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Spirituality, Religious Coping, and Depressive Symptoms in Hospice Patients: A Terror Management Perspective

Janine Siegel
Walden University

Walden University

College of Social and Behavioral Sciences

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Janine Siegel

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Dr. John Astin, Committee Member, Psychology Faculty
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Dissertation Submitted in Partial Fulfillment

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Abstract

Facing imminent death can be an unremitting problem for hospice patients who lack psychological support for existential concerns that contribute to depressive symptoms and suffering. According to terror management theory, spiritual and religious beliefs are a common means of coping with mortality at the end of life, and few studies have considered how hospice patients feel about their impending death. This was a quantitative, cross-sectional study that examined whether spirituality and religious coping moderated the relationship between imminent death concerns and depressive symptoms in 54 hospice patients. Participants completed a self-administered survey that included the Templer Death Anxiety scale, Brief RCOPE, Hospital Anxiety and Depression scale, and Functional Assessment of Chronic Illness Therapy Spiritual Well-Being scale. Data analyses included multiple regression, Pearson correlation, independent sample *t* tests, and Cronbach's alpha test of reliability. Spirituality and religious coping did not significantly moderate the relationship between imminent death concerns and depressive symptoms. Total spirituality, meaning, and peace were significant predictors of depressive symptoms. A recommendation is to develop more research using terror management theory with participants such as hospice patients who are directly facing their imminent death. Positive social change is promoted by highlighting the importance of discussing death and dying with hospice patients, and recognizing religion and spirituality as valid influences to psychological health. This study's findings could lead to further research in developing psychological interventions that target depression and minimize existential distress for patients at the end of life.

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Chapter 1: Introduction to the Study

In the 2001 movie *Wit* (Brokaw & Nichols, 2001), Emma Thompson played Vivian Bearing, a stoic and demanding English professor diagnosed with advanced, metastasized ovarian cancer. Vivian fights to maintain her sense of dignity in a medical establishment that treats her with indifference and detachment. In one poignant scene, Vivian laments to a nurse her experience of powerlessness, fear, confusion, and regret over losing a life that will end long before her deepest desires have been realized. The scene highlights the distress, vulnerability, grief, and fear that can emerge in individuals who are facing their mortality. As Kubler-Ross said: "Fear of death is universal. Death is a fearful, frightening happening even if we think we have mastered it" (Kubler-Ross, 1969, p. 5).

For terminally ill individuals such as Vivian, the confrontation with one's imminent death can be fraught with psychological distress that contributes to pain and suffering (Crunkilton & Rubin, 2009), hinders treatment options (Hultman, Keene-Reder, & Dahlin, 2008), increases morbidity and mortality (Block, 2006; Ryan, Gallagher, Wright, & Cassidy, 2012), and prolongs the dying process (Cassell & Rich, 2010; Rodin et al., 2007). Moreover, the symptoms of distress, mainly depression and anxiety, are often overlooked in the terminally ill who have little or no access to psychological or psychiatric support (Jenkins et al., 2010). A growing number of researchers have suggested the origins of psychological distress at the end of life (EOL) involve existential, religious, or spiritual concerns (Alcorn et al., 2010; Byock, 1997; Chochinov et al., 2009; Edmondson, Park, Chaudoir, & Wortman, 2009; Puchalski, 2013). However,

there has been less agreement about how existential and religious/spiritual (R/S) concerns interact to influence psychological well-being at the EOL. The purpose of this study was to contribute knowledge to EOL research and explore the role of R/S beliefs in a terminally ill population. The relationship between spirituality, religious coping, imminent death concerns, and depressive symptoms in hospice patients was explained using terror management theory (TMT; Greenberg, Pyszczynski, & Solomon, 1986).

This research has the potential for positive social change by promoting respect and dignity for persons at the EOL who some people often avoid or disregard (Cohen, 2009), similar to how people treat the topic of death in the United States (Petasnick, 2011). When I presented the topic, population, and theory of the present study to fellow students and instructors at a university research seminar, several persons asked why anyone would bother studying people who were going to die, and why they mattered. The founder of the modern hospice movement, Saunders (1996), argued passionately that persons at the EOL deserved the same recognition, quality care, and research opportunities as other populations. Hospice patients matter because they can help educate clinicians on the efficacy of EOL treatments and identify the concerns that exacerbate pain and suffering as death nears (Petasnick, 2011; Pickert, 2009). Moreover, positive social change from this study may come from recognizing the important role R/S beliefs and practices have in psychological well-being and how religion and spirituality assist in coping with life-limiting illness. EOL distress is associated with requests for euthanasia, physician-assisted suicide, (Cassell & Rich, 2012; Schuman-Olivier, Brendel, Forstein, & Price, 2008) and decreased quality of life (Hauser & Walsh, 2009). With the outcomes

from this study, my hope is to engender positive social change by highlighting relationships that can lead to increased understanding of existential distress and new treatments that minimize suffering at the EOL.

In the remainder of Chapter 1, the structure and grounding of the study will be outlined, including statistics and data that situate the challenges facing EOL care. I will discuss the problem statement and purpose of the study and review the research questions and hypotheses. There are a number of terms whose meanings are unique to palliative care, which I will operationally define. Finally, I discuss the scope and significance of the study.

Background

Maintaining life and vitality, and avoiding psychological distress are costly endeavors in the health care industry. Americans spent $263 billion for prescription drugs in 2012, more than double the amount from 1999 (Gu, Dillon, & Burt, 2010), and retail psychotropic drug spending in 2009 exceeded $380 million, with most of the cost going to antidepressants (Greenblatt, Harmatz, & Shader, 2010). In addition, health care expenditures have been consistently higher among patients with psychological distress, who need increased outpatient visits, physician support, and medications (Pirraglia, Hampton, Rosen, & Witt, 2010).

For persons at the EOL, health care expenses have risen at a steady pace of 15% to 35% each year, due to extended stays in intensive care units, more frequent emergency room visits, and increased physician use (Goodman, Esty, Fiser, & Chang, 2011). Moreover, 27.3% of the annual $327 billion Medicare budget is attributed to expenditures

in the last year of life, and the cost is expected to rise steadily as the largely populated baby-boom generation (those born between 1946 and 1964) turns 65 (Calfo, Smith, & Zessa, 2009). Ironically, a concurrent trend in EOL care has been greater use of hospice services, a delivery of care that has been associated with decreased costs and increased longevity (Berman et al., 2011; Unroe et al., 2011).

Patients under hospice care have an advanced, life-limiting illness with a prognosis of 6 months or less if the disease runs its expected course. In 2011, 42% of patients who died in the United States were under the care of a hospice program, and approximately 1.6 million patients received services from hospice, up from 1.2 million in 2005 (National Hospice and Palliative Care Organization [NHPCO], 2013). Patients on hospice may live up to 29 days longer than those receiving standard medical care (Connor, Pyenson, Fitch, Spence, & Iwasaki, 2007), and individuals who begin palliative treatment earlier in their disease process may live up to 2.7 months longer than those who delay comfort measures (Ternel et al., 2010). Traditional hospice services are often characterized by a philosophy of compassionate, holistic care that supports the medical, emotional, and spiritual aspects of patients and their families (NHPCO, 2013).

To qualify for hospice care, a physician must certify that a patient has a terminal diagnosis with a prognosis of 6 months or less if the disease process follows its normal course. Per Medicare guidelines that establish admission and discharge criteria for hospice eligibility (Centers for Medicare and Medicaid Services [CMS], 2012), patients must be certified as eligible for hospice services 3 months after the initial admission, then every 2 months thereafter. To continue with hospice care, there must be evidence of

ongoing physical decline and advancement of the disease process along with the 6 month prognosis (Centers for Medicare and Medicaid [CMS], 2012). In the event that a patient's medical condition stabilizes, or that it is determined the patient has an extended prognosis beyond 6 months, then the patient is discharged from hospice services and transferred to routine medical care. Thus, hospice patients are continually facing their imminent death even if they have remained on service beyond 6 months as their condition continues to worsen.

Depressive Symptoms at the EOL

Despite the increased medical attention given to persons at the EOL, most patients experience some form of psychological distress as they near death (Chochinov et al., 2009; Breitbart & Dickerman, 2014). Depression is one of the most common psychiatric diagnoses at the EOL, affecting 25% of hospice patients (Handsaker, Dempsey, & Fabby, 2012). Moreover, 70% of patients at the EOL reported depressive symptoms (Rayner et al., 2011) that ranked as one of the top 10 most prominent symptoms for hospice patients (Bache & Boton, 2005). The symptoms included feelings of anhedonia, sadness, doom, and hopelessness, which are frequently overlooked and undertreated because they are regarded as disease progression, medication side effects, or a normal response to the anticipation of death (Handsaker et al., 2012; Rayner et al., 2011).

Several factors influence depressive symptoms at the EOL. Patients have difficulty coping with grief, managing disease progression, accepting death, and finding meaning and purpose in life (Anderson, Watson, & Davidson, 2008; Block, Arnold, & Liao, 2006; Hultman et al., 2008). Addressing depressive symptoms is especially crucial

at the EOL due to its role in requests to hasten death by euthanasia or physician-assisted suicide (Cassell & Rich, 2010; Hauser & Walsh, 2009; Monforte-Royo et al., 2012) and its association with decreased quality of life (Mystakidou et al., 2008), increased perception of pain (Middleton-Green, 2008), and loss of meaning and dignity (Chochinov et al., 2009). Antidepressants are a common treatment for depressive symptoms, but they are not always useful at the EOL due to the amount of time (4 to 6 weeks) it takes for the medications to start working in the body (Handsaker et al., 2012; Irwin et al., 2008). Many people at the EOL do not have time to spare in getting treatment for their distress.

Death Concerns, Religion, and Spirituality

Much has been written about death and dying, and a number of authors surmised that a considerable amount of human energy is consumed with the denial of death (Becker, 1973; Greenberg et al., 1986; Kastenbaum, 2000; Tomer, 1994; Yalom, 1980). Greenberg et al. (1986) developed TMT to explain how people respond to threats of death when they are reminded of life's transience. TMT holds that when confronted with their own mortality, people cling to their personal and cultural beliefs and behaviors to shield the awareness of death and manage the conflict between knowledge of mortality and the innate desire for survival (Greenberg et al., 1986). Over 300 TMT studies have affirmed that when threatened with death, people flock toward others who embrace similar worldviews, beliefs, and practices that bolster their personal self-esteem and provide a sense of meaning and immortality to their lives (Schimel, Hayes, Williams, & Jahrig, 2007). In turn, the threat of death is minimized, while the personal and collective beliefs become more strongly held (Greenberg, Pyszczynski, Solomon, & Maxfield,

2006). The nationalism expressed after the 9/11 attacks on the World Trade Centers and during the 10th anniversary remembrances are examples of how people express TMT collectively in a culture (Morgan, Wisneski, & Skitka, 2011; Osborn, Johnson, & Fisher, 2006; Pyszczynski, Greenberg, & Solomon, 2003).

One of the enduring ways people have coped with mortality is through R/S beliefs that inevitably serve as a reminder that physical life is impermanent. Most major religions offer doctrines that promise personal immortality through reincarnation, heaven, or some other belief that part of one's existence will continue to survive after death. R/S beliefs also support people in being part of something larger than themselves: a mission, value framework, or significant group that strengthens personal importance and sense of purpose (Pyszczynski, Greenberg, & Solomon, 1999). According to the Pew Forum on Religion and Public Life (2008), R/S beliefs are woven in the everyday fabric of most Americans' lives. As of 2008, 92% of adults believed in God or a universal spirit, 74% believed in life after death, 70% believed that most religions can lead to eternal life, and 52% admitted to experiencing spiritual peace and well-being at least once per week (Pew Forum on Religion and Public Life, 2008).

Within the context of terror management, R/S beliefs and practices are some of the most common worldviews that provide meaning, purpose, and values that protect people from the perils of death and influence their motivations to become—in some aspect— immortal (Solomon, Pyszczynski, & Greenberg, 1991; Vail et al., 2010). Followers can be immortalized literally in some form of afterlife, or symbolically through collective practices and beliefs that will continue long after they die (Solomon et al.,

1991). Deep-rooted and uplifting R/S beliefs minimize death anxiety, fears, and thoughts (Arndt, Cook, Goldenberg, & Cox, 2007; Jonas & Fischer, 2006) and sustain a positive mood and sense of self-efficacy when individuals are confronted with threats of death (Fischer, Greitmeyer, Kastenmuller, Jonas, & Frey, 2006). However, not all R/S beliefs serve a beneficial terror management function. Negative and conflicting R/S beliefs can cause inner turmoil that increases death-related fear and anxiety (Edmondson et al., 2009), while confrontational challenges to rigid and fundamentalist religious beliefs increase death awareness and defensiveness (Friedman & Rholes, 2007). In Chapter 2, I will explore in depth the role of R/S beliefs and practices in the management of death concerns and psychological distress.

There is a gap in knowledge with regard to the relationships between spirituality, depressive symptoms, and death concerns in hospice patients, and how to address their concerns in an integrated way. Despite the high incidence of psychological distress at the EOL, access to specialty mental health services has been severely lacking for terminally ill patients (American Psychiatric Association, 2009). There have been appeals to increase involvement of psychologists in EOL care and research, but movement is slow and funding sources are very limited (American Psychological Association [APA], 2014; Kastenbaum, 2000; Nydegger, 2008). Moreover, one of the biggest challenges in EOL care today is finding respectful ways to support terminally ill patients who are struggling with existential and spiritual issues (Block, Arnold, & Liao, 2006; Callahan, 2011). In this study, I sought to address the challenge and contribute psychological knowledge to hospice and palliative medicine by incorporating TMT (Greenberg et al., 1986) to explain

how existential issues interact with depressive symptoms. Incorporating TMT to the experience of hospice patients can provide a framework from which to understand the sources of distress at the EOL and a grounding from which new interventions can be developed to treat hospice patients who are suffering.

Problem Statement

The confrontation with imminent death can be a challenging problem for hospice patients who are facing the EOL with little interventional support for existential distress, which contributes to depressive symptoms and suffering (Puchalski et al., 2009; Yardley et al., 2009). Prevalence rates of depressive symptoms at the EOL have varied, but research showed that approximately 70% of hospice patients reported feeling depressed at any given time (Rayner et al., 2011), while 25% were actually diagnosed with clinical depression (Handsaker et al., 2012). Minimizing and controlling psychological distress is central in hospice care and key to helping patients accept their mortality (Kon & Albin, 2010; Thompson & Chochinov, 2010) and maintain quality of life (Hultman et al., 2008).

An abundance of research supported the use of R/S beliefs and practices as a means of coping with illness and psychological concerns (Ardelt & Koenig, 2007; Doka, 2011, Johnson et al., 2011; Puchalski, 2008). In palliative medicine, there has been a growing recognition that R/S beliefs and practices contribute significantly to patients' quality of life throughout their disease process (Kandasany, Chaturvedi, & Desai, 2011; Winkelman et al., 2011). There are consistent associations between R/S beliefs, well-being, and lower levels of psychological distress (Braam, Klinkenberg, & Deeg, 2011), while negative religious coping predicted increased depressive symptoms and worse

mental health (Hebert et al., 2009). In regards to medical conditions, positive religious coping helped seriously ill patients to understand their illness and resolve fears of pain and suffering (Hanson et al., 2008), while negative religious coping was associated with increased anxiety, depression, and symptom-related distress in myeloma patients (Sherman et al., 2009).

Few studies have explored how spirituality and religious coping influence depressive symptoms at the EOL among hospice patients. Moreover, there has been very little research addressing how hospice patients felt about and viewed their impending death and the impact it had on their psychological well-being. With this study, I sought to bridge the gap and contribute knowledge to TMT research by examining whether spirituality and religious coping moderated the relationship between death concerns and depressive symptoms in hospice patients. To my knowledge, it was the first to empirically test TMT with a hospice sample, a group in which death is an imminent reality and expected to occur within 6 months or less. The majority of TMT researchers have treated death concerns as an abstract concept that the participants need to envision far away in the future (Arndt et al., 2007; Vail et al., 2010).

