the experience; thus, the focus of this research was the current experience these people brought with them to the interview. Participants shared their current memories of the event that occurred several years in the past with an emphasis on the current texture and structure of the experience. As a result, this research project provides a glimpse into how the lived experience has evolved over time.

This study stands out as compared to similar research (e.g., Wiegand, 2008) due to the extended amount of time since the participants' experience. Anderson, Arnold, Angus, and Bryce (2008) studied families 6 months after their ICU experience. The amount of distress that continues to be associated with this experience by the participants of this study suggests it has had a significant impact beyond six months. This impact took on many forms, such as guilt and anger.

The results of this study provided mixed support for the literature review previously presented. For instance, the structural finding that the decision to remove life-support is most often made as a family consensus (Tilden, Tolle, Nelson, & Fields, 2001; Wiegand, 2008) was not the case for three of these four participants. Only one of the participants had family members involved in the decision process. This is relevant due to the considerable amount of stress expressed by each of these participants. Thus, these cases may not represent the “ideal” case as referenced by Gordon and Daugherty (2003), which suggests the “ideal” may not be the norm. For instance, one study (Breen, Abernethy, Abbott, & Tulsky, 2001) found a significant amount of conflict in the majority of cases studied in the ICU involving withdrawal or withholding of life-support. These conflicts most often surrounded end-of-life decisions, and the conflicts were most frequently between family and ICU healthcare providers. Indeed, it may be through studies such as the current research that pave the way for understanding and acceptance of ambivalence surrounding end-of-life decisions (Ohnsorge, Keller, Widdershoven, & Rehmann-Sutter, 2012).

Overall Experience

The participants in the current study unequivocally communicated the difficulty of this experience. Participants used words and phrases like “traumatic,” “my whole world fell apart,” and “it shook me to do this.” This finding is consistent with other research (Anderson, Arnold, Angus, & Bryce, 2008; Tilden, Tolle, Nelson, & Fields, 2001; Wiegand, 2008), and it demonstrates the ongoing effect this experience can have on a person. Thus, the creation of meaning is an ongoing process for these participants. A communication imparted by one of the participants after a transcribed version of her interview was sent for validation illustrates this:

> It was very cathartic. Going through it step by step all over again has given me some sort of “freedom.” I feel better about my decisions regarding (my husband). It was extremely emotional to experience it all over again. I feel stronger because of our meeting.

Mental Perspective

The lived experience of handling a death in the ICU was filtered and processed through emotional and intellectual interpretations of the surrounding events. For an experience to be considered traumatic depends on the mental perspective of the subject (Sar, 2006). For instance, participants expressed the memory of dissociation (Nijenhuis & Van der Hart, 2011) from the trauma. One participant said, “It's almost like it was happening somewhere else. There was this sense of, um, detachment, or you know I... I had to go away, you know. At some level I couldn’t...” Another participant described it this way: “It's like this tunnel vision kind of just trying to get to the door.”

The intensity and weight of this responsibility was clearly communicated by each of these participants. Tension accompanying this responsibility was also found in a study by Schenker et al. (2012), in which the participants struggled with a desire to abide by the patient's wishes and a desire to avoid being responsible for the patient's death. Another study found that end-of-life discussions were ineffectual when family members were emotionally numb (Maciejewski & Prigerson, 2013). Thus, it would logically follow that if families were experiencing emotional numbness due to the trauma of experiencing the decline of their loved one, they would also be incapable of engaging in meaningful dialogue or decision making. In other words, a person who has retracted into numbness due to threat or the perception of trauma does not have the capacity to process such information and options. The authors of this study suggested these discussions be avoided in this circumstance, and they found that when it did take place the discussion frequently led to inappropriately aggressive care (Maciejewski & Prigerson, 2013). Attention to the psychological state of family decision makers might mitigate their later feelings of ambivalence about the care provided in the ICU. In fact, a suggestion provided by one of the participants addressed this issue directly by referring to the experience as “an emotionally charged moment.”

Ambivalence About Care

Participants reported that conflicts most often centered on issues of coordination and communication, and this finding is consistent with previous research (Apatira et al., 2008; Azoulay et al., 2009; Teno et al., 2004). A lack of communication and miscommunication about the severity of the patient's condition, disregard for advanced directives, and disregard for the after-care for the families were paramount concerns. Confusion about the source and veracity of information surrounding end-of-life decision-making in the ICU came to the forefront. The emotional response to the confusion carried forth into the present during the interviews, and it seemed to be the main source of ambivalence regarding the care provided. These findings are consistent with an ethnographic study (Baggs et al., 2012) in which confusion amongst ICU physicians about role and responsibility during end-of-life decision-making within the ICU was demonstrated. Baggs et al. wrote:

> With multiple ‘‘attending’’ physicians involved in care at EOL (End-of-Life) and different rotation schedules by specialty, families experienced a constant turnover of physicians to approach about EOLDM (End-of-Life-Decision-Making). This was especially distressing to families trying to come to terms with the potential loss of a family member, who were being asked to make difficult decisions in a complex and unfamiliar situation, as has been noted by other researchers. (p. 61)

These issues impacted the participants' current memories of the ICU experience with meaning created and shaped by these memories. Shift turnover and ICU chaos make it difficult for candid and honest discussions to take place.

However, other research has shown that patients and their families have expressed a desire for open and honest discussions about end-of-life options (Apatira et al., 2008). The authors (Zhang, Nilsson, & Prigerson, 2012) of a longitudinal cohort study of 396 advanced cancer patients and their families in the ICU sought to determine what contributed to quality of life at the end of life. They discovered that one of the major contributions was a strong “therapeutic alliance” (Zhang, Nilsson, & Prigerson, 2012, p. 1139) with the physician. This notion of therapeutic alliance was also reflected in statements made by the participants of the current study. For example, “And they were very attentive, and it was a whole different experience,” was a comment from one participant who indicated a contrast to when there was not therapeutic alliance. Another participant voiced her displeasure for how she perceived the communication with her mother's physician, “He's giving us this grim picture of if she does stay alive this is what it's going to be for her: on a ventilator, you know, um, complete care—like in a nursing home.” She went on to say how much she appreciated the care they received from the other members of the ICU care team:

> The next phase of the support we got from the nurses in the ICU, the chaplain, um, you know, they were wonderful. We had a social worker come up and talk to us. They didn't overdo it, they weren't pressuring us. They gave us the time to spend with her. Everyone had their time to say goodbye. They just made it comfortable. The chaplain took us down to

> the chapel and prayed with us, um, you know there was just... that part was comforting.

Another study (Mularski et al., 2005) of quality of death in the ICU found that, among 94 family members surveyed, symptom control was paramount, with several other factors playing important roles:

> After controlling for pain rating, the quality of the dying experience for the severely ill patients in this study was most strongly associated with three aspects of the dying experience (feeling at peace with dying, keeping one's dignity and self-respect, and having control over what was going on around the dying patient). (p. 285)

A review of the participants' transcripts from the current study revealed very few statements reflecting peace, dignity, or the feeling of "control over what was going on around the dying patient" (p. 285).

The emotional distance from health care workers felt by the current participants is consistent with much of the literature on the subject of end-of-life care in the ICU (Hinderer, 2012; Pattison, Carr, Turnock, & Dolan, 2013; Schaufeli, Keijsers, & Reis, 1995). This also may have contributed to the ambivalence expressed by these participants regarding the care they and their loved ones received. The stories they imparted made it clear that the images of these healthcare providers were alive within them. Each of the participants expressed an impression imparted from the interaction with individual healthcare providers. The impressions from these interactions were lasting, and they contributed to the meaning that was being formed based on these memories. Many of these images were endearing and contributed to enduring feelings of care and compassion shown by the hospital staff. One participant recounted how the nurse ran after her after the death to give her a quilted blanket made by hospital volunteers.

> So we kinda walked out of the room, and then this nurse came running after me and said, “Would you like the quilt?” And I said, “Of course.” So she gave me the quilt. Which I still have, of course. I had it on my bed for a long time, and finally decided I needed to take it off the bed.

However, just before that exchange, this participant reported that she had been rebuffed by the hospital staff when she requested to stay with her husband's body. The dissonance generated from these two staff interactions was alive in the room during the interview. Emotional dissonance regarding patient care was one of the most prominent themes expressed during these interviews.