Purpose of Study

The intent of this study was to contribute knowledge to hospice and palliative care research by exploring how existential concerns relate to symptoms of depression at the EOL. Specifically, I used quantitative analysis to determine whether religious coping and spirituality significantly influenced imminent death concerns and depressive symptoms in a sample of hospice patients. The variables were examined with a framework of TMT.

The independent variables were religious coping, spirituality, and imminent death concerns; the dependent variable was depressive symptoms. I envision that this study will lead to further research in developing interventions that target symptoms of depression and enhance psychological well-being for patients at the EOL. Moreover, I wanted to introduce TMT into hospice and palliative care, a branch of medicine that has been overlooked in terror management research and could benefit from the theory's insights. The present study also served as a response to find definitive and creative ways to incorporate psychology theory, methods, and practices into hospice philosophy and care, an area where there has been little psychological practice (APA, 2014; Nydegger, 2008).

Research Questions and Hypotheses

The following research questions and hypotheses were developed to guide the study.

Research Question 1: Do imminent death concerns predict depressive symptoms in hospice patients after controlling for age?

$H_0$1: Imminent death concerns will not significantly predict depressive symptoms in hospice patients after controlling for age.

H_a1: Imminent death concerns will significantly predict depressive symptoms in hospice patients after controlling for age.

Research Question 2: Does spirituality moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age?

$H_0$2: Spirituality will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

H_a2: Spirituality will significantly moderate the relationship between death concerns and depression in hospice patients after controlling for age.

Research Question 3: Does positive religious coping moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age?

$H_0$3: Positive religious coping will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

H_a3: Positive religious coping will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

Research Question 4: Does negative religious coping moderate the relationship between imminent death concerns and depressive symptoms after controlling for age?

$H_0$4: Negative religious coping will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

H_a4: Negative religious coping will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

Nature of Study

This study was a quantitative, cross-sectional, survey design that examined the influences of the independent variables—spirituality, religious coping, and imminent death concerns—on the dependent variable, depressive symptoms. Patient characteristic variables were age, spiritual identity, race, diagnosis, and gender. Age was a control variable as elderly hospice patients may have been more accepting of their imminent death over younger patients who were expected to have longer lives (DeRaedt & Vander Speeten, 2008; Missler et al., 2011). The decision to use a quantitative method was influenced by the research questions and hypotheses, which I developed to examine relationships between variables. Moreover, the majority of TMT research has been quantitative, and I wanted to contribute to the existing body of TMT research by using a similar method and established variables.

The data analysis plan was as follows. First, preliminary analyses included descriptive statistics that showed the frequency distribution, central tendencies, and dispersion (standard deviations) of the four primary variables: imminent death concerns, spirituality, religious coping, depressive symptoms, and for patient characteristics taken from the electronic medical record (EMR): age, race, gender, spiritual identity, and diagnosis. Next, I conducted correlation analyses to identify relationships among the primary variables: imminent death concerns, spirituality, religious coping, and depressive symptoms.

I conducted hierarchical regression analyses to examine each of the research questions. A simple linear regression was conducted for the first research question to

determine whether there was a significant correlation among death concerns and depressive symptoms. A moderated, hierarchical multiple regression was run for Research Questions 2, 3, and 4 using the stepwise procedure. A moderated regression includes centering independent variables and creating interaction terms that represent the interaction between the predictor and moderating variables. Multiple regressions were conducted with and without the age control variable. A full description of the data analysis plan for each research question and hypothesis set appears in Chapter 3.

I recruited a convenience sample of 54 participants by phone from patients receiving care from a hospice in San Diego, California. Potential participants were made aware of the study content during recruitment. The participants were asked their willingness to respond to statements about their R/S beliefs and practices, death concerns, and depressive symptoms. Demographic information was obtained from the participants' medical records and data collection continued until there were 54 completed surveys. A detailed description of the study design, including psychometrics of the survey tools, population sample, and statistical methods, is in reviewed in Chapter 3.

Participants completed the survey at their place of residence. As the researcher, I was present to address questions and ensure the surveys were completed. Research variables were quantified with the following instruments:

- Spirituality: Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being Scale (FACIT-Sp; Peterman, Fitchett, Brady, Hernandez, & Cella, 2002).

- Religious coping: Religious Coping Short Form (Brief RCOPE; Pargament, Koenig, & Perez, 2000).
- Imminent death concerns: Templer Death Anxiety Scale (TDAS; Templer, 1970).
- Depressive symptoms: The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983).

Theoretical Base: TMT

TMT was developed in the mid-1980s by three graduate students who were inspired by Becker's (1973) book, *The Denial of Death*. In the book, Becker asserted that much of human behavior was influenced by the both the awareness and denial of death. Becker added that groups of people unconsciously create and share cultural beliefs as a mechanism to protect them from the uncertainty of what happens during and after death. The cultural beliefs transcend death and provide meaning, value, and a sense of immortality to people's lives. The threat of death is minimized when there is meaning and purpose to one's life and when others share the same values (Becker, 1973).

TMT assumes that much of human behavior functions to deny the threat of personal death in day-to-day life (Solomon et al., 1991). Humans and animals come from the same life force and have an instinct and proclivity to survive. The human capacity for self-consciousness makes people aware that death will occur at a time and place that are not known. Thus, humans have both a drive to preserve life and the knowledge that human life will someday end. The pairing of the instinct for self-preservation and the

awareness of personal mortality creates the potential for a debilitating terror and anxiety that make goal-directed behavior nearly impossible (Solomon et al., 1991).

TMT incorporates psychodynamic theory in the use of proximal and symbolic defense mechanisms that function to minimize the threat of death (Greenberg, Arndt, Simon, Pyszczynski, & Solomon, 2000). Proximal defense mechanisms are activated when conscious thoughts of death arise, such as in a serious health diagnosis or a crisis. Proximal defense mechanisms immediately remove the death-related thoughts from focal attention by placing death as something that will occur far into the future, or denying vulnerability to the threat at hand (Greenberg et al., 2000). More subtle symbolic, or distal, defenses are activated to manage the persistent knowledge of mortality that lingers in the unconscious. The symbolic defenses are not connected to direct stimuli or thoughts of death, but are concerned with abstract meaning and value systems.

In TMT, the symbolic defenses of meaning and value are the most effective protectors against the unconscious threat of death (Greenberg et al., 2000). Two psychological components facilitate the symbolic defenses of meaning: worldview defense and self-esteem (Greenberg et al., 2000). People turn to their cultural worldview, values, and ideologies, which provide a framework of reality that is infused with meaning, order, stability, and permanence. In living up to the standards and social roles of the particular worldview, people acquire and maintain self-esteem, which in turn minimizes anxiety. Trust in the cultural worldview and the resulting self-esteem allow people to view themselves as valuable members of a reality or trust in a symbolic immortality that exists beyond their own physical demise. Together, cultural worldview

and self-esteem provide a buffer to help people to cope and manage the disabling terror of death.

TMT Hypotheses

Two primary hypotheses are derived from TMT: anxiety buffer and mortality salience (Greenberg et al., 1986; Schimel et al., 2007). The anxiety buffer hypothesis argues that if self-esteem buffers or protects people from anxiety, then building self-esteem ought to be associated with decreased anxiety and weakening it ought to be associated with increased anxiety (Pyszczynski et al., 2004). Moreover, strengthening or bolstering self-esteem will make death thoughts either more accessible or diminished in one's consciousness—a concept called death thought accessibility (DTA; Hayes, Schimel, Arndt, & Faucher, 2010). DTA refers to how active and dominant thoughts about death are in a person when his or her defense mechanisms are weakened.

In the mortality salience hypothesis, reminders of death intensify the need to strongly embrace cultural worldviews and enhance self-esteem, both of which function to minimize the threat of death (Greenberg et al., 1986). When mortality becomes salient, people will increase fidelity and alliance to their worldviews and others who share the same beliefs and become more aggressive and challenging to those who oppose their worldviews (Burke, Martens, & Faucher, 2010). Likewise, when worldviews are threatened or undermined, then DTA increases.

In the more than 20 years since TMT first emerged, a substantial amount of research from around the world has tested and supported the main hypotheses in a variety of settings (Burke et al., 2010; Hayes et al., 2010). Chapter 2 will provide more detail

about the hypotheses of TMT and review empirical evidence that has supported the theory. This study focused on mortality salience, and how specific R/S worldviews impact death concerns and depressive symptoms in hospice patients. Spirituality and religious coping variables represented worldview beliefs and practices, while death concerns represented the level of death anxiety experienced by patients at the EOL.

Definition of Terms

Anxiety: An uneasy feeling of discomfort, dread, or apprehension caused by anticipation of danger and often accompanied by an autonomic response (Venes, 2005).

Death anxiety: Intense anxiety derived from "anything that threatens one's continued existence," or the "absolute annihilation that might result from death (Solomon, Greenberg, & Pyszczynski, 1991, p. 101)."

Death thought accessibility (DTA): A concept that refers to the level of activation of death-related thoughts in persons (Hayes et al., 2010).

Depressive symptoms: A loss of interest or pleasure in things or activities that used to bring enjoyment (anhedonia); feelings of sadness and being slowed down (Irwin et al., 2008; Zigmond & Snaith, 1983).

Existential: Themes that relate to human existence such as being, choice, freedom, death, isolation, possibility, and limitations (Yalom, 1980).

Hospice care: A team-oriented approach to health care for patients who have a life-limiting illness with a prognosis of 6 months or less. Patients are cared for at home, in medical centers, or long-term care facilities. The interventions focus on the patient's comfort and quality of life, rather than curing the disease process (NHPCO, 2010).

Imminent death concerns: For purposes of this study, imminent death concerns included fears, anxiety, disruptive thoughts, or concerns that relate to one's personal death that is imminent and are expected to occur within a set period of time (Edmondson et al., 2008; Neimeyer et al., 2011).

Mortality salience: Subtle reminders of death (Hayes et al., 2010).

Palliative care: Specialized medical care with a goal of increased quality of life that can be delivered at any stage of a chronic illness or injury. The primary focus of treatment is on pain management, psychosocial and emotional stress, and suffering (NHPCO, 2010).

Psychological distress: Mental and/or emotional disturbance, especially anxiety or depressive symptoms that contribute to pain and suffering (Venes, 2005).

Religion: A search for "significance in ways related to the sacred" that revolves around a specific set of beliefs, practices, and rituals that provide a framework for living (Pargament, 1997, p. 32).

Religiosity: A construct of religious orientation and devotion that varies along a continuum of intrinsic and extrinsic expressions (Allport & Ross, 1967).

Religious/spiritual coping: A multidimensional construct that measures the level and depth of how religious and spiritual beliefs and practices are involved in coping with negative or stressful events (Pargament, 1997).

Spirituality: An aspect of human beings that refers to "the way individuals seek and express meaning and purpose and the way they experience their connectedness to the

moment, to self, to others, to nature, and to the significant or sacred " (Puchalski et al., 2009, p. 887).

Terror management theory (TMT): A theory that posits the knowledge and awareness of one's own mortality creates the potential for existential terror, which is controlled by adherence to and defense of cultural worldviews, and building personal and collective self-esteem (Solomon et al., 1991).

Terror management: The psychological defenses people use to minimize threats to their existence (Solomon et al., 1991).

Assumptions

The fundamental assumption of this study was that hospice patients were under a chronic siege of mortality salience, or had a constant awareness that death was imminent due to their life expectancy of 6 months or less. Other researchers have often cited the assumption as a reason why potential patients decline signing onto hospice care despite being medically appropriate for admission (American Hospice Foundation, 2011). Moreover, there is an assumption in TMT that the encounter with death is a fundamental problem for humans (Arndt et al., 1997; Becker, 1973; Yalom, 1980). Not everyone has agreed with that assumption. Kastenbaum (2008) argued that death anxiety can be more of a concern to researchers than those facing death, while other scholars suggested that death need not be an experience that is pathologized, overestimated, or undignified (Byock, 2010; Chochinov et al., 2006; Fowler, 1981). Granted, there are persons who face the EOL with equanimity, peace, and acceptance, but it is not clear whether those

qualities were always present in the person's psychological framework or whether they are the outcome of working through previous death-related concerns and struggles.

Finally, the survey was self-administered. It was assumed that study participants responded to statements about the variables truthfully and to the best of their ability, and that the measures for the variables were appropriate for the population and study design.

Scope and Delimitations

The scope of this research centered on hospice patients in San Diego County who were pain free at the time of the study delivery and cognitively willing and able to answer questions related to their R/S beliefs, imminent death concerns, and psychological experience. While hospice patients confront a variety of psychological issues at the EOL (Block, 2005), this research focused solely on symptoms of depression due to its high prevalence in hospice patients (Irwin, 2008; Rayner et al., 2011). Spiritual well-being, and positive/negative religious coping were included in the survey to cover a broad range of R/S experiences. TMT guided the discussion about variable relationships and predictors, and the study administration continued until there were 54 completed surveys.

The study was conducted within the parameters of the research questions and directed by the variable measures and cross-sectional design. In the literature review, I outlined research related to spirituality, religious coping, imminent death concerns, and depressive symptoms in terminally ill patients for whom the proximity of death is closer than those with milder forms of illness. Spiritual and religious orientation of patients were reviewed in demographics but were not individually analyzed for their associations to the other variables due to time and space constrictions. Moreover, not all participants

identified with a particular faith tradition, as they had the option to identify as "spiritual" without any religious designation.

The discussion and results were framed within the scope of TMT. Because this study was the first to examine TMT with a hospice population, terror management research in the literature review focused on indices and outcomes related to health and R/S worldviews. A general model of stress and coping (Lazarus & Folkman, 1984) was outlined in the literature review but not addressed directly in the present study as it does not relate directly to mortality. However, the work of Lazarus and Folkman (1984) served as a basis for the model of religious coping (Pargament et al., 2000) outlined in Chapter 2 and incorporated into the Brief RCOPE (Pargament et al., 2011).

Due to the small sample size (54) that is typical in hospice research (NHPCO, 2010), the ability to generalize the results to the larger hospice population is limited. Moreover, the results are not easily generalized to people with life-limiting illness who are at the EOL but not under hospice care. They may want curative treatment, decline hospice services, desire to remain in the hospital, or they may not meet the hospice criteria (death in 6 months or less if the disease follows its normal course). Whatever the reason, other research is needed to examine mortality salience in persons outside of the hospice framework who are not given a specific timeframe for their impending death.

Limitations

There were several limitations to the current study. First, the cross-sectional design limited the measurement of variables to a singular place and time, and may not have accurately gauged the fluctuations of experience related to spirituality, religious

coping, death concerns, and depressive symptoms. Hospice patients may experience varying levels of pain throughout their disease process, which may influence symptoms of depression or feelings of R/S support (Lysne & Wachholtz, 2011; Mystakidou et al., 2007). Second, rapid change of symptoms, persistent functional decline, and sudden death are significant barriers associated with the identification, enrollment, and retention of hospice patients in research (Steinhauser et al., 2006). The barriers represented an anticipated deterrent to garnering a large sample size and may have limited the generalizability of results and external validity of the study. Third, I was present while the participants completed the survey. The participants' responses may have been influenced by my presence as the researcher, which might have impacted the internal reliability of the measures. Participants may have overestimated their level of religious coping or spiritual well-being as positive or minimized symptoms of depression. Fourth, participants volunteered to be part of the study. There was the potential for self-selection of participants interested in the study topics, which may have also reduced generalizability of results and external validity.

There are challenges in measuring R/S beliefs and practices (Blazer, 2009). Spirituality is difficult to operationalize, and most R/S measures focus on generic indices of belief and do not address individual nuances of various religious traditions (Peterman et al., 2002). The R/S measures used in this study were limited to general spiritual experiences and beliefs/practices that were primarily associated with Judeo-Christian-Muslim traditions. Eastern beliefs and practices have not been well represented in R/S measures in general, including the brief RCOPE that was used to measure religious

coping (Kraus & Sears, 2009). However, the R/S measures chosen for this research have strong psychometrics and have been used regularly with participants with serious or life-limiting illness. There is a more extensive review of the measures in Chapter 3.