Perceptions of Technology

Advances in medical technology have led to the common expectation that illness and injury can be alleviated by the proper administration of a technological antidote (Chapple, 2010). Participants of this study reported their interface with technology most often came by way of the monitors that graphically displayed the blood pressure and heart activity. One of the participants said, “I'd point to all the screens, I mean all the machines, and I’d say, ‘What is this one? What is that one? What medications is he on?’ ” Hadders (2009) pointed out that the monitor video screens become a familiar aspect of the family’s connection to the patient throughout the ICU stay:

> Nevertheless, when the demise of a patient is drawing near the nurses describe how relatives may become more focused on the monitor screen.

> Many nurses feel that relatives show a tendency to focus excessively on bedside monitors, in anticipation of a flat ECG line as a confirmation and an enactment of death. (p. 581)

One of the participants of the current study commented, “And we watched the monitor, you know, the number of breaths” while recollecting sitting by her husband's bedside during his dying process. Another participant commented on her mother's death:

> And we came back up and the monitor was alarming and, you know, I said, “Oh gosh, just shut it off.” I think I went over and shut it off. ‘Cause my dad was kind of freaking. At least she never opened her eyes through any of this. She was, you know, her eyes were closed the whole time, um, and we just turned off the monitors and, ah, she wasn't breathing anymore. So I went out and got the nurse and she came in and she said, “Yeah, she's gone.” So then each of us got to say goodbye again and, you know, kind of walk out.

The barrier between the equipment and the patient was another aspect of technology that participants emphasized. One participant indicated the technology seemed to detract from the intimacy of the event of death:

> But personally I wish I would have been able to see him alive before he passed... without all that on him. Because there was quite a bit. You know, he had the tubes and (sniff) the, you know, he was intubated, and he had two very large tubes coming out that were draining. I mean he had a lot. He had a lot on his face, you know.

Another participant said, “Not just when you see that ventilator come off, you know it's like... when that... then you see the whole person, the whole thing.” Thus, it seemed clear that the technology of dying in the ICU presented barriers to intimacy. In an article exploring the medicalization of dying, Clark (2002) wrote, “All physicians face the problem of balancing technical intervention with a humanistic orientation to their dying patients” (p. 905). Almerud et al. (2007) describe the environment of the ICU as “frightening” (p. 154).

> Our data show that caretakers rarely meet and match the patients’ need to talk about their predicaments. Instead, they filter communication through objective data: a diagnosis, a list of symptoms or the readings of instruments. Thus patient-caretaker interactions vibrate off-kilter, indicating participation in illness mostly at the technical-mechanical level. Caretakers flaunt their specialty but seem to hide behind routines and structures. With deep needs and anxieties unaddressed and reduced to a nameless number on a plastic bracelet, the ICU patient feels lost and uncertain how to act or react. (p. 156)

They go on to speak of the necessity of professional caregivers to negotiate the relationship between technology and caring, as if to say the two can exist in tandem (Almerud et al., 2007). However, it is important to remember that the physician’s primary responsibility is to her or his patient (Beauchamp & Childress, 2001), and carrying out this responsibility may seem harsh or uncaring from the perspective of others including family. In spite of this, Hadders (2009) suggested the healthcare professionals attempt to view the situation from multiple points including interdisciplinary and family perspectives in order to better meet the needs of all who are involved.

The Decision

The outcomes for all of these experiences were the same: the decision to remove life-support and the patient's subsequent death. However, the circumstance leading to these decisions were very different (see Table 5.1).

(Table 5.1) *Table of Decision Outcomes*

Outcome	Examples
Decision Circumstances	1. Decision made for the participant by the physician 2. Physician abdicated participation in the decision 3. Misinformation presented that influenced decision 4. Decision necessary after placement on life-support contrary to wishes

For one participant, the decision to stop life-support was made without her input, and for another participant, the physician seemed to have abdicated even a consultative role in the decision-making process. Still another participant related her experience of misinformation influencing her decision to remove her mother's life support. The final participant had to make the decision to withdraw life-support after her mother had been placed on life support contrary to her mother's documented wishes. Each of these instances have bioethical ramifications. For instance, the most harsh accusation might surround the guiding principle of non-malfeasance (do no harm). To whom harm is being done—the patient and or the family—is a salient question.

In retrospect, it seems clear in at least two of the examples that the potential for harm existed. The misinformation provided by a nurse was harmful because it contradicted the physician's subsequent contention that the patient had some level of brain function. From the perspective of the family, it is important for the medical team to appear as a united front. Thus, as a result of this misinformation, the family may perseverate on the decision due to it having been made prior to accurate information being available. It may be that the family would have made the same decision if they had the physician's input, but they are now left with questions that seem to outweigh any other memory of the event.

The physician seemed to abdicate his role in the decision-making process in the second example presented in Table 5.1. This example raises another issue surrounding non-malfeasance when the participant reported that the physician said, "It's you and your family's decision to take him off life support." On the face of it, this stance may be adhering to a strict interpretation of the guiding principle of autonomy. If this were the case, then it was absent the influence of the other guidelines (do good, do no harm, and equality for all), which is a good example of how the bioethical guiding principles need to be applied in concert (Miyaji, 1993). For instance, in this case, total responsibility for this decision seemed to have done harm to this participant as demonstrated by her expression of anger over the experience. The incorporation of the principle of beneficence (do good) would have held the physician to attempt to find out if the patient's desires had been expressed and to determine the nature of these desires (Henig, Faul, & Raffin, 2001). If this were not possible, the physician could have gauged the caregiver's level of understanding and ability to make such an important decision. In an ideal situation, the physician might have provided an opinion about the best direction to proceed. The participation of the hospital bioethics committee would only be necessary if there were irreconcilable differences in opinions about the course of treatment from that point (Henig, Faul, & Raffin, 2001). Thus, if the patient were suffering and would not benefit from any further life sustaining therapies, then the principle of beneficence would indicate the removal of life-support. This would be the best course of action but in conjunction with the other three bioethical principles.

In contrast, the example in which the physician seemed to have made the decision independently of the participant (see Table 5.1, example #1) appeared to be in the patient’s and his wife's best interest, and this was demonstrated by his wife's report during the interview. Although she initially said, “They didn't offer a lot of alternatives or choices or anything,” she eventually said, “I had pretty much given up hope by then myself.” Thus, the physician's proclamation validated the wife’s interpretation of the situation. This example may inspire one to question the outcome if the wife’s interpretation had not been consistent with the physician’s.

It is sometimes the case in which the physician and family are at odds (Breen et al., 2001), and this is where bioethical principles are most helpful. Adherence to these guidelines might label the situation medically futile care (Baily, 2011) for which there is no more benefit to any further curative treatments. However, this is a value-laden term (Ackerman, 1991) in which the word “benefit” may have different meanings. The term “physiologic futility” (Truog, Brett, & Frader, 1992) clarifies futility in terms of the medical goals that may be in place for each patient. Thus, if the medical goal is life prolongation regardless of quality of life, then ongoing provision of the ventilator, kidney dialysis, and the other tools found within the ICU are justified. This removes the judgment surrounding quality of life that seems to pervade the term. A family member faced with the binary decision of stop life-support or to maintain it, even though the patient's quality of life is questionable, may opt for simple life support and prolonged life. Due to the progress in medical technology, many of these services can now be maintained outside of the ICU in specially adapted sub-acute facilities. In fact, it is estimated that more than 4,000 people now live on life-support in sub-acute care facilities in California (Faryon, 2014). Researchers have noticed this discrepancy in ICU care. For instance, Clinch and Le (2011) have been conducting research regarding the possibility to have removal of the ventilator at home, and Battle et al. (2014) have explored procedures and policies to allow patients to die at home from the ICU.

Aftermath

In this context, the word “aftermath” implies the leftover feelings and thoughts from the ICU death of a loved one. The aftermath of the deaths reported upon by each of these four participants was alive in the room during the interviews. “Well, I think it's important to talk about processes like this” was how one participant phrased it. These women expressed their experiences of the time just after the death, and they conveyed a progression from confusion and “stupor” to anger and finally to some form of acceptance. Just after her husband was removed from life support and died, one woman said, “At first I was too much in shock and too much of the whole experience was so overwhelming.” This progression may be considered akin to what had been noted by Kubler-Ross (1969) in her studies of patients’ contemplations of their own deaths. The progression may not be exactly the same, but the effect is consistent with those stages noted by Kubler-Ross