Finally, a limitation of the study involved age as a potential confounding variable that may have hindered validity. Elderly hospice patients may not have been concerned about their own dying as younger patients who were in a different stage of life. To address the limitation of confounding variables, the literature review examined conflicting research on the correlations between age, R/S beliefs, and death concerns. Age as a confounding variable was addressed in the data analysis section of Chapter 3.

Biases

There were several biases in this study. Given its proximity to Mexico, San Diego has a large Hispanic population (32%; U.S. Census Bureau, 2011). Omission bias was a reality in that only English-speaking participants were accepted into the study, which excluded those who primarily spoke and read Spanish. There was the potential for procedural bias to pressure participants to complete the survey and consent documents within a specific time limit through my body language, presence, or tone of voice as the researcher. There may have been response bias if participants answered survey items in a manner that was acceptable or fitting to the study outcomes. Likewise, there was the potential for social desirability bias if participants provided responses that were motivated by the desire to be viewed favorably by others. For example, someone who experienced spiritual struggle or depressive symptoms may not have acknowledged it if they were role models in their family or expected to be strong in their faith according to

cultural standards. The social desirability response bias may have been a threat to study validity, and was discussed further in Chapter 3.

Several procedures in the study were created to address biases and limitations. Participants who needed more time had the option to meet twice to complete the consent documents and survey. None of the participants chose that option, and all were able to complete the consent forms and survey within 1 hour. Participants were also given the option to complete the survey in a room apart from me. Again, none of the participants chose that option. In order to facilitate honesty and confidentiality in survey answers, participants were reminded several times during the administration of the study that all surveys would be identified numerically and their names would not be attached to the completed questionnaires. If a participant stated or demonstrated physical discomfort during the designated appointment, such as feeling minor pain or fatigue, the administration of the survey was rescheduled or postponed in order to minimize the influence of fluctuating disease symptoms on survey responses. Overall, the study design was developed to protect participants and maintain a high level of internal validity without detracting too much from external validity. While external validity is important, the focus of this study was to draw conclusions about what TMT (Greenberg et al., 1986) stipulates persons ought to be experiencing as they face mortality, rather than draw conclusions about the hospice population.

Significance of Study

To the best of my knowledge, this study was the first to test TMT in hospice patients, a population that is directly facing mortality and under the constant threat of

death. Only one other study was found that evaluated a TMT hypothesis in a terminally ill population (Edmondson et al., 2008); most others have employed college students or other participants who were not directly confronting death and had to imagine their dying. Moreover, the present study filled a gap in hospice and palliative care research by examining more closely whether specific existential variables (spirituality, religious coping, death concerns) influenced depressive symptoms at the EOL. The findings contribute to EOL research by stressing the importance of improving access to specialty services that include psychological and spiritual support for hospice patients, with goals of decreasing depressive symptoms and increasing well-being at the EOL.

Professional application of study findings include the following: (a) implementation of TMT in hospice research, (b) use of TMT insights in explaining psychological distress in patients, (c) greater understanding of the mechanisms that contribute to symptoms of depression in hospice patients, and (d) future development of psychological and spiritual assessment tools and interventions that stem from the findings. In a more broad application, findings can go beyond hospice care to provide a basis for educating health care practitioners about the important role death concerns and R/S beliefs and practices have in influencing depressive symptoms in medically ill patients. Findings could broaden ways to discuss spirituality, religion, and death concerns within a medical context in a manner that is respectful of individual differences.

Implications for Positive Social Change

In 2011, approximately 2.5 million people died of disease-related illness in the United States (Centers for Disease Control and Prevention, 2011), and 1.57 million of

those deaths were in hospice care (NHPCO, 2014). While people are living longer, there are demands for more specialized EOL care that calls for social change in how death and dying is viewed and treated in the United States (Candy, Holman, Laurent, Davis, & Jones, 2010). One of those calls comes from the APA (2014) that identified how psychologists could contribute their expertise to EOL issues. The APA emphasized the need for more psychological research on EOL issues, collaboration with other institutions (e.g. hospices and hospitals) that provide EOL care, and clinical support to patients at the EOL.

Progress is slow. There has been a lack of adequate training for psychologists about EOL issues, so fewer psychologists become specialized in the areas of death, dying, and bereavement (Eckerd, 2009). Moreover, psychologists do not have a long history of working with patients at the EOL. Physicians, nurses, and chaplains in a hospital setting typically support most individuals at the EOL. Thus, the EOL field is not something foremost in the practices of many psychologists (Nydegger, 2009). Another deterrent to having more psychologists involved in EOL care is funding. There is no public funding source for psychological support under hospice or palliative care (APA, 2005; NHPCO, 2012). The hospice Medicare benefit does not provide reimbursement for psychological interventions (e.g. therapy), and most palliative care teams do not employ psychologists (APA, 2005).

This study engenders positive social change within the field of psychology by answering the APA's calls for research about the EOL and collaboration with hospices. It also highlights the importance of talking about death concerns with those who are facing

their imminent mortality. There has been a pervasive attitude among health care professionals that death ought not to be discussed at length with the terminally ill because it might increase their anxiety and diminish hope (Clabots, 2012). The scales used for this study may have triggered more openness for patients and clinicians to discuss mortality with candor and honesty, rather than dread and avoidance (Black, 2007; Clabots, 2012; Goldenberg & Arndt, 2008). The positive social change is to know that it is acceptable to have death discussions with persons who are facing the end of their lives.

Moreover, this study brought attention to a population that has been invisible in psychological research: hospice patients (APA, 2000; Meladze, 2012; Nydegger, 2008). Terminally ill patients have often been marginalized, avoided, and ignored in research (Cohen, 2009; Connelly, 2009), yet they are best suited to identify the psychological challenges, struggles, and strengths needed at the EOL. By engaging a sample of hospice patients, this study recognizes the vital role and voice the terminally ill ought to have in sharing their experiences so that health care providers and the community at large can learn from their struggles. The underlying attitude of hospice care comes from Saunders (1996), the founder of the modern hospice movement, who advocated that patients at the EOL deserved the same compassionate care, attention, research, and treatment as any other relevant population.

This research also promotes positive social change with its inclusion of religion and spirituality as valid research and clinical variables that influence emotional and psychological health. Health care has a history of neglecting or devaluing R/S beliefs and practices as areas that were not within its scope of practice (Koenig, 2008; Wulff, 1996).

Times have changed, and now the Society for the Psychology of Religion and Spirituality, Division 36 of the APA, has a mandate to promote the application of psychological methods to diverse forms of religion and spirituality. In palliative care, there are new textbooks that integrate spirituality with patient care outcomes (Puchalski & Ferrell, 2010; Puchalski & Rumbold, 2012).

The positive social change engendered by this study validates and normalizes the importance of R/S beliefs in assessments and helps clinicians to better understand how R/S beliefs relate to depressive symptoms at the EOL. In 2007, 77% of patients at the EOL wanted support for spiritual and existential needs, yet only 10% of clinicians (doctors, nurses, and social workers) addressed the issues and incorporated them into the plan of care (National Quality Forum [NQF], 2007). Patients may feel more comfortable sharing with their health care providers how R/S beliefs influence their health, and clinicians may be more receptive in listening to them. Understanding R/S contributions to psychological well-being promotes sensitivity to imposing conversations about spirituality, religion, and death to vulnerable patients (Neimeyer et al., 2008).

Moreover, there is a need to incorporate nonpharmacological interventions to address depressive symptoms and anxiety at the EOL, especially when pharmacological agents are not the preferred intervention (Kon & Ablin, 2010; Puchalski, 2007). For example, antidepressants take time to be effective, and hospice patients need more immediate relief due to their limited prognosis, while anxiolytics may produce a sedating effect that is not desired by patients who want to remain cognitively alert (Garcia, Lynn, & Breitbart, 2009; Templer et al., 2004). The study outcomes may encourage the

development of nonpharmacological interventions that target psychological distress at the EOL and support the myriad of spiritual and religious beliefs of patients. Dignity therapy (Chochinov, 2005) is an example of a successful, newer intervention designed for the terminally ill that addresses existential distress and promotes the value and dignity of each patient (McClement et al., 2007). In addition, this research may encourage social efforts to recognize and respond to suffering and depressive symptoms in persons with terminal illness and incorporate individuals' R/S beliefs systems into treatment plans.

Summary and Transition

The confrontation with death in terminally ill patients can be fraught with existential and spiritual concerns that contribute to increased psychological distress and suffering at the EOL. Existential issues often involve concerns, fears, and anxiety about death and dying (Alcorn et al., 2010; Callahan, 2011) that can be minimized or intensified by spiritual beliefs or religious coping (Edmondson et al., 2008; Vail et al., 2010). TMT provides an explanation of how people manage the threat of death by embracing cultural worldviews and belief systems that enhance self-esteem and provide personal security (Solomon et al., 1991). In TMT, R/S beliefs function to reduce death-related cognitions and increase personal striving that fosters a sense of immortality and personal security (Vail et al., 2010). Applied to hospice and palliative medicine, TMT concepts can help explain how R/S beliefs and death concerns influence psychological outcomes at the EOL.

Symptoms of depression are some of the most common psychological experiences that increase morbidity and mortality in hospice patients (Bache & Boton, 2005; Irwin et

al., 2008) and play an important role in requests for euthanasia or physician-assisted suicide (Hauser & Walsh, 2009; Wilson et al., 2007). Depressive symptoms significantly decrease quality of life (Mystakidou et al., 2008) and exacerbate pain in terminally ill patients (Middleton-Green, 2008). Depression, and psychological distress in general, contribute to rising costs at the EOL due to increased physician contact and medication use, prolonged in-patient stays, and intensified symptoms (Goodman et al., 2011). An abundance of research attributed existential and spiritual concerns as the underlying components that fuel depressive symptoms and psychological distress at the EOL (Chochinov et al., 2009; Puchalski, 2008). This study addressed existential issues at the EOL by examining whether spirituality and religious coping influenced the relationship between death concerns and depressive symptoms in hospice patients.

In Chapter 2's literature review, I outlined pertinent findings that served as the basis for the present study. I included empirical evidence that associates the variables of spirituality, religious coping, death concerns, and depressive symptoms in persons with advanced or terminal illness. TMT research was included, too, as it related to religion, spirituality, and health, to enhance understanding of how the variables work together to minimize the threat of death. Taken as a whole, the empirical evidence of the next chapter provided the backdrop against which the present study adds knowledge to the relationships between religion, spirituality, death concerns, and symptoms of depression in patients with life-limiting illness.

Chapter 2: Literature Review

Palliative care at the EOL emphasizes the prevention and relief of suffering in patients with advanced, life-limiting illness. Treatment focuses on pain management, comfort care, and psychosocial, spiritual, and emotional issues that arise in patients who are confronting their mortality (National Consensus Project for Quality Palliative Care (2009). Despite the commitment to a biopsychosocial-spiritual model of support, the diagnosis and treatment of EOL distress remains a challenging problem for palliative care clinicians (Crunkilton et al., 2009; Galfin, Watkins, & Harlow, 2010). Most research has focused on the physical and psychosocial sources of EOL distress, with less empirical understanding of the existential and R/S factors that contribute to suffering at the EOL. It is difficult to quantify existential and R/S concerns (Blazer, 2009); however, they are some of the most salient issues patients and families want addressed as they face mortality (Chochinov et al., 2006; Mystakidou et al., 2008; Puchalski et al., 2009). TMT provides a framework in which to understand the fears and concerns people experience when they are faced with their mortality (Pyszczynski et al., 2009). This study applied TMT to the problem of existential suffering at the EOL by examining the role of spirituality, religious coping, and death concerns as they relate to depressive symptoms at the EOL. The study used quantitative analysis to examine whether religious coping and spirituality moderated the relationship between death concerns and depressive symptoms in a sample of hospice patients.

For the following literature review, I examined the most relevant and current research related to the research questions of the current study. I have situated the present

work as an extension of existing research, and the review revealed a gap in empirical data related to existential and spiritual issues at the EOL. The content of the literature review emphasized research that pertained to TMT and the variables in this study: spirituality, religious coping, death concerns, and depressive symptoms. There is a growing body of research addressing religion, spirituality, and health, but only outcomes related to death concerns and depression or depressive symptoms in persons with advanced or life-limiting illness were reviewed. There was a gap in TMT research that evaluated health outcomes in participants with serious illness. Thus, the present review included TMT studies about how R/S beliefs influence death concerns in general populations. In an effort to contribute to the use of TMT in health care, to my knowledge this study the first to examine TMT in a palliative care setting.

The literature review begins with an overview of TMT. It expands on concepts that were introduced in Chapter 1 and adds a more detailed explanation of new movements in TMT that involve health and religion, which are pertinent to this study. A review of TMT empirical evidence will follow, which was organized around two areas of research. The first involved TMT studies that contributed understanding to how R/S beliefs and death concerns are related. There has been a growing trend in using TMT to explain health outcomes, so additional literature and research that incorporated TMT and health was reviewed. The second area of research focused on palliative care and the variables pertinent to the present study. Included were studies that contributed information related to spirituality, religious coping, death concerns, and depression or depressive symptoms in persons with advanced or life-limiting illness.

Research Related to Method

The majority of literature reviewed involved quantitative research. Moreover, all the TMT studies incorporated quantitative, cross-sectional and/or longitudinal designs. Palliative care research designs have varied and included both quantitative and qualitative methodologies. The latter method contributes rich insight and understanding related to suffering at the EOL (Dees et al., 2011), thus relevant qualitative research was included in the review. In palliative care research, there were few longitudinal studies due to method challenges such as attrition, missing data, progressive illness, and death (El-Jawahri, Greer, & Temel, 2011). However, when I discovered salient longitudinal research, I included it in the review.

Literature Search Strategy

The literature search was conducted primarily through the Walden University Library, with secondary searches conducted in local health care libraries. The majority of articles were obtained electronically using EBSCOhost searches in the following databases: PsycARTICLES, CINAHL, Academic Search Complete, Medline, SocINDEX, and Cochrane Database of Systematic Reviews. A variety of key words were used individually and in groups to identify the most pertinent research: *terror management, spirituality, religion, coping, depression, depressive symptoms, palliative, hospice, death, anxiety,* and *dying*. TMT and palliative care research studies were reviewed from 2004 to 2014, although as much as possible, the most recent data and studies were included in the literature review with an emphasis on research within the past 5 years. The majority of the literature review involved direct empirical research,

including literature reviews and quantitative and qualitative analysis from peer-reviewed journals from the following disciplines: psychology (clinical and social), hospice and palliative care, oncology, nursing, social work, medicine, religion, and spirituality. The variety of disciplines involved in the literature review reflects a multidisciplinary approach and biopsychosocial model of health care that is indicative of palliative medicine and health psychology.

The research reviewed in this section was directly driven by the research questions and focused on studies related to TMT and variables examined in the current study: imminent death concerns, spirituality, religious coping, and depressive symptoms. The majority of research came from primary sources and was focused on samples of hospice patients or persons with advanced, life-limiting disease. Emphasis was given to studies that evaluated the variables in relationship to one another, such as spirituality and depression/depressive symptoms, or spirituality and R/S coping with death concerns. In order to provide a comprehensive review of pertinent literature related to the research questions, I included both qualitative and quantitative studies in cross-sectional and longitudinal designs. Emphasis was given to studies that contributed to social change and provided new insight or methods that would foster understanding of the contributing factors to EOL distress.