(1969). Shock, as noted above, is defensive in nature and allows the person to regroup and rally resources. Once this has been accomplished, a movement toward understanding seems to include an emotional reaction such as deep sadness and anger. Participants conveyed a sense of incorporation of the event following the emotional response, and this incorporation means learning to live with the ambiguities of the death and the conflicting emotions that accompanied it. For instance, each of the participants expressed both gratitude and frustration with the health care staff who took care of their loved ones. Thus, participants seemed to experience an instinctual defensive reaction initially, and then they spoke of opening the door to a reaction that came from an emotional center, and finally they were able to incorporate an intellectual response to help them attempt to make sense of the event.

The aftermath of the ICU experience was an ordeal for participants, and this is consistent with other studies of survivors after death in the ICU (Lemiale et al., 2010; Wright et al., 2010). Participants described the time following the death as imbued with thoughts and activities to help create meaningful narrative. For instance, one participant who lost her husband said:

> And there is this song that I hear on the radio that came out shortly after he passed away. It’s a country song. It’s a very beautiful song, ‘Till I See You Again’. It’s Carrie Underwood, and whenever I hear that song I know that he's letting me know that something good is going to happen, or if it doesn't I'll still get through it.

Both participants who lost their mothers felt the deceased were communicating with them. The experience of communication from the dead has been shown to be a fairly common phenomenon that can assist the process of grieving (Bennett & Bennett, 2000; Drewry, 2003). It is likely that it served to help make sense of the chaotic and seemingly senseless way their loved one died. For instance, one participant said:

> So anyway, being as religious as she was and knowing how mad I was at God, it was almost like... or how I interpreted it... she was trying to tell me, "Let it go." You know, like, "It's nobody's fault." (She was) almost trying to help me heal. Now that could probably be my own brain doing that, my subconscious, whatever, but for me it felt comforting to think it was my mom trying to help me through it.

Another example was explained by a participant whose mother seemed to be playing tricks after her death. The participant described it this way:

> I don't know if you want to get into that, but she did visit for quite a while afterwards, after she died. And my son will tell you the same thing. I mean the first night that she died, you know, I turned off the lights and they came back on again. You know, I just said to her, "Mom, if that's you, I just hope you're in a better place."

Finally, the other participant who lost her husband described the aftermath of her experience this way:

> So I know that it's okay for me to go on and do whatever I'm going to do and write and do my art projects and play in my garden and have friends. And I push myself some days to do more of that. Other days I just say, "Ah forget it, I just feel lousy." But I've gotten more and more into just, I can just do things and go places and it's okay. I don't feel, um, there's a

> rare moment when I feel guilty, like I'm not observing the memory well enough. And then I kind of laugh at myself.

Each of these examples of aftermath after the ICU death are narrative building, and it is the building of a narrative that helps incorporate it into the ongoing lived experience of the bereaved person (Neimeyer et al., 2002). It is the incorporation that allows a person to adapt to the loss. The function of the narrative is to bring homeostasis to an unbalanced sense of self in the face of the tragic loss of a person with whom one shares an intimate history. Upon that history is a large part of what a person bases a sense of self; therefore, when important characters no longer exist, it threatens the person’s overall sense of self (Neimeyer et al., 2002). In addition, the loss of a loved one also challenges the survivor’s general worldview:

> Research has demonstrated that the compelling need to grapple with an explanation for the loss attends the great majority of traumatic bereavements and that survivors’ ability to make sense of the death and to find some important existential benefit or life lesson in the loss are among the best predictors of their eventual adaptation. (p. 240)

Thus, the attribution of meaning to the loss has been shown to be essential to the eventual adaptation to the loss as has been demonstrated by the four women involved in this research. The current research diligently depicted their ability to face this experience and come away from it with some semblance of meaning derived from it.

Guidance for Psychotherapists

The themes generated from these interviews are instructive for psychotherapists. It is important for them to be sensitive to the effects of these experiences for their clients.

Defense mechanisms such as denial and intellectualization are frequently employed in an adaptive fashion to shield the user from distress at a time when most vulnerable. Over time the chronic use of these defense mechanisms can impede the user's understanding and emotional processing of the event (Agich, 2011; Kubler-Ross, 1969). A therapist may see a client who has been responsible for the decision to stop life-support for a loved one and may not understand from where their client's distress arises. This client may be harboring unexpressed guilt and anger that may be displaced onto other areas of life for which the client is seeking therapy. A psychotherapist who can express understanding of these reactions would potentiate the therapeutic bond and enhance the client's ability to express themselves. More importantly, the psychotherapists' familiarization with these reactions will communicate ease and acceptance to clients who may be feeling ill at ease and unaccepted by their usual support network and family.

Depression and PTSD have been shown to be common among this population (Kirchhoff et al., 2002; Siegel, Hayes, Vanderwerker, Loseth, & Prigerson, 2008), and it would behoove psychotherapists to be alert to this phenomena. Doka (2005) suggested that bereavement therapy goals include reframing the experience from responsibility for death to responsibility for the end of suffering. This reframing of the experience would alleviate the sense of guilt and replace it with a feeling of benevolence that might have been lacking in the initial perception of the experience. The relations between the psychology of death and the technology of medicine may seem disempowering from one perspective, but from another perspective these relations may impart a sense of compassion, given that these technologies are merely tools to be used at our discretion.

Truog et al. (2008) presented recommendations for end-of-life care in the ICU that include bereavement care for the surviving family. Referrals to mental health professionals “with expertise in bereavement” (Truog et al., 2008, p. 959) were central to these recommendations. The current study of unique circumstances surrounding the decision to remove life-support suggests bereavement expertise. Becoming informed by the themes expressed by the participants of the current study will help psychotherapists to move toward this expertise. This study was not exhaustive or extensive, but it was descriptive and instructive. Moreover, the participants demonstrated exacting detail and breadth in the communication of their experiences. Awareness of the seven themes delineated in this study will help psychotherapists normalize and validate these adaptations as communicated by their clients.

Kubler-Ross wrote, “In the long run it is the persistent nurturing role of the therapist who has dealt with his or her own death complex sufficiently that helps the patient overcome the anxiety and fear of his impending death” (p. 46). Sensitivity to the themes expressed by these participants will allow psychotherapists to join with their clients in their unexpressed experience and move toward adjustment to living with the loss. Reading these themes and recounting provided by the participants of this study will allow therapists the opportunity to imagine themselves and their families in place of the participants of the current research.

ICU Staff

Another important group impacted by the situation of death in the ICU are healthcare professionals. The ambiguities that have arisen due to the impact of technology have had a pronounced consequence on decisions about end-of-life care

(Chapple, 2010). These ambiguities have brought confusion and anxiety to what was once an inevitable and natural process. Because of this new tension between the potential to keep a person's body alive versus allowing a natural death, it is important for physicians and ICU staff to communicate and clarify these options to patients and their surrogate decision-makers (Billings, 2011).

The effect these circumstances have on the healthcare professionals in the ICU is profound (Doka, 2005; Truog et al., 2008) and has been shown to detract from the quality of care provided (Stayt, 2009; Wiegand & Funk, 2012). One of the participants in the current study described the physician’s response this way:

> The surgeon that was doing her heart surgery was very close to my mom. I had gone to the pre-op visit with her to see him. He said, “Oh, all the other doctors had said ‘You better take good care of her, she’s like my mom.’ ” He said, “Nothing's going to happen to you.” He was really reassuring to her talking about how many of these surgeries he had done, you know, and she was assuring him (laughter) that everything’s going to be fine. So, when it happened, he was devastated. He came to see us in the ICU and he was like as devastated as we were. Because, you know, he said he wasn't going to let anything happen. He had to let all these other doctor's know. And he said, “I don't know how to explain it. We just couldn't get her off the pump. And then she had this clot—”

This surgeon seems to have been reacting to the death of his patient because he adopted a “heroic” stance which includes an overt and/or covert promise to rescue (Buchman et al., 2002). The heroic stance implies the paradox between the health care professional's perceived power over death and the inevitability that death will overcome all.