Overview of TMT

In his Pulitzer Prize winning book, *The Denial of Death*, Becker (1973) wrote that most human motives are influenced by a terror of death that lies beneath the subconscious, yet is readily accessible the moment individuals are confronted with their

mortality. Becker argued that human beings were unique to other organisms in the knowledge and awareness of their own mortality. The threat of death was so powerful and all consuming, that it would become a "terror" when people faced it directly (Becker, 1973, p. 15). To alleviate the threat of death, people developed "armors of character" comprised of various defense mechanism that engendered feelings of self-worth, meaningfulness, and power to the point that death concerns and fears could be controlled (Becker, 1973, p. 55). The armors of character could also be cultural constructs. Cultural beliefs were unconsciously created and shared by groups of people, who provided a collective source of meaning and value that fostered a sense of immortality. According to Becker, the ultimate irony of the human condition is that people have a deep-rooted need to be free from the anxiety caused by death and annihilation. However, it is life itself that awakens the terror of death in the first place, so "we must shrink from being fully alive" (Becker, 1973, p. 66).

TMT was developed by Greenberg et al. (1986), who took interest in Becker's (1973) ideas, added some of their own, and developed TMT to test the ideas empirically. An assumption of TMT is that most of human behavior functions to deny the threat of death, which lies in the unconscious. The pairing of the instinct for self-preservation and the knowledge and awareness of one's own mortality create the potential for a debilitating terror and anxiety that make goal-directed behavior a challenge (Greenberg et al., 1986). Two psychological components facilitate the symbolic defenses of meaning: worldview defense and self-esteem. People turn to the cultural worldview, values, and ideologies, which provide a framework of reality infused with meaning, order, stability,

and permanence. In living up to the standards and social roles of the particular worldview, people acquire and maintain self-esteem, which in turn, minimizes anxiety (Greenberg et al., 1986). Trust in the cultural worldview and the resulting self-esteem allow people to view themselves as valuable members of a reality or symbolic immortality that exists beyond their own physical demise. Together, cultural worldview and self-esteem provide a buffer to help people to cope with and manage the disabling terror of death and keep thoughts of death out of ordinary awareness.

Primary Hypotheses of TMT

As noted in Chapter 1, two general hypotheses have been developed and tested in the years since TMT was first introduced: anxiety buffer and mortality salience (Greenberg et al. 1986; Pyszczynski et al., 2004). Each of the hypotheses were reviewed in this section. The hypotheses serve as grounding for more recent strands of TMT theory that have expanded to religion, spirituality, and health. The application of TMT to religion, spirituality, and health was the focus of this literature review, and is detailed in the next section.

Anxiety buffer. The anxiety buffer hypothesis is rooted in the role of self-esteem as an experience of personal value that comes from two sources: (a) a belief in the truth and supremacy of a cultural worldview, and (b) the reassurance and solace that one is living up to the standards and social norms of the cultural worldview (Pyszczynski et al., 2004). Thus, self-esteem provides a sense of meaning and purpose to one's life because of the contribution to and participation in a worldview that is shared and validated by others.

According to TMT, self-esteem provides another important function in human development: it shields people from deep-rooted anxiety related to a fear of death that is inherent in all human beings (Pyszczynski et al., 2004; Greenberg, 2008). In the anxiety buffer hypothesis, self-esteem is a safeguard to death anxiety (Greenberg et al., 1994; Pyszczynski et al., 2004). When self-esteem is strong, fears and concerns about personal mortality are mitigated, and DTA remains low. That is, concerns or fears about mortality do not readily arise in the face of danger. Problems occur when self-esteem is challenged or weakened. Then the core death anxiety emerges, and people engage in behaviors that bolster their diminished self-esteem and reduce the threat of death (Greenberg et al., 1994). According to the anxiety buffer hypothesis, people are psychologically and behaviorally invested in strengthening and defending their self-esteem because of its role in managing death-related thoughts (Greenberg, 2008; Schmeichel et al., 2009).

Early support for the anxiety buffer hypothesis showed that participants with high self-esteem reported less anxiety, defensiveness, and psychological arousal after being exposed to stimuli that threatened their existence (Greenberg et al., 1993; Harmon-Jones et al., 1997). In current studies, researchers addressed relationships among self-esteem, threats of death, behaviors, and activities. For example, college students who smoked as a means to increase self-esteem were more amenable to quit smoking after they received messages that they would be excluded from important relationships if the behavior continued (Martin & Kamins, 2010). Students who received messages only about the future health risks continued to smoke because their social standing was not altered.

Likewise, young men with high self-esteem showed greater motivation to enter military service, expectations of hardship during their service, and less DTA than those with low self-esteem (Ben-Ari & Findler, 2006). The authors explained that the high self-esteem participants saw military service as a challenge, an opportunity to test their skills, and a means to live up to social norms, whereas the lower self-esteem group saw the military service as a threat their well-being and existence because they were preoccupied with mortality.

Researchers provided further empirical support for the anxiety buffer hypothesis that included the following findings: (a) people felt better about themselves and reported higher scores of implicit self-esteem after being exposed to terrorist threats meant to demoralize them and their culture (Gurari, Strube, & Hetts, 2009); (b) people exaggerated the closeness and positive regard that their parents or romantic partners held for them after reading personal death scenarios that increased their DTA (Cox & Arndt, 2012); (c) individuals with low self-esteem who were exposed to existential threats reported increased negative affect, anxiety, DTA, and socially avoidant behavior more so than those with high self-esteem (Routeledge et al., 2010); and, (d) people attributed higher levels of self-esteem and "humanly" traits such as empathy and warmth to those they considered part of their peer group after being exposed to scenarios of their death (Vaes, Heflick, & Goldenberg, 2010). Taken as a whole, the findings reinforced the anxiety buffer hypothesis that self-esteem is intricately related to death concerns, and serves a security function to decrease fears of mortality and DTA. Individuals are invested in

bolstering and defending self-esteem, which in turn acts as a buffer to threats of death and keeps thoughts about death away from consciousness (Pyszczynski et al., 2004).

Mortality salience. The mortality salience hypothesis posits that reminders of death cause people to intensify, strengthen, and defend their beliefs in a cultural worldview (Burke et al., 2010; Rosenblatt, Greenberg, Solomon, Pyszczynski, & Lyon 1989; Solomon et al., 1991). Within the TMT framework, strengthening one's belief in a worldview aligns the person with others who share their beliefs, increases self-esteem, and bolsters a sense of immortality because the worldview and culture will transcend personal death (Greenberg et al., 1994; Rosenblatt et al., 1989).

The emphasis in the mortality salience hypothesis is how people defend and align to their worldview, particularly in the level of aggression or negativity toward others who are perceived to threaten or violate a particular belief system. According to the mortality salience hypothesis, the aggressive response to worldview threats is an experiential and primitive defense mechanism that helps people to assert and bolster their convictions, but not have to address criticisms of the worldview (McGregor et al., 1998). It also actively reduces DTA. After the 9/11 attacks in the United States, researchers tested the mortality salience hypothesis with measures of nationalism that assessed the level of aggression toward those with opposing cultural beliefs (Moskalenko et al., 2006, Osborn et al., 2006; Pyszczynski et al., 2003; Yum & Schenck-Hamlin, 2005). In the majority of studies, the researchers concluded that individuals with strong nationalistic beliefs exhibited greater aggressive tendencies toward people with opposing views.

Empirical support for the mortality salience hypothesis focused on the protective aspects of cultural worldviews that shielded people from death anxiety. Early TMT research showed that death reminders led to: (a) more critical and aggressive judgments against people who challenged or violated a worldview (Greenberg et al., 1992); (b) positive and embellished assessments toward those who validated and supported the worldview (McGregor et al., 1998), and, (c) harsher judgments and prejudice from persons who were highly authoritarian against those who were less stringent in their ideas and beliefs (Altemeyer & Hunsberger, 1992; Quinton, Cowan, & Watson, 1996).

More current empirical evidence expanded the earlier findings to apply the mortality salience hypothesis to current societal issues. For example, in the face of increased terrorism that served as a death reminder (Landau et al., 2004), persons who were considered authoritarian and unyielding in their belief systems were less tolerant of immigrants than individuals who were less authoritarian and more open-minded to different viewpoints (Weise, Arciszewski, Verlhiac, Pyszczynski, & Greenberg, 2012). In another study of immigrants, Bassett and Connelly (2011) found that after a reminder about death, American students were more intolerant of indigenous Mexican immigrants who were different from the dominant culture than undocumented Canadian immigrants who exhibited similar cultural characteristics.

People are more apt to tolerate cultural differences if their cultures and beliefs are validated. After participants received affirmation and support of their cultural worldview followed by a reminder about their mortality, they were more willing to buy foreign products that represented different worldviews (e.g. fair trade products such as coffee and

jewelry) and to pay higher prices for the items (Sullivan, Jonas, & Jodlbauer, 2012). The participants also showed reduced DTA. Without the worldview affirmation, participants were not as amenable toward foreign products and had greater DTA. Moreover, death reminders increased acceptance and allegiance toward others who shared the same worldviews (Taubman & Findler, 2006), encouraged sexual prejudice toward gay men but not lesbian women among male subjects (Webster & Saucier, 2011), and increased aggression and intolerance toward those with opposing views (Niesta, Fritsche, & Jonas, 2008). In the mortality salience findings as a whole, there was support that individuals felt more safe and secure within their own worldviews that protected them from threats to mortality. When worldviews were validated and supported, people were less anxious about death, more tolerant of differences, and less likely to use aggression toward alternate viewpoints.

Researchers from around the world have tested the hypotheses of TMT. The strengths of the studies were the diverse populations, cultures, and societal issues that were examined using a TMT application. The major weakness of TMT studies was that the participants had to imagine their death. Researchers used a "death prime" (Cox & Arndt, 2008) to get participants to envision, anticipate, or preview their actual dying process. Usually the death prime involved reading a paragraph or article that threatened one's safety or had participants write out answers to questions about their death. It was hard to determine whether an imagined death evoked the same feelings and beliefs of someone who actually faced his or her death. Moreover, many of the participants were college students in a developmental phase of life where they perceived themselves as

being invincible and removed from death concerns (Lapsley & Hill, 2010; Millstein, & Halpern-Felsher, 2002). A youthful population may have provided different outcomes than an older population who lived with chronic, terminal illness.

Relationship of TMT and the Present Study

The anxiety buffer and mortality salience hypotheses were the precursors to the application of TMT to religion, spirituality, and health. The hypotheses provided theoretical grounding to understand how R/S worldviews interacted with health considerations to build self-esteem, foster socialization with like-minded individuals, and minimize the threat of death. In the following two sections, I reviewed empirical evidence and new theoretical developments that expanded TMT into the realms religion, spirituality, and health.

The rationale for choosing TMT as a framework for the current study was the relevance of the content to hospice patients, a population who are directly facing their mortality. Many hospice patients experience some form of distress during their illness (Rao et al., 2011; Rodin et al., 2009). An application of TMT may provide insight into the basis of their distress and information that informs psychosocial and spiritual interventions to relieve suffering. Moreover, to my knowledge, TMT has not been tested directly with hospice patients. The present study provided an opportunity to test TMT with an appropriate and relevant sample.

I was influenced by the work of Edmondson et al. (2008) when I developed the research questions for this study. Edmondson et al. (2008) found that spirituality and religious struggle did not mediate between death concerns and depression in terminally ill

cardiac patients with an unspecific prognosis. However, religious struggle was associated with increased death concerns and greater depression. The researchers argued that religious struggle represented a breakdown in TMT. Religious beliefs as a worldview did not buffer from the threat of death, but actually exacerbated death concerns (Edmondson et al., 2008). In the current study, I expanded on those results by using more detailed measures of spirituality and religious coping with hospice patients with a definitive prognosis of 6 months or less of life. Spirituality and religious coping represented specific worldviews that interacted with death concerns in a hospice population.

TMT and Religion

There is a growing body of research that has examined R/S beliefs as a means of terror management. Most TMT studies have focused on religiosity, or specific religions that represent a cultural worldview within a particular doctrine. The subjectivity and diversity of spirituality is more difficult to conceptualize into one specific worldview (Blazer, 2009), and thus the term 'spirituality' has not been widely used in TMT research. The term was included here to represent the diverse and numerous beliefs that exist within religious concepts and to reflect the widening use of 'spirituality' in palliative care research as a concept that includes, but is not limited to, religious beliefs and practices (Puchalski et al., 2009).

Terror management theorists are influenced by Boyer's (2001) cognitive and evolutionary understanding of religion as belief systems that rely on the existence of supernatural entities and/or agencies that influence events and processes in the natural world and control access to some form of existence after physical death (Vail et al.,

2010). TMT purports that the primary function of R/S worldviews is to provide a solution to the "persistent and pervasive problem of death" by addressing existential concerns that arise from the awareness of mortality (Vail et al., 2010, p. 85). R/S beliefs do so through cosmologies that promise a literal immortality, a belief that some form of existence will continue after physical death, whether in heaven, paradise, or through reincarnation or ongoing consciousness. In TMT, the primary mechanisms from which R/S worldviews provide a terror management function are through a literal belief in afterlife and/or in deities (e.g., God, Allah, Buddha, Brahman) that hold the key to the afterlife (Vail et al., 2010). According to TMT, a belief in literal immortality is the most potent form of terror management (Dechesne et al., 2003).

R/S worldviews also provide humans with symbolic immortality, or a sense that one is part of something more significant and long-lasting that will live beyond personal death (Dechesne et al., 2003). Symbolic immortality can also be attained through other means that live on after death, such as having children, producing legacies of art, wealth, writings, scientific discoveries, or other contributions to culture. Whatever the means to achieve immortality, the underlying motivation for symbolic and literal immortality is to deny the notion that death involves total self-annihilation (Vail et al., 2010).

The Existential Function of Religion and Spirituality

Allport and Ross' (1967) distinctions between intrinsic and extrinsic religiosity have influenced terror management. Intrinsic R/S beliefs are internally motivated, and provide a significant value in life that gives rise to a sense of purpose, while extrinsic R/S beliefs are used to attain other benefits, such as solace, social support, and safety (Allport,

1966). In an application to TMT, participants in a coffee shop who scored high in intrinsic R/S beliefs had lower worldview defense, DTA, and death concerns to the point where they were comfortable talking about death several days following a terrorist attack (Jonas & Fisher, 2006). However, those with extrinsic R/S beliefs did not experience the same terror management protection, and showed increases in DTA and defense mechanisms related to their secular beliefs.

Results were varied in participants with an Orthodox Jewish orientation who were given a mortality salience intervention. Pirutiusky (2009) compared Orthodox Jews who had left and returned to the faith ("returnees") with those who had remained steadfast to their beliefs throughout their lives. The death reminder did not influence the intrinsic R/S beliefs of the "returnee" Jews, whereas the Jews who were faithful all their lives scored lower in intrinsic religiosity. Pirutiusky (2009) argued that different theological beliefs about afterlife might have influenced the outcome. Orthodox Judaism is more ambiguous about afterlife than Christianity, and focuses on an ultimate judgment about how one had lived rather than emphasizing a positive, heavenly experience. Thus, participants may have reacted with more apprehension about their faith after the death reminder. Pirutiusky (2009) claimed that the fear of having to account for one's behaviors and actions may have contributed to the lower intrinsic religiosity scores. He suggested that the terror management role of religion differs according to the theological tenets and beliefs of various faith traditions.

Supernatural beings and afterlife. For those who believe in God, deities, and afterlife, death reminders can reinforce their beliefs and strengthen commitment to

worshipping a supernatural agent. A group of mostly Christian participants read three different stories that involved a death scenario, but also included images and references of prayer to God, Buddha, and Shamanic deities. In all three studies, religious participants reported stronger fidelity to their own Higher Power or supernatural agent, more so than nonreligious participants (Norenzayan & Hansen, 2006). According to TMT, a belief in supernatural agents serves a vital terror management function because they are the "gatekeepers to the afterlife," and thus promise literal immortality—a distinguishing feature between secular and spiritual worldviews (Vail et al., 2010, p.86).