> The masks of shame may or may not underlie the surgical temperament. But if this hypothesis is even partially correct, it suggests that the surgeon may perceive the impending death of his or her patient quite differently from the patient, family, and other caregivers. For the heroic surgeon, that death may well reveal to the world that he, the surgeon, is "not good enough," unworthy, and so on. (p. 671)

Thus, the reality of death is possibly seen by the surgeon as a failure and a sign of ineptitude and shame. The residual effect of this perception can be enough to cause burnout and health problems not to mention the increased potential for mistakes and possibly resentment and avoidance of family members. Truog et al. (2008) wrote: "Similarly, clinicians also have important bereavement needs. Although the needs of clinicians have not been routinely addressed, their unrecognized suffering and grief may undermine the effectiveness and quality of care" (p. 959). The experiences shared by these participants may help healthcare professionals to be more able to understand both the experiences of their patients and families but also to better understand their own psychological reactions to chronic exposure to suffering, loss, and grief.

Medical providers sometimes feel as if they are inflicting harm on their patients, which, in turn, affects the quality of care they are able to provide (Ferrell, 2006; Shorter & Stayt, 2010; Wiegand & Funk, 2012). Barnhill (2006) uses the terms "torture, execution, and abandonment" (p. 105) to describe what health care providers sometimes feel they are inflicting on their ICU patients at the ends of their lives. These words reflect the countertransference in which health care professionals engage during the course of a typical day. Countertransference refers to the feelings and thoughts of the healthcare professional in response to the presence of a patient and his or her family in the healthcare setting (Katz, 2006). These feelings sometimes cause healthcare professionals to distance themselves from patients and their families (Shorter & Stayt, 2010). Thus, this distance nullifies the chance for a dialogue about choices.

ICU staff may benefit from the opportunity to debrief with a staff psychologist or social worker (Doka, 2005). It is unhealthy for healthcare staff to go on without the opportunity to speak about the effect of these experiences (Maslach, Schaufeli, & Leiter, 2001; Shorter & Stayt, 2010). Debriefing may inspire compassion through an imaginal trading of places with the patient and surviving family members. This is especially necessary after a very stressful encounter that included the perception of undue suffering (Ruopp et al., 2005; Weir, 2005). Imagination and familiarization will likely work to break down the adversarial nature of the patient-family/healthcare relationship when it comes to addressing terminal illness or the possibility to withdraw or withhold life-support (Gordon & Daugherty, 2003). This inspired compassion may open the door for a clinician to "be" with their patient after there is no longer anything to "do" for the patient (Arbore, Katz, & Johnson, 2006).

Limitations

The most glaring limitation in the present study is the small group of participants. This small group size limits any ability to generalize these findings to a greater population. However, generalization to the greater population was not the intent of this research. The temptation to resort to a “natural science” methodology is ever present, but it goes against the core premise of Transcendental Phenomenology. The intent was simply to thoroughly explore these participants’ experience. This research solely focused on white women with a middle class socio-economic background. This fact must be taken into consideration when interpreting these findings, and expansion of this research to other populations will be necessary.

Suggestions for Future Research

Research of this type that focused on other populations of people may expand the clinical relevance of this area. For instance, the expansion of this methodology to a group of men who have had the experience of a loved one’s removal of life-support in the ICU would be instructive. The impact this experience has on people from a lower socio-economic status might clarify a different type of experience. A study regarding the financial burdens of this process, both on society and individuals, would investigate another source of stress surrounding this phenomenon.

Changing the methodology from one-time cross sectional interviews to a longitudinal format may show how this experience changes with time. Other research cited above (Azoulay et al., 2005; Gries et al., 2010) demonstrated methodologies spanning 90 days and 6 months, but to follow-up sequentially years after the experience is likely to demonstrate an adaptation process that has not been clarified yet.

What of those who choose to live on artificial life-support technology? A complementary research project might focus on the lived experience of caregivers for those who decide not to remove life support. Technology has evolved to the point in which people are able to leave the hospital and be cared for in sub-acute care facilities. The number of people living in sub-acute care facilities is on the rise from the present estimation of 4,000 in California alone (Faryon, 2014). A video presentation (Faryon, 2014, September 30) of ventilator-dependent patients who live in a sub-acute care facility aired on PBS in September of 2014. Ambivalence regarding the chronic state of suffering these people experience was powerful, emotional, and pervasive throughout the documentary. The medical director of the facility was interviewed, and he was clear about how difficult it was for him to see these helpless people having to undergo painful procedures to merely maintain their nominal state of existence. For instance, a suction tube was shown to be pushed down the throat of one patient to suck out the mucus from her lungs because she had lost the ability to cough it up. The camera showed the woman lurch forward as she was trying to expel the suction tube from her body. Her husband was interviewed for the documentary. The interviewer asked him if he would want this for himself, and he was adamant that he would not. Yet he was insistent in believing this is what his wife would want even though she had no communicative ability to express her wishes. Research into the circumstances leading to this level of care and the effect it has on caregivers, both professional and family members, might shed some light on these discrepancies. It seems as though the automaticity of technology has overtaken the humanity of the decision-making process to manifest what was once science fiction envisioned in the Robin Cook (1977) novel *Coma*.

Chapter 6
Conclusion

This study underscores how difficult death in the ICU can be even under the best circumstances. In spite of the chaos and confusion expressed by the participants, many of their stories reflected caring and compassionate interactions with hospital staff. It is not the point of this research to find a source upon which to lay blame or to indict healthcare professionals in any way. In large part, they are equally suffering the effects of this maladjustment to the speed at which technology has taken medicine and healthcare in general.

The level of medical technology now available to cure and heal is remarkable. However, the expectation of rescue and resuscitation has resulted in tension between reality and this expectation. The tension is most clearly exemplified in the ICU when death is inevitable, and this expectation has been exacerbated by contemporary media depictions. This research illustrates the phenomenon of carrying out the decision to remove life support for a dying patient. Four caregivers of dying patients were interviewed to explore the lived experience of removal of life-support for a loved one. The caregiver reactions were categorized into seven themes that were common to all four participants. The themes were discovered through implementation of transcendental phenomenology in which the researcher's past experience was bracketed out from interpretations of the interviews. Thus, the participants' words were taken without preconception to the greatest extent possible. Even though the outcomes were identical—the death of the patient—the circumstances leading up to the decisions were each very different. Each circumstance had bioethical ramifications, including breaches in scope of practice, communication breakdown, and caregiver reactions. The results suggest several areas of improvement including those areas that were suggested by the participants themselves.

The intention of this research is to shed light on this experience for mental healthcare professionals, such as psychologists and social workers who provide care for the families before, during, and/or after the experience of a loved one's death in the ICU. Moreover, it is hoped that this research will help mental health clinicians to better understand the needs of professional healthcare providers who are exposed to these untenable circumstances on a regular basis.

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Appendix A

Informed Consent

Title of the research study:
“The Effect of Technology on the Psychology of Death and Dying”

1. I agree to have Dana Hodgdon ask me a series of questions on the topic of my experience of my loved-one's death in the hospital Intensive Care Unit (ICU).

2. These questions will be asked in my home or an office, and the interview will take about 60-90 minutes.

3. The purpose of asking these questions is to investigate the nature of psychological experience relating to the experience of the death of a loved-one in the hospital ICU.

4. I understand that some questions may cause stress and some level of psychological discomfort. I may take a break or discontinue the interview at any time. If necessary, Dana Hodgdon will provide me with referrals for psychotherapy; the cost of which will be my own responsibility. I understand that a number will be used in place of my name to insure my confidentiality and that my answers will only be used by the researcher and his committee for data analysis.

5. I understand that this research may result in no direct benefit to me personally, but the interview material will be used to further the understanding of death and dying in the hospital ICU.

6. Information about this study and the place of my interview in it has been given to me by Dana Hodgdon. I am aware that I can reach him by calling (xxx) xxx-xxxx. I can reach Michael P. Sipiora, Ph.D., Dissertation Chair, at (xxx) xxx-xxxx.

7. Participation in this study is voluntary. I may decide not to enter the study or to refuse to answer any questions. I may also withdraw at any time without adverse consequences to myself. I also acknowledge that the researcher may drop me from the study at any point.

8. I am not receiving any compensation for participating in this study.

Signature ____________________________________ Date ____________________

Appendix B

Demographic Information

Interview Information

Name: ____

Age: ___________ Ethnicity: ____________________ Gender: __________

Relationship: __________________

Date of ICU Experience: ____________________ Location: ____________________

e-mail address __________________________________