Moreover, R/S worldviews strengthen the notion that humans are enlightened, spiritual beings who are separate from an animal nature (Vail et al., 2010). TMT theorists have described animal-like qualities that humans experience as our "creatureliness" nature—something that most humans want to ignore because they are potential reminders of our mortality (Goldenberg & Arndt, 2008). Creatureliness attributes include pain, bodily deterioration, broken bones, excretion, bleeding, sex, and physical decline—almost anything that both human and animal bodies experience. Empirical evidence in TMT has supported the notion that individuals have denied their creatureliness nature. For example, several researchers found that death reminders followed by pictures or descriptions of basic bodily functions resulted in increased DTA and feelings of disgust and separation from animals (Cox, 2007; Goldenberg, 2005; Goldenberg, Goplen, Cox, & Arndt, 2007). The creatureliness of human bodies also posed a challenge for Christians who believed in the Incarnation—the belief that God took human form in the name of Jesus. Christians with unyielding beliefs and high defensiveness rejected scenarios that

portrayed Jesus experiencing bodily functions such as dandruff, vomit, tooth decay, body odor, diarrhea, and bad breath (Beck, 2008). The participants rated the bodily scenarios as being highly uncomfortable, demeaning, unbiblical, and unrealistic, thus denying that Jesus participated fully in the human experience. From a TMT perspective, R/S beliefs that reinforce an eternal life free of earthly limitations serve as an escape from our corporeal nature and ultimately from death itself (Vail et al., 2010). Applied to a health care context at the EOL, patients may be less prone than their caretakers to notice their bodily deterioration as a defense to the threat of death and a means to minimize their physical nature.

R/S worldviews and social support. Another terror management function of R/S worldviews has been to increase social support and bolster a sense of belonging, trust, and group cohesiveness that shields individuals from thinking about their own mortality (Maselko, Hughes, & Cheney, 2011). Typically, personal faith is individualized and not subject to scientific validation. However, social support provides validation from others that one's R/S beliefs are relevant and worthwhile (Boyer, 2001). Beliefs that are validated and shared by others often convey a sense that they are legitimate and correct. Conversely, when beliefs are challenged or rejected, there is an implication that the beliefs are wrong (Boyer, 2001). Moreover, social validation of R/S views can assuage confusion when the beliefs run counter to one's personal experience (Tillich, 1952; Yalom, 1980). In studies that evaluated the role of social validation, spiritual and secular worldview beliefs have provided a similar terror management function (Vail et al., 2010). For example, individuals with shared R/S belief systems that were rigid and unyielding

demonstrated hostility, intolerance, and violence toward those with differing beliefs and viewpoints (Vail et al., 2010). According to TMT, people can feel their R/S beliefs are legitimate when there is support from others and deepen the validity of their beliefs by condemning, criticizing, or converting opposing beliefs (Davis, Juhl, & Routledge, 2011).

TMT research has shown that the fear of death has partly fueled religious conflict and increased negativity and criticism toward those with opposing viewpoints (Greenberg et al., 1997). For example, non-Jewish participants showed increased anti-Semitism and lowered support for Israel after a mortality salience induction where they wrote about severe pain and death (Cohen, Harber, Jussim & Bhasin, 2009), and fundamentalist Christians experienced increased death cognitions after they heard strong assertions that the Bible was filled with inconsistencies and contradictions (Friedman & Rholes, 2007). In another study, two groups of Christians read a threatening article that described a growing Muslim influence in Nazareth (Hayes, Schimel, & Williams, 2008). One of the groups was also told that Muslims died in a plane crash en route to Nazareth. The group that only read the article showed increased death cognitions and hostile worldview defense, while the plane crash group showed neither. In a study that examined the attitudes of Israeli students and settlers in the former Palestinian territories, those who scored high in denial condoned increased violence and military resistance in response to the 2006 Israeli pullout after they were reminded of death (Hirschberger & Ein-Dor, 2006). In addition, regular attendance at religious services by Muslim and Jewish participants predicted less fear of death and support for suicide attacks in defense of R/S beliefs and ideologies (Ginges, Hansen, & Norenzayan, 2009).

The overall findings have indicated that people with rigid R/S belief systems have asserted and defended their R/S worldviews when mortality was salient, and that the death of people who held opposing and threatening views alleviated death concerns. As long as the worldview threat was eradicated—even by death itself—the fear of personal mortality dissipated. Applying the evidence to a healthcare context, patients at the EOL who hold rigid and unyielding R/S beliefs may be more likely to reject and dismiss countering belief systems, and advocate the correctness of their own beliefs. They may also experience increased death concerns, particularly when their belief system is challenged.

TMT and meaning. One of the important aspects of R/S beliefs is the role it plays in providing meaning and purpose to life (Pargament, 1997; Vail et al., 2010). After a death reminder, a strong sense of life meaning and purpose mediated between intrinsic R/S beliefs and death anxiety in a group of Christian Chinese students who were less concerned with their own dying than the death of loved ones (Hui & Fung, 2009). Those with extrinsic R/S beliefs showed increased death anxiety for both themselves and their loved ones with no mediating influence of meaning or purpose. Moreover, intrinsic R/S beliefs were negatively correlated with death anxiety in a sample of funeral directors and embalmers who also scored high in believing their lives were meaningful (Harrawood, 2010). Taken as a whole, the evidence has suggested that simple or extrinsic R/S beliefs do not automatically provide a buffer from the threat of death. It is the quality, depth of belief, and intrinsic type of R/S commitment that has served a terror management function.

While most traditional religious traditions offer a systematic and historical set of beliefs, more contemporary R/S constructs, often typified in the word *spirituality*, provide a more flexible approach to existential concerns. For example, a quest orientation (Batson, Eidelman, Higley, & Russell, 2001) focuses on a R/S search for meaning and understanding to life. Thus, R/S beliefs are not the end, but the start of an ongoing spiritual exploration without the need to be rooted in one religious orientation or dogmatic structure (Baston & Stocks, 2004). Vess et al. (2009) found that persons who had a low need for structure found increased life meaning and an opportunity to explore their cultural beliefs after a mortality reminder. The participants did not defend their worldviews, and saw the death threat as an invitation to explore life. Rogers (2010) examined differences between death experiences that were either meaningful or meaningless in undergraduates. The students who imagined a meaningful death were non-judgmental and more tolerant of other R/S viewpoints than those who thought about a pointless death. The findings point to R/S worldviews that are not clearly defined through a traditional of set of religious beliefs, but still provide sufficient meaning to assuage death concerns, reduce defensiveness, and foster robust living. Clearly more TMT research is needed to identify how intrinsic R/S beliefs not tied to one faith tradition serve a terror management function.

TMT and Health

Weaving TMT into health outcomes is a relatively new endeavor. Goldenberg and Arndt (2008) developed a terror management health model (TMHM) that explained how psychological defenses in response to mortality awareness influenced health decisions. In

the TMHM, there are three propositions: First, when a health threat triggers mortality awareness, there is strong motivation to remove thoughts of death from consciousness by engaging in positive health behaviors or minimizing the health danger through active suppression. Second, when thoughts of death are unconscious and not predominant, health decisions are informed by how much they add to the overall meaning and value to the person's life and not by the overall health benefit. Third, people separate themselves from the creatureliness of animals that are fated to death by viewing the body in symbolic terms and focusing on values, meaning, and uniqueness (Goldenberg, et al. 2001). When nonconscious death thoughts are activated, people will engage in body-oriented health behaviors to the extent that they are comfortable with the physicality of their bodies, but not reminded of their creatureliness, animal tendencies, or death. Goldenberg and Arndt (2008) argued that incorporating the TMHM into health interventions could facilitate better understanding of health care decisions and influence motivations toward greater health care adherence.

Empirical Evidence: TMHM

There is converging evidence that shows after health-related mortality salience, defense mechanisms are triggered that actively suppress thoughts about death. In a series of studies with undergraduates, DTA was decreased after participants actively contemplated the word "cancer," and felt vulnerable that they would get the disease (Arndt et al., 2007). However, DTA was elevated after the participants were given challenging cognitive tasks that made the activation of defense mechanisms difficult. In their study of hospice volunteers' perceptions of communication difficulties with patients

and families, Planalp and Trost (2008) found that denial was the most common factor cited in the lack of willingness to discuss mortality issues, suggesting low DTA. In addition, occasional smokers decreased their smoking after they were made aware of personal mortality, and reported lower DTA in subsequent measures (Cox et al., 2008). With the findings, there is support that people use active suppression as a response to reminders of death to rid their minds of personal mortality.

Conscious thoughts of death not only trigger defense mechanisms, but also encourage health-promoting behaviors. After being reminded of death, young adults (aged 20-35) were more likely to engage in health-promoting behaviors than those over 60 (Bozo, Tunca, & Simsek, 2009), while adults who had medical procedures were more likely than younger adults to follow doctor recommendations for healing (Kim et al., 2009). Even the tenth anniversary of 9/11 in 2011 prompted speculation that the reminder of our mortality resulted in increased health-promoting behaviors such as exercise, proper diet, and regular church attendance to ensure a pleasant afterlife (Knolls, 2011).

However, warnings that certain negative health behaviors, such as binge drinking and smoking, increase death-related thoughts but are not guaranteed to keep people away from the behavior. Jessop and Wade (2008) exposed alcohol drinkers to messages of the death-related risks of binge drinking. Both heavy drinkers and individuals who thought binge drinking would increase self-esteem were more willing to binge drink despite the warnings. Likewise, death-related warnings on cigarette boxes did not deter individuals from smoking when the behavior increased self-esteem (Hansen, Winzeler, & Topolinski, 2010). The body of research shows mortality salience can lead to health promoting

behaviors, except in cases when a negative behavior enhances self-esteem, bolsters a sense of immortality, and overrides the need to minimize the mortality threat.

As noted earlier, there is a tendency to denounce the physicality and creatureliness of the human body that reminds us of our mortal vulnerability. The studies that examined that position used what is called a "creatureliness" manipulation—an essay that describes the similarities between humans and animals—to prime participants to recognize the frailty of the human body, while a control group reads an essay that emphasizes the uniqueness of humanity. For example, after a creatureliness prime, participants reacted negatively towards pregnant images of actress Demi Moore but not to painted nude images of the actress, while a pregnant Gwyneth Paltrow was considered less competent (Goldenberg, Cox, Goplen, & Arndt, 2007). It was determined pregnancy induced a sense of vulnerability to mortality. In addition, after the creatureliness prime, participants with low cancer risk and high neuroticism opted against preventative mammography screenings, while other women who underwent a mammography found the experience to be more unpleasant and uncomfortable than those who read about the uniqueness of humanity (Goldenberg, Routledge, & Arndt, 2008). There were similar results in a follow up study: after a creatureliness prime, women reported less intention to conduct breast self-exams, and practiced shorter breast exams on a model compared to those who received the human uniqueness prime (Goldenberg, Arndt, Hart, & Routledge, 2008). Taken as a whole, the findings have provided support that reminders of our human physicality can trigger mortality salience and lead to fewer body-oriented health behaviors.

TMT, Religion, and Health

There is a handful of research that has incorporated TMT, religion, and health. In the only other study that was found evaluating TMT in patients with advanced disease, Edmondson et al. (2008) examined whether death concerns mediated between R/S worldviews and depression in persons with end-stage cardiac disease in outpatient treatment. The patients with stable and secure R/S worldviews felt comforted and secure in their beliefs, and were not overly concerned with their mortality. However, patients who reported religious struggle and a breakdown of their R/S beliefs in light of their illness were vulnerable to increased death concerns and depression. The Edmondson et al. (2008) results are in line with previous research that has found only deep-rooted R/S worldviews provided comfort and protection from death concerns, particularly in those with serious medical illness.

When it comes to faith-based medical decision-making, people high in R/S fundamentalism were more inclined to rely on prayer and faith over medicine and supported others who refused medical treatments based on R/S beliefs (Vess, Arndt, Cox, Routledge, & Goldenberg, 2009). Moreover, after affirming one's R/S belief in a divine being or intervention, fundamentalists experienced deepened meaning and purpose to their lives, yet were still reminded of their mortality (Vess et al., 2009). In the context of TMT, R/S beliefs that provided meaning interacted with self-esteem to influence overall psychological adjustment and well-being. In a series of five experiments with healthy undergraduates who either wrote about their physical dying or failing an exam, Routledge et al. (2010) found those with low self-esteem reported low vitality for life, decreased

meaning and purpose, low desire for life exploration, and increased negative affect and state anxiety. Those with high self-esteem did not experience the same effect after the mortality salience induction. Evaluating the results together within a TMT framework, R/S beliefs interacted with death concerns to influence health care decisions and psychological adjustment in both healthy and ill individuals. However, the depth and integration of belief was important. R/S beliefs that were more superficial or extrinsic did not provide a buffer against death concerns or assist in coping with illness.

Aside from Edmondson et al. (2008) in which participants were end-stage cardiac patients, the majority of TMT studies involved healthy individuals who were induced to think about their death in order to make mortality salient. Moreover, many of the studies had participants who were undergraduate college students who typically embody a sense of immortality and feel distant from death due to their development and age (Cavanaugh, & Blanchard-Fields, 2011). What sets this study apart from other TMT research is that the participants are actually facing their death as a lived reality and not an abstract concept.

TMT Critique

Despite the abundance of empirical evidence for TMT, not everyone has supported the basic premise that much of human behavior is fueled by a nonconscious desire to avoid mortality. Kastenbaum (2009) argued that death anxiety need not be pathologized or overestimated, and can be more of an issue to those who write about it than those who have actually faced death. In one of the few qualitative studies related to TMT, Kastenbaum and Heflick (2010) examined the content of previous TMT participant

essays that contained thoughts evoked from imagining death. Significant themes other than anxiety emerged: sorrow, regret over life's incompletion, and indifference, suggesting that facing personal death summoned up a variety of feelings and experiences. Moreover, the authors critiqued the mortality salience induction process in which participants described feelings that arose after contemplating their death, calling it an "ambush" and intrusive with little time to develop a meaningful, insightful response (Kastenbaum and Heflick, 2010, p. 320). Holbrook, Sousa, and Hahn-Holbrook (2010) offered another perspective to TMT's understanding of worldview defense as a response to death cognitions. Worldview defense stemmed from "unconscious vigilance," reactions to evocative stimuli that provided subtle cues that threatened emotional stability but did not always relate to death (Holbrook et al., 2010, p. 451). Unconscious vigilance operated unnoticed until an emotionally charged stimuli activated it; worldview defense was simply a byproduct that maintained equilibrium and did not minimize the threat of death.

Other critiques of TMT come from proponents of evolutionary psychology who argue that the worldview defense is merely an adaptive and habituated response to potentially harmful circumstances (Fessler & Navarrete, 2005). The defense mechanisms develop over time not because of death concerns, but from ongoing exposure to harsh features of one's environment. Wisman (2006) called TMT incomplete in ascribing only symbolic defenses, such as immortality, meaning, or belief in deities, as primary mechanisms to manage existential anxiety. He identified other basic and evolutionary "presymbolic" defenses from our social and physical environments that can be invoked to

shield from mortality threats. Presymbolic mechanisms included behaviors such as eating, drinking, sex, sleeping, and immersing oneself in a crowd that reduced objective self-awareness and helped to avoid psychological confrontations with death.

Moreover, there have been challenges to two basic tenets of TMT: all living beings possess a survival instinct and all humans have an innate and debilitating fear of death. An evolutionary perspective has posited that natural selection occurs from information that can be replicated and reproduced (i.e. genes)—not from an instinct to survive, and that a debilitating fear of death would not be something that would evolve (Fessler & Navarrete, 2005; Kirkpatrick & Navarrete, 2006; Leary, 2004; Leary & Schreindorfer, 1997). A survival instinct to avoid death does not include specific behaviors that accomplish the goal, nor does it make sense that death anxiety would evolve from an adaptive to a maladaptive trait (Leary, 2004; Paulhus & Trapnell, 1997). Rather, animals' evolved psychology engenders functional mechanisms that help them to avoid dangers in the environment and successfully reproduce (Kirkpatrick & Navarrete, 2006; Navarrete, Kurzban, Fessler, & Kirkpatrick, 2004).

The critiques to TMT add robust discourse to one of the most mysterious, challenging, and complicated experiences all human beings must face: the confrontation with death. The present study added to the discourse by examining spirituality, religious coping, depression, and imminent death concerns in hospice patients, who by definition are in the final weeks or months of their lives. The next section reviews non-TMT related research on spirituality and religious coping in persons with advanced illness or at the EOL.

Spirituality at the EOL

One of the key components of palliative care is the response to R/S concerns that contribute to suffering and decreased quality of life in persons facing mortality (Boston, Bruce, & Schreiber, 2010; Chochinov et al., 2009; Gijsberts et al., 2011; Kandasamy et al., 2011; Puchalski et al., 2009). Moreover, assessment and treatment of R/S issues are considered fundamental quality standards of palliative care (National Consensus Project for Quality Palliative Care, 2009). In their review of suffering at the EOL, Boston and colleagues (2011) found that existential and spiritual concerns at the EOL were some of the most debilitating challenges that patients experienced and were often overlooked by clinicians who lacked effective interventions for treatment. This section examines empirical evidence on spirituality as a whole and its influence of depression and death concerns in a non-TMT context. It will also review research on positive and negative religious coping with illness. When used alone, the term *spirituality* will include the belief and practices of specific religious traditions, as outlined in the definition of the term from the previous section. The term *religiosity* used alone will refer to Allport and Ross' construct of religious orientation that varies along a continuum of intrinsic and extrinsic expressions (Allport and Ross, 1967).

Spiritual Concerns

Religion and spirituality are complex variables that include cognitive, behavioral, emotional, physical, and intra-and-interpersonal aspects of one's being (Hill & Pargament, 2008). There is evidence that several recurring R/S themes contribute to psychological distress at the EOL, including loss of meaning, despair, isolation, and sense

of abandonment from God and others. Loss of meaning and lower quality of life were identified in 86% of advanced cancer patients (n = 69) receiving outpatient palliative radiation (Winkelman et al., 2011). Patients were diverse in their R/S beliefs and younger patients had higher levels of meaninglessness and worse quality of life. However, for many patients the meaninglessness prompted a spiritual search to find meaning and purpose to their lives. In a similar study, 13 younger patients at the EOL in an acute palliative care unit reported higher levels of spiritual distress than older patients (Hui et al., 2010). Of all the patients, 44% reported feelings of despair, dread, and brokenness fueled by a loss of control, isolation, and hopelessness. Pain was associated with decreased spiritual well-being and greater sense of alienation. Of note, previous research has shown that younger patients with life-limiting illness experienced greater psychosocial and spiritual distress than older patients, fueled by a loss of future and unfulfilled dreams (Chibnall, Videen, Duckro, & Miller, 2002). An often-cited remedy to despair and meaninglessness at the EOL has been hope (Breitbart, 2003; Mok et al., 2010; Puchalski, 2008; Woelk, 2008), which can be difficult to foster in people who say they have nothing left to live for (Groopman, 2003).

In addition to despair, many palliative care patients reported feelings of regret about past life decisions or the loss of a future (Mako, Galek, & Poppito, 2005), while others described a sense of abandonment from God, friends, or family at various times during their disease process (Hebert et al., 2009). In contrast to abandonment, some patients have felt connected to God, but question the role of illness in their lives. In a qualitative study of mostly Latino patients (n = 18) with advanced cancer or organ failure

who visited the emergency department for symptom control, the majority expressed a sense of resignation, believing their fate and future were in the hands of God (Grudzen et al., 2011). All of the participants disclosed a strong desire to live as long as possible, yet relinquished control to God and expressed confusion about why they contracted the illness. For African Americans, a significant theme throughout the EOL was a belief in miracles and divine intervention, and that God had complete power to give and take away life (Johnson, Elbert-Avila, & Tulsky, 2005). There was a sense of trust in God, along with a strong desire to fight the illness. Taken as a whole, the findings highlight the influence R/S beliefs have at the EOL, both in patients' quality of life and their interpretation of the illness experience.

Spirituality and Depressive Symptoms

Clinical depression and depressive symptoms are common experiences at the EOL. Prevalence rates range from 25% of hospice patients diagnosed with clinical depression (Handsaker et al., 2012) to 77% of hospice patients reporting depressive symptoms (Irwin et al., 2008; Rayner et al., 2011). Risk factors include uncontrolled pain, progressive physical and cognitive impairment, medication side effects, family history of depression, substance abuse, and a lack of social support (Taylor, Ashelford, & Fernandes, 2008). Despite its prevalence, depressive symptoms are often underdiagnosed and undertreated at the EOL because they are confused with disease progression, medication side effects, or anticipatory grief (Handsaker et al., 2012; Rao, Ferris & Irwin, 2011; Taylor et al., 2008). Moreover, requests to hasten death or threats of suicide are often indications of undiagnosed depression or unremitting depressive symptoms (Bache

& Boton, 2005; McClain, Rosenfeld, & Breitbart, 2003; van der Lee et al., 2005). Early diagnosis and treatment for depressive symptoms is essential, as pharmacological agents take time before they become effective. Unique to the hospice population, antidepressants are often used as pain adjuvants or sleep aids (Irwin et al., 2008). Some patients might have already used an antidepressant off label and benefitted from its positive effects. Moreover, symptoms of depression at the EOL can be unstable and fleeting. Many patients have reported remitting symptoms at some point during their illness, partly due to the attentive psychosocial and spiritual support offered in palliative care (Murray et al., 2007; Rayner et al., 2010).

Empirical evidence is mixed in studies that assessed the relationships between R/S and depression or depressive symptoms in persons with advanced, life-limiting illness. Findings in a majority of studies showed that spiritual well-being— a stable sense of meaning, purpose, and faith in one's life—had a strong inverse relationship with depression in persons with advanced, terminal disease (Bekelman et al., 2009; Bussing, Matthiessen, & Ostermann, 2005; Kandasamy et al., 2010; Koenig, 2007; Lo et al., 2010). Likewise, measures of spiritual pain—defined as inter-or-intra -personal conflict or nonphysical, existential pain—have been positively correlated to depression (Delgado-Guay et al., 2011; Mako et al., 2009). Several qualitative studies highlighted themes that show R/S beliefs offset feelings of sadness, grief and despair by bolstering meaning and inner peace, and decreasing fear and the unpredictability of illness (Murray et al., 2007; Penman, Oliver, & Harrington, 2009; Pevey, Jones, & Yarber, 2008).

Although in the minority, several studies reported that R/S beliefs were not associated with depression in persons with end-stage illness. In a study of 82 advanced cancer patients in Greece, Mystakidou et al. (2007) found no significant relationship between spirituality and four variables: depression, hopelessness, pain, or cognition, while Braam and his colleagues (2011) found no association between religiousness and depressed mood or anxiety in the last week of life as reported by patients' caregivers. However, respondents did report some aspects of religiousness contributed to increased peace at the EOL. Menon et al. (2000) reported that religiousness had no influence in the desire for life-saving treatments in medically ill male veterans who disclosed high levels of hopelessness and feelings of depression. The mixed findings about the impact of R/S beliefs on depression revealed the challenges in finding a unifying and singular conceptualization of spirituality as it relates to other significant variables at the EOL. How spirituality and depressive symptoms are related depends on which aspects of religion and spirituality are measured. In general, spiritual well-being has been negatively related to depressive symptoms, whereas spirituality in a cognitive-behavioral context has shown little or no significance in relation to symptoms of depression (Gijsberts et al., 2011). Unifying three aspects of spirituality: R/S well-being, religion and spirituality in a cognitive-behavioral context, and R/S coping into a single measure may alleviate the difficulties in assessing the role of spirituality in psychological outcomes at the EOL (Gijsberts et al., 2011).

Religious and Spiritual Coping

Stress and Coping Theory

At the EOL, individuals are dealing with a variety of stressors that include pain and treatment side effects (von Gunten, 2005), the unknown of how and when death will occur (Byock, 1997), financial hardship (Block et al., 2006), concerns of being a burden (Crunkilton & Rubins, 2009), and a loss of dignity (Chochinov et al., 2006), functioning and relationships (Knight & Emanuel, 2007). However, there is wide variability in the levels of stress among patients. Lazarus and Folkman (1984) developed the notion of *appraisal* and its importance in assessing outcomes in stress and coping research. Appraisal refers to how an individual perceives and evaluates the stressful event, and generally involves two steps. First, *primary* appraisal is the process of discerning the degree of danger or threat the stressor might bring to one's well-being. If it is determined there is little to no risk, then there may be no response. However, if the stressor is likely to be a threat or danger, individuals move to the next step. *Secondary* appraisal involves a personal estimation of one's ability to cope with the stressor and the available options to manage the problem. It is at this point where individuals move into specific coping strategies.

Coping is a universal activity in which people manage stimuli that are perceived to be emotionally, physically, or cognitively threatening, demanding, or beyond one's ability to deal with the situation. Folkman and Lazarus (1980) identified two strategies for coping: problem-focused and emotion-focused coping. Problem-focused coping serves to manage or change the source of the stress through actions that deal directly with

the problem itself. It often occurs when individuals feel that something constructive can be done about the stressor. Emotional-focused coping tries to regulate upsetting emotions that arise from the stressor. It often occurs when individuals feel powerless about the stressor, or that it is something to be endured with no apparent solution in sight. In general, most people use both problem and emotion-focused coping to some degree when they encounter stress (Tennen, Affleck, Armeli, & Carney, 2000).

Coping itself is not always indicative of successful or positive outcomes. Negative emotional responses to stress, such as hostility or self-blame, and unhelpful coping strategies such as avoidance, indecisiveness, or escape can increase negative feelings and overall distress (Kleinke, 1998). Not taking medications as prescribed or the avoidance of important medical screenings are some examples of negative coping strategies in a health care setting. Empirical evidence of both positive and negative RS coping will be examined later in this section.

Religious and Spiritual Coping at the EOL

Using the theoretical framework of Lazarus and Folkman (1997), Pargament (1997) developed a model of R/S coping that can be applied to various situations. Integral to the model is Pargament's (1997) conceptualization of religion that incorporates spirituality as, "a search for significance in ways related to the sacred (p. 32)." Whatever a person perceives to have divine, reverent, or holy qualities, and is of ultimate, personal significance is considered sacred. Moreover, that which is sacred knows no boundaries and transcends reality, yet is not limited to deities or religious pursuits (Pargament, 1997). Good health, serenity, a heavenly afterlife, strong family ties, and meaningful

goals are examples of what may be sacred to individuals. R/S coping is activated when a stressor related to a sacred goal arises, or when a coping method that is considered sacred is used in response to a stressor (Pargament, 1997). For example, most individuals consider life itself a sacred matter and turn to R/S coping when threatened with serious illness or death (Cummings & Pargament, 2010). They may also use sacred methods for coping with illness such as prayer, meditation, or healing rituals.

Pargament and his colleagues (2004) identified five functions of R/S coping with stressful events. The first function is meaning. R/S beliefs provide a context for meaning in life and a way to interpret challenging experiences. The second is control, and refers to gaining the upper hand and mastery in an otherwise overwhelming situation. Third, R/S coping provides comfort in one's desire to connect with a power greater than oneself, which in turn reduces dread and apprehension. Fourth, R/S coping fosters a sense of connectedness and solidarity with others, and gives people a social identity. Finally, the ultimate goal of R/S coping is transformation. It motivates individuals to change what matters in their lives and to find " a new source of significance" (Pargament, 1997, p. 198). In the context of EOL, the first four functions resonate with the TMT understanding of R/S worldviews providing a protective buffer from the threat of death. However, the transformative function departs from TMT, and offers a broadened view of R/S coping as a means toward enduring change and transformation that can lead to a deep sense of peace and acceptance (Pargament, 1997).

In general, R/S beliefs and practices are related to both positive and negative outcomes at the EOL, depending on the variables that are measured and the depth and

integration of one's spiritual beliefs and practices (Cummings & Pargament, 2010; Wachholtz et al., 2007). The next section examines empirical evidence related to positive and negative R/S coping in persons with advanced illness or at the EOL.

Positive Religious Coping

Positive religious coping is conceptualized as the ability to make meaning in life, and the ability to express a personal sense of spirituality and secure connection with others, which includes God, higher power, or some other divine being (Pargament, Smith, Koenig, & Perez, 1998). There is empirical support that suggests positive religious coping minimizes and distracts from pain, reduces stress, and provides meaning and emotional support in persons with medical illness (Wachholtz et al., 2007; Wachholtz & Pargament, 2005). Chronic pain patients reported their R/S beliefs freed them from guilty feelings about their health and prompted more connection to others and God (Glover-Graf et al., 2007). Bussing et al. (2009) examined R/S coping in 580 chronic pain patients who also had comorbid, advanced illness, and found positive religious coping significantly influenced pain appraisals and pain management decisions. In addition, R/S activities such as prayer, worship attendance, home visits from one's faith community, and trust in God served as active coping strategies. Overall, the evidence suggested that patients involved in R/S activities experienced better pain management and greater healing when they maintained contact with their faith communities or others who supported their spiritual beliefs.

For persons unable to engage actively with their faith communities, an interior sense of R/S support can aid in quality of life assessments and feelings of well-being.

Tarakeshwar et al. (2006) assessed the relationship between religious coping and quality of life in 136 advanced cancer patients. As expected, positive religious coping was associated with increased quality of life and higher scores in existential and social support dimensions. Positive religious coping included a sense of God's presence and love, and feelings of strength and comfort from the faith community. In a longitudinal study of 136 persons hospitalized with depression and serious illness, Murphy and Fitchett (2009) found participants who scored in the top third of the religious well-being scale and identified strong beliefs in a personal and caring God showed the greatest gains in treatment response and quality of life 8 weeks later. Positive religious coping was prominent in 284 women with breast cancer, in which 76% reported turning to their R/S beliefs and practices moderately or a lot throughout their disease process (Hebert et al., 2009). Most of the women cited a partnership with God or higher power and R/S beliefs as a source of ongoing strength and support. Ironically, there were no associations between positive religious coping and measures of well-being, although the authors concluded that R/S coping stimulated personal growth (Hebert et al., 2009).

Positive religious coping at the EOL can also elicit a sense of control and order in a situation that is fraught with many unknowns. In a qualitative study of 38 hospice patients, a primary theme of positive religious coping was that God was in control and would see the patients through the dying process (Pevey et al., 2008). Secondary themes included a sense of relationship with the divine when other relationships were fading away, and a belief in afterlife or karma that would offset current suffering. Taken as a whole, the findings suggested that positive religious coping provided benefits beyond

physical indices of well-being, and induced properties of healing and peace that were not associated with curing the underlying disease process.

Spiritual journey and inquiry. Other studies examined specific types of R/S coping as they related to health outcomes at the EOL or increased acceptance of death. One common theme in hospice patients has situated spirituality as a journey (Byock, 2002; Puchalski 2009). Terminally ill patients often assess their spiritual experience in terms of a journey that begins when they were first diagnosed, progresses toward explorations of the meaning and purpose of life, and ends at death when the spiritual explorations cease (McGrath, 2004). For persons who believe in an afterlife, a new leg of the journey begins after death. The once-in-a-lifetime journey toward death is also considered a developmental phase that can include movement from existential distress to a profound sense of wellness and life completion (Byock, 2002). Some patients at the EOL described positive personal transformation through their religious coping, or caregivers noticed significant changes in the attitudes and outlooks of loved ones as they neared death (Alcorn et al., 2010; Puchalski, 2009).

In a longitudinal study that included dyads of caregivers and patients with end stage cancer, heart disease, and spinal stenosis, a dual process of spiritual inquiry emerged (Reed & Rousseau, 2007). Spiritual inquiry involved thoughts and deliberation that had supernatural and humanist perspectives. The supernatural perspective included self-transcendent thoughts that pertained to God or other divine spirits, afterlife beliefs, and existence beyond the visible world that most respondents had not contemplated before. The humanist perspective emphasized the human condition, science-based

explanations and inquiry, secular concerns, and human reason. Taken as a whole, the study outcomes indicated that positive religious coping that emphasized meaning and inquiry was related to beneficial outcomes at the EOL. The implication for clinical practice is to create an environment that recognizes spirituality as a dynamic process.

Prayer and meditation. Significant spiritual practices that contribute to religious coping at the EOL include prayer, meditation and guided imagery, and reading sacred scripture or spiritual texts (Alcorn et al., 2010; Banzinger, van Ulden & Janssen, 2008; Pargament et al., 2004). Prayer is one of the more common R/S practices that can provide immediate relief and a sense of peacefulness (Francis & Evans, 1995). Common motivations for prayer are to ask for strength and guidance from God or a Higher Power, and to feel that one is not alone. Prayer was cited as the most important spiritual practice for 68 cancer patients who were at the EOL (Alcorn et al., 2010). Patients reported various methods of prayer, including praying for themselves, praying with others, receiving prayer from others, praying for strength, and praying more frequently.

Banzinger et al. (2008) distinguished between different styles of prayer as they related to religious coping: petitionary, religious, and meditative. The first two styles involved communication with God or a Higher Power, whereas the third type was focused more on personal comfort and self-reflection. Coping styles included: (a) a deferred style, where control of the situation was put into God's hands; (b) a collaborative style where control was considered a partnership between God and the person praying, and (c) a receptive style, where the person praying and the object of prayer were both passive recipients of the process. There were significant associations

between religious prayer and the collaborative and deferring coping styles, and between meditative prayer and the receptive coping style. There were no associations between petitionary prayer and coping styles, which is surprising given that petitionary prayer often represents the hope for a solution to a challenging problem. Thus, it is insufficient to focus solely on whether or not patients pray or meditate as a means of religious coping (Banzinger et al., 2008; Stanley, 2009). Inquiry into the frequency, content, and method of prayer and meditation may produce more clinically significant information as to how patients are coping with, and adapting to, their life-limiting prognoses (Cummings & Pargament, 2010).

Negative Religious Coping

Negative religious coping reflects an insecure relationship with God or divine being, a threatening or paranoid view of the world, ongoing spiritual search with no answers, and persistent spiritual struggle (Pargament et al., 1998). Pargament and his colleagues (2003) outlined some warning signs of unhealthy religious coping styles that included self-neglect, self-worship, religious apathy, belief in punishment from God, and religious denial, passivity, and vengeance. The unhealthy coping styles are in contrast to common R/S struggles that are part of a healthy, spiritual developmental process such as interpersonal conflicts with church members, conflicts with religious teachings, anger at God, and religious doubt. Such concerns are generally not maladaptive, but signal a deepening of one's own spiritual agency. Pargament et al. (2003) caution about assuming a causal relationship between maladaptive religious coping and diagnostic

psychopathology. When patients present with apparent “red flag” religious coping styles, it is a merely a sign that further assessment about the religious coping style is warranted.

In patients with life-limiting illness, negative religious coping may intensify the pain experience, contribute to physiological decline, and exacerbate symptoms at the EOL. Persistent thoughts of abandonment from God, unanswered prayers, loss of meaning, illness as punishment, and excessive guilt were associated with increased pain, spiritual distress, and death concerns in patients with advanced pain and disease (Rippentrop et al., 2005; Zwingmann et al., 2006). Negative religious coping was associated with gradual physical decline and lower psychological well-being over time in 429 patients with HIV-AIDS over a 19 month period (Trevino et al., 2010). In other research, negative religious coping contributed to worsening psychological outcomes. Tarakeshwar and his colleagues (2006) found that negative religious coping decreased quality of life and lowered scores in existential and support dimensions in persons with serious illness. Negative religious coping included feelings of abandonment, illness as punishment, lack of support from faith community, and questions about the power and fidelity of God. Alcorn et al. (2010) reported that 85% of participants with advanced cancer experienced one or more struggles or concerns related to R/S in general. The most common struggles involved perceived losses: a loss of connection with God, faith, and with life’s meaning and purpose. A feeling of being abandonment by God was reported in 43% of the respondents. Even prayer, usually considered a positive religious coping mechanism, can contribute to psychological distress in persons with illness. Andersson (2008) found that prayer predicted depression and exacerbated feelings of distress in

patients who experienced severe, chronic pain after they realized their prayers for relief had not been answered.

In an interesting turn, hospice patients who scored high in intrinsic religiosity tended to see death as an escape from a life filled with burdens, or they avoided the topic of death altogether (Neimeyer et al., 2011). Other findings have shown that persons high in intrinsic religiosity had better adjustment to and acceptance of dying, or they were not afraid to discuss their own death (Hui & Fung, 2009; Jonas & Fisher, 2006; Pirutinsky, 2009). In the Neimeyer et al. (2011) study, the authors surmised that the participants high in intrinsic religiosity experienced a healthy dose of negative that did not contribute to significant or enduring psychological distress; overall they scored high in psychological well-being. A unique consideration when examining negative religious coping in EOL care involves the role of pain. As the EOL nears, many patients experience increased pain and discomfort, which may be a precursor to negative religious coping or simply signal a need for more adequate pain management (Puchalski, 2007).

It is clear religious coping can be beneficial, uneventful, and perhaps even burdensome to some patients. The function of religion and spirituality at the EOL may be more dependent on the roles they had in the person's life prior to illness. Individuals who have actively integrated R/S beliefs within the context of their daily lives may find religious coping beneficial, while those who have not been religious or spiritual might be harmed in the sudden incorporation of R/S pursuits (Gall et al., 2009).

Summary and Transition

In the literature review, there was an abundance of research related to TMT and how mortality salience increased worldview defense and minimized the threat of death in a variety of populations. Religious beliefs were shown to provide a buffer to the threat of death, yet it was revealed that the depth and level of religious belief was associated with how much relief participants would experience from death anxiety. I outlined a gap in literature that examined TMT hypotheses in persons who were directly facing their mortality, as most of the mortality salience inductions were made with otherwise healthy and young participants. I designed this study to minimize the gap by evaluating TMT in a sample of hospice patients who have a life expectancy of 6 months or less.

The review also incorporated non-TMT research that evaluated associations between variables that were used in the present study: death concerns, spirituality, religious coping, and depressive symptoms in persons with serious and terminal illness. The review showed how each of the variables were associated, and how they influenced quality outcomes for terminally ill patients. R/S beliefs were associated with increased coping and decreased symptoms of depression in seriously ill patients. However, maladaptive R/S beliefs were shown to intensify pain and symptoms. Moreover, the review highlighted a gap in literature that examined relationships between spirituality, religious coping, and depressive symptoms in hospice patients. Finally, the review provided examples of how the integration of TMT into hospice and palliative care research represented an opportunity to incorporate psychological theory into health-related outcomes in EOL care.

Chapter 3 outlines the research methodology for this study. It includes a detailed description of the research design and implementation, including review of the research questions, hypotheses, variables, statistical approaches, information about the hospice sample, and ethical considerations. I also provided descriptions and psychometric information about the instrumentation materials. The structure of the study mirrors other palliative care research, and expands the Edmondson et al. (2008) study to evaluate whether spirituality and religious coping moderated the relationship between imminent death concerns and depressive symptoms in hospice patients at the EOL.

Chapter 3: Research Method

The literature review highlighted relationships between religious coping, spirituality, death concerns, and depressive symptoms in persons with advanced, life-limiting illness and showed how R/S beliefs influence death concerns within a terror management framework. The intent of this study was to contribute to TMT research by examining whether spirituality and religious coping interact between imminent death concerns and depressive symptoms in a sample of 54 hospice patients. Specifically, the study incorporated quantitative analysis to examine whether spirituality and religious coping moderated the relationship between imminent death concerns and depressive symptoms in hospice patients who were directly facing their death. The variables were examined within a TMT framework. The independent variables were religious coping, spirituality, and imminent death concerns; the dependent variable was depressive symptoms.

An aspect that sets the present study apart from other TMT research is, to my knowledge, that it is the first to examine the mortality salience hypothesis with participants for whom death was expected to occur within a specific time frame (6 months or less from hospice admission). Thus, the death concerns were imminent and not something that was abstract or far off into the future. Most TMT research has been conducted on healthy participants who imagined their death as something that would occur in the future. In contrast, hospice patients were invited to participate in this study.

The purpose of this chapter is to present the study design that was used to address the problem statement and hypotheses. The chapter begins with a description of the

research design, followed by the methodology that will include detailed information about the setting and sample. I review the measures for the variables, including psychometric information and scoring, followed by an outline of the data analysis procedures. The chapter concludes with sections on threats to validity and ethical procedures to guarantee the safety of participants and veracity of data.

Research Design and Approach

I incorporated a quantitative, cross-sectional survey design to examine the influences of the independent variables of spirituality, religious coping, and imminent death concerns on the dependent variable, depressive symptoms, in a convenience sample of 54 hospice patients. Spirituality and religious coping were moderating variables to examine the strength of relationship between imminent death concerns and depressive symptoms. A quantitative design was chosen because the research questions focused on relationships among variables that are measured on instruments that yield numerical outcomes. Moreover, the majority of TMT studies have been quantitative (Goldenberg & Arndt, 2008; Greenberg et al., 2008). One of the aims of quantitative designs is to test objective theories (Creswell, 2008), which the present study did by examining terror management in hospice patients. A cross-sectional strategy was chosen due to the transient nature of symptoms, rapid decline, and death in hospice patients that increased the probability of missing data in longitudinal research designs (McMillan & Weitzner, 2003).

The survey questionnaire was self-administered and included four validated scales: the FACIT-Sp (Peterman et al., 2002), the Brief RCOPE (Pargament et al., 2000),

the TDAS (Templer, 1970), and the HADS (Zigmond & Snaith, 1983). The scales are reviewed at length later in this chapter. The scales are directly linked to the research questions and variables, and the scores from the scales provided the basis to evaluate the hypotheses.

A survey design provides a numeric description of trends or beliefs in a sample in order to make inferences about the population from which the sample is taken (Creswell, 2009). In the present study, a survey design was chosen to address the four research questions:

1. Do imminent death concerns predict depressive symptoms in hospice patients after controlling for age?
2. Does spirituality moderate the relationship between imminent death concerns and depressive symptoms after controlling for age?
3. Does positive religious coping moderate the relationship between imminent death concerns and depressive symptoms after controlling for age?
4. Does negative religious coping moderate the relationship between imminent death concerns and depression symptoms after controlling for age?

The advantage of a survey design is its flexibility (Keough & Tanabe, 2011). It can be used for both large and small samples and can be implemented in a variety of ways that support both quantitative and qualitative research designs. For example, survey structures can range from short feedback forms and in-depth one-on-one interviews, to a series of questions or statements that elicit a specific response from the participant. The survey in this study consisted of standardized questions and statements from each of the

four scales. A benefit to using standardized scales is they can measure variables precisely by using uniform definitions and structured response formats for each participant (Trochim, 2006). A key assumption in this study's survey questionnaire design was that respondents would answer questions and respond to statements honestly.

Methodology

Setting and Sample

In 2013, an estimated 1.6 million people utilized hospice services to manage their illness at the EOL, and the hospice population is anticipated to grow steadily in the next 10 years (NHPCO, 2013). The setting for the present study was a local hospice located in San Diego, California.

The local hospice provides hospice and palliative care services to adults and children with a prognosis of 6 months or less who live in San Diego County, a multicultural urban and rural county with a population of almost 3.1 million in 2011 (U.S. Census Bureau, 2012). A primary interdisciplinary team (IDT) supports patients enrolled at the hospice. The IDT consists of a medical doctor, a nurse and/or nurse practitioner, social worker, spiritual counselor, and home health aide. Additional optional team members include volunteers and prebereavement counselors. Hospice care is funded by a "hospice benefit" that is included in most private health care insurance plans, and Medicare/Medicaid insurance. To qualify for hospice care, a physician must certify that a patient has a terminal diagnosis with a prognosis of 6 months or less. Hospice care is delivered in benefit periods that consist of two 90-day periods, followed by an unlimited number of 60-day periods. Strict hospice eligibility requirements state that the IDT and

physician must document evidence of symptoms and disease progression for each benefit period (CMS, 2012). In the event that a patient's medical condition stabilizes and there is no evidence of disease progression, or the prognosis is extended beyond 6 months, then the patient is discharged from hospice services and transferred to routine medical care. The average length of stay in hospice was 71 days in 2012 (NHPCO, 2013). While patients may stay in hospice care for multiple benefit periods, they are still facing imminent death as long as their medical condition fits the strict hospice eligibility requirements.

A systematic, convenience sample was randomly selected from patients receiving care from the local hospice. Inclusion criteria were as follows: (a) over 18 years of age, (b) understanding and ability to speak and read English, (c) ability to sustain wakefulness and attention for several hours per day, (d) pain and symptoms that are well-palliated at the time of recruitment and interview, (e) over 14 days since initial hospice admission, (f) no clinical or chart diagnosis of dementia, delirium, or any other overt cognitive impairments, and (g) patients must have decision-making capacity without the use or need of surrogate decision makers. Participants were informed that their involvement in the study would be voluntary, and they could withdraw at any time without penalty. If patients chose to withdraw or not participate in the study, there was no change in their hospice services. Participants were ineligible for the study under the following criteria: (a) under 18 years of age, (b) nonverbal, (c) comatose, (d) inadequate cognitive status by diagnosis or clinician report (dementia, Alzheimer's, confusion, agitation, delirium), (e) unable to speak or read English, (f) HIPAA consent not signed, (g) legally incompetent to

make decisions, or have a conservator, (h) lack decision-making capacity and need a surrogate decision-maker for all consents, and (i) there were barriers to approaching the patient (e.g. isolation, family gate keeper). Patients were initially screened using the inclusion/exclusion criteria at weekly interdisciplinary team meetings.

General characteristics of the selected sample were anticipated to mirror the larger hospice population. Hospice data for 2012 included the following: (a) 83% of patients were over 65 years of age (b) 56% were female (c) 82% were White/Caucasian, and (d) the majority of patients died at their place of residence (NHPCO, 2013). Specific patient characteristics that were collected for the present study were age, race, spiritual identity, gender, and terminal diagnosis. Patient characteristics were collected directly from the patients' EMR prior to administration of the survey. An example of the EMR is available in Appendix A.

Sample Size and Power Analysis

The sample size for the present study was 54 participants. An *a priori* F test power analysis was conducted using G*Power 3.1.1 (Erdfelder, Faul, & Buchner, 1996) to compute the minimum statistical sample size for a multiple regression with a total of 9 predictors: imminent death concerns, religious coping, spirituality, depressive symptoms, and demographics that included age, race, spiritual identity, diagnosis, and gender. G*Power performs power analyses for common statistical tests in behavioral research, and computes sample sizes for given effect sizes, alpha levels, and power values. The effect size (R^2) for the present study was estimated from literature (Arving, Glimelius, & Brandberg, 2008; Gall et al., 2009; Hui et al., 2011; Kandasamy et al., 2011, &

Pargament et al., 2011). The G*Power input was as follows: $R^2 = 0.35$, power = 0.80, $\alpha = 0.05$, and predictors = 9. Output data indicated that 54 complete subjects were needed for 80% power (Critical $F = 2.10$, $df = 9, 44$).

Procedure

The researcher identified eligible participants for the study through the EMR. I notified members of the patient's IDT for feedback as to whether the patient might be eligible for the study using the inclusion/exclusion criteria as guidelines. I called eligible patients and asked them whether they would be interested in participating in the study using a recruitment script (Appendix B). During the phone call, I informed potential participants that the study involves responding to statements about their religious/spiritual beliefs, depressive symptoms, and death concerns so patients were aware of the study content. Patients were also notified that the following characteristics or demographics would be collected from their EMR: age, race, gender, spiritual identity, and diagnosis. After patients expressed their willingness to join the study, I made an appointment to visit them at their place of residence to obtain informed written consent and help administer the survey. While the survey questionnaire was self-administered, I was present to assist with questions and ensure that the forms were filled out completely and correctly so there were no missing data.

Participants took 30 minutes to 1 hour to complete the survey. Breaks were included as needed. Participants exited the study after completion of the survey. I thanked the participant for his or her time, and provided contact information if there were further questions about the study. Any follow up concerns from the patients were addressed by

the IDT if they were related to the patient's psychosocial functioning, or, as needed, the hospice's bereavement department. Members of the bereavement department provided follow up counseling for participants who requested additional support related to grieving and death concerns. There were no financial incentives or other gratuities for participants in the study. The patient characteristics collected from the EMR were: age, race, gender, spiritual identity, and diagnosis. All of the characteristics are routinely updated and completed by the IDT to ensure they remain correct.

Informed consent. Prior to data collection, all participants reviewed and signed the informed consent forms with the researcher. The participant consent form for this study is in Appendix C and included required elements from the local hospice and the University. The two institutions cooperated in allowing me to conduct the study.

Instrumentation and Operationalization of Constructs

The research survey questionnaire included four published, validated scales that were used to measure the variables: imminent death concerns, depressive symptoms, religious coping, and spirituality. All questions/statements were provided in the same order for each participant. The scales were chosen for their strong psychometric scores and measurement properties for the variables in this study.

Data Collection Instruments

The four scales outlined in this section were approved for use in the present study. The TDAS is in the public domain and available for publication without registration or financial obligation. The FACIT-Sp required registration of the study to their website (www.facit.org) and a licensing agreement that was obtained and documented in the IRB

papers. The researcher received an institutional license to administer the HADS and approval to use the Brief RCOPE from its author.

TDAS. The TDAS developed by Templer (1970) is a 15-item, single dimension construct of death anxiety, and one of the most widely used measures for death concerns (Beshai, 2006; Kastenbaum, 2000; Neimeyer, 1997-1998; Pierce et al., 2007). The TDAS was used to measure the death concerns variable in this study. Choosing the right scale proved to be challenging. To my knowledge, there are no death anxiety scales that have been created for use with persons who are confronting their imminent death such as hospice patients, and other multi-dimension death anxiety scales were much longer, and not used as frequently as the TDAS in research. The TDAS was selected due to its ease of application, wide use with diverse populations, and items that appeared relevant for a hospice sample. Moreover, Templer (1970, 2006) himself interchanged the terms *death concerns* and *death anxiety* in his work, which provided the doorway for me to pick the TDAS to measure the death concerns variable. The full TDAS is in the public domain on the Internet and available at http://www.donaldtempler.com.

For purposes of this study, the imminent death concerns variable was operationalized by the fears, anxiety, disruptive thoughts, and concerns that relate to one's own imminent death and dying process (Edmondson et al., 2008; Neimeyer et al., 2011). The TDAS represents a two-factor theory of death anxiety that includes one's overall psychological health and one's personal experiences with death, however the overall score of the scale is considered to represent a single-operational definition of death anxiety that specifically measures the degree of anxiety about one's own death

(Templer, 1970, 1971; Lonetto & Templer, 1983). The similarity of Templer's (1970, 1971) operational definition of death anxiety and the operational definition used for death concerns was another factor in choosing the TDAS to measure imminent death concerns.

The TDAS has solid psychometric properties: concurrent validity was .74 correlating with the Fear of Death Scale, internal consistency coefficient was .76 using a Kuder-Richardson formula, and the test-retest correlation was .83 (Templer, 1970; Lonetto & Templer, 1983). Moreover, the TDAS has been tested with a variety of populations and cultures and all correlations were significant at the .001 level (Lonetto & Templer, 1983). The most updated mean and standard deviations scores of the TDAS among various populations and nations are outlined in Lester, Templer, and Abdel-Khalek (2006).

There have been several applications of TDAS with elderly populations or those with illness. Dougherty, Templer, and Brown (1986) administered the TDAS to 30 terminally ill cancer patients, chronically ill arthritic patients and a healthy control group, and found the cancer patients had significantly lower death concerns than the other two groups. In contrast, the TDAS was used with the Death Depression Scale (Templer, Lavoie, Chalgujian, & Thomas-Dobson, 1990) to determine the level of death anxiety and depression in gay men (Hintze, Templer, Cappelletty, & Frederick, 1994). The correlation coefficient between the two measures was high at .91, and death anxiety was higher for the participants with the most advanced illness. Moreover, three variables predicted increased death anxiety: state anxiety (R^2 =.58), depression (R^2 = .63) and family knowledge of disease (R^2 = .65). Among the elderly, death concerns were

significantly lower in those with advanced age compared to younger populations (r (111) = -340, $p < .000$).

The TDAS consists of 15 true-false, self-report statements such as "I am very much afraid to die," "It doesn't make me nervous when people talk about death," and "The thought of death never bothers me." The scale can be administered in written or oral form (Templer, 1970, 1971). Statements are scored by assigning one point for each item answered correctly according to the answer key, then totaled for the final score. Normative mean death anxiety scores for males and females in the U.S. were 6.2 and 6.5, while the high anxiety mean score in psychiatric patients was 11.6 (Templer, 1970, 1971; Lester, Templer, & Abdel-Khalek, 2006). The scores are keyed in a high death anxiety direction, so the level of anxiety increases with the score.

HADS. The HADS (Zigmond & Snaith, 1983) is a 14-item self-report scale that measures the severity of anxiety and depressive symptoms in medically ill individuals. The HADS is divided into two subscales labeled anxiety and depression. One subscale measures anxiety symptoms; the other measures depressive symptoms (Zigmond & Snaith, 1983). The present study used only the depression subscale to measure the depressive symptoms variable. The HADS operational measure of depressive symptoms is the same operational definition that is used for this study, and is based on anhedonia, or a loss of capacity to feel pleasure or interest in things or activities that used to bring enjoyment (Zigmond & Snaith, 1983). The operational definition also includes feelings of sadness and being "slowed down." The authors focused on anhedonia for this measure

because it is the primary symptom for the type of depression that responds well to antidepressants in persons with medical illness (Zigmond & Snaith, 1983).

The HADS is different from other depression scales in that it does not include items that rate somatic symptoms such as loss of appetite, fatigue, or sleep problems, which can be attributed to medication or illness and lead to a misdiagnosis of depression. The HADS focuses on items related to loss of pleasure and was chosen for its frequent use in both outpatient and inpatient settings (Campbell & Martin, 2004), and its validation with a variety of diagnoses and populations including persons at the EOL (Loosman, Sieger, Korzec, & Honig, 2010; Honamand & Feinstein, 2009; Hunt-Shanks et al., 2010). Moreover, the HADS is the most frequently used depression screening tool in the palliative care population (Wasteson, 2009).

The HADS depression subscale includes seven statements such as "I feel cheerful" and "I feel as if I am slowed down." Each item has four response choices on a Likert scale. The authors deliberately put in different responses for each statement to minimize response bias (Zigmond & Snaith, 1983). Scoring is the sum of the 7 items added together with the following severity level guidelines: normal (0-7), borderline-abnormal (8-10), and abnormal (11-21). Authors suggest cut off scores of 7/8 for the possibility, and 10/11 for the probability of depression (Snaith & Zigmond, 1994).

Original psychometrics for the HADS are limited, and included a small normed sample (n = 50) consisting of patients with physical symptom complaints aged 16 to 65 from a general medical setting (Zigmond & Snaith, 1983). Test-retest reliability coefficients were 0.92 for depressive symptoms. Item selection included psychiatric

interviews with patients and somatic diagnostic criteria from the DSM-III. The authors (Zigmond & Snaith, 1983) indicated construct validity with psychiatric patient interviews ($r = 0.79$), and psychiatric ratings of depression ($r = 0.70$). In a larger study referenced in the manual, Moorey et al. (1991) reported alpha coefficients of 0.90 for depressive symptoms in a sample of 568 cancer patients.

Since the test's inception in 1983, there have been many studies that have evaluated the psychometrics of the HADS with different medical conditions. Walker et al. (2007) cited optimal predictive validity (0.35) in identifying major depression disorder (MDD) in cancer patients ($n = 361$), and noted cutoff scores of 14/15. In a study with rehabilitation patients ($n = 296$), findings indicated supportive validity of HADS as a global measure of psychological distress with a cut-score at 12 (Pallant & Tennant, 2007). The HADS demonstrated good concurrent reliability with the Geriatric Depression Scale ($r = 0.72$) and the Hamilton Rating Scale for Depression ($r = 0.61$) in patients with Parkinson's disease (Mondolo et al., 2006) with cutoff scores at 10/11. A score ≤ 10 indicated an absence of depression, while a score ≥ 11 indicated depression. In patients with end stage renal disease, Martin, Tweed, and Metcalf (2004) found high internal reliability for the HADS depression subscale with Cronbach's α value of .73, and both the HADS depression and anxiety subscales were significantly and positively correlated ($r = .67$, $p < .001$). However, for the end stage renal patients, there were irregularities in the HADS factor structure, and treatment modality had a significant effect on depression. Of hospice inpatients that were able to take the HADS ($n = 17$), nine of them reported

depressive symptoms that resulted in a clinical diagnosis of depression and interventional support (Urch, Chamberlain, & Field, 1998).

Brief RCOPE. The Brief RCOPE (Pargament et al., 2000) is one of the most commonly used sales of religious coping for life's stressors (Pargament, Feuille, & Burdzy, 2011) and was used to measure the religious coping variable. The operational definition of the religious coping variable for this study comes from Pargament (1997), and is the same definition that is used in the Brief RCOPE. Religious coping is defined as a multidimensional construct that measures the level and depth of how religious and spiritual beliefs and practices are involved in coping with negative or stressful events (Pargament 1997; 2000).

The measure was chosen for its articulation of behavioral and emotional components of religious coping and its wide use in health care settings (Pargament et al., 2011). The Brief RCOPE is a two-factor scale that measures positive and negative religious coping. Each subscale has seven items that that consist of positive clusters of religious coping (e.g., "Looked for a stronger connection with God," "Focused on religion to stop worrying about my problems"), and negative clusters of religious coping (e.g. "Wondered whether God had abandoned me," "Wondered what I did for God to punish me"). Responses are based on a Likert scale and rated numerically from 1 ("not at all") to 4 ("a great deal").

Positive religious coping items focus on one's sense of connectedness to something or someone transcendent, such as a caring God, or a belief that life has a benevolent meaning (Pargament et al., 2011). Negative religious coping statements tap

into spiritual struggle, discontent, and questioning, and is marked by a sense of conflict with God or some other benevolent source, and a negative appraisal of God's powers and support (Pargament et al., 2011). Scoring consists of adding up the total scores for each subscale, with us of an algorithm for one of three acuity ranges: low (all items = 1 or 6 items = 1, and 1 item = 2), Moderate (two items = 2 and remaining items =1), and High (two or more items = 3 or 4; 3 or more items are > or = 2, or one item = 2 and one or more items = 3 or 4). Mean scores for positive religious coping range from 17 to 21 and negative religious coping from 8 to 14 (Pargament et al., 2011).

A recent review of the Brief RCOPE psychometrics revealed the scale was both reliable and valid (Pargament et al., 2011). Internal consistency was good in diverse samples that ranged from cardiac, HIV, and cancer patients to religious school students and adult residents who lived in Eastern seaboard states (median α for positive religious coping = 0.92 and negative religious coping = 0.81), and there were nonsignificant relationships between the positive and negative religious coping subscales. Concurrent validity was favorable, with positive religious coping associated with greater well-being and negative religious coping tied to signs of poor functioning (e.g., depression, anxiety, and pain). There has been initial support for predictive validity of the Brief RCOPE in medically ill patients. Tsevat et al. (2009) found positive religious coping to be significantly related to improvement in quality of life and negative religious coping associated with decreased quality of life in HIV outpatients, while Ai et al. (2010) found positive religious coping predicted less hostility and negative religious coping more hostility before and after surgery in cardiac patients. A limitation of the Brief RCOPE is

that the majority of studies were conducted in the United States and Western Europe with predominantly Christian samples (Pargament et al. 2011), limiting strong validity with more diverse cultures. However, the Brief RCOPE fits the demographic overview of the sample that was studied in the present research.

FACIT-Sp. The FACIT-Sp (Peterman et al., 2002) is a 12-item questionnaire developed to measure aspects of spirituality or faith that contributes to quality of life in medically ill patients. It was used to measure the spirituality variable in this study. The operational definition of spirituality in this study referred to how people seek and express meaning and purpose to their lives, and the way they experienced connectedness and peace in the moment (Puchalski et al., 2009). The FACIT-Sp was chosen for its similar operational construct for spirituality and its frequent use in palliative and health care settings (Bredle, Salsman, Debb, Arnold, & Cella, 2011).

The FACIT-Sp was developed from the Functional Assessment of Cancer Therapy Scale (Cella et al., 1993). Original research for the scale emphasized a two-factor analysis labeled meaning-peace and faith (Peterman et al., 2002). The meaning and peace subscale focuses on respondents' sense of meaning, purpose, and peace in life with statements such as: "I have reason for living," and "I feel peaceful." Faith emphasized the relationship between one's illness and one's faith or spiritual beliefs with items such as: "My illness has strengthened my faith or spiritual beliefs," and "I know that whatever happens with my illness, things will be okay." Studies that are more recent separated meaning and peace, and identified a 3-factor analysis of meaning, peace, and faith representing "a psychometric improvement over the original 2-factor model" (Bredle et

al., 2011; Canada et al., 2008; Murphy et al., 2010, p. 264). Responses are based on 5-point Likert scale that ranges from 0 (“not at all”) to 4 (“very much”). Scoring consists of noting items that must be reversed before being added to the total subscale (Cella, 1997/2010). Subtracting the response from the number “4” reverses negatively stated items. Then all of the items are summed to a total, which is the subscale score. There are no norms for the scores. Higher scores indicate greater spiritual well-being and quality of life (Cella, 1997/2010).

The FACIT-Sp has strong psychometrics and the scale has been validated across a variety of cultures and literacy levels. Reliability and initial validity was established with a sample of 1617 participants with medical illness—53% female and 47% male with an average age of 54 years. Eighty-three percent of the sample had cancer, the rest were diagnosed with HIV/AIDS, and all participants had been living with disease for at least 2 years. Reliability was solid for the total scale ($\alpha = 0.87$) and the original two factors (meaning/peace, $\alpha = 0.81$; faith, $\alpha = 0.88$). There were moderate to strong correlations between the FACIT-Sp and a variety of quality of life and R/S scales with scores ranging from 0.31 to 0.48 (Peterman et al., 2002). In the 3-factor model, there were positive correlations of FACIT-Sp for meaning, peace, and faith: Cronbach’s $\alpha = 0.78$, 0.83, and 0.84 on quality of life (Canada et al., 2008) in female cancer patients and survivors.

The FACIT-Sp has been used as a measure of spirituality in a variety of seriously ill populations around the world. In men with terminal prostate cancer, those with higher FACIT-Sp scores were more likely to enroll in hospice care and receive palliative radiation than those with lower scores (33% vs. 13%, $p = 0.69$) who opted for more

curative treatment (Bergman et al., 2011). In 50 advanced cancer patients enrolled in hospice, the FACIT-Sp subscales of meaning/peace and faith were significantly correlated with fatigue ($r = 0.423$, $p = 0.004$), symptom distress ($r = 0.717$, $p = 0.001$), and sadness ($r = 0.720$, $p = 0.001$) (Kandasamy et al., 2011). Parents of children who were on palliative care service were given the FACIT-Sp to measure their spirituality (Knapp et al., 2011). Findings indicated that non-White parents had overall higher spiritual well-being scores than White parents. Taken as a whole, the multiple uses of FACIT-Sp for palliative care populations made it a practical and relevant measure of spirituality for the present study.

Data Collection and Analysis

The intent of the present study was to determine whether imminent death concerns, spirituality, and religious coping, influenced depressive symptoms at the EOL in hospice patients. The scores from the questionnaire scales formed the basis of measurement for the primary variables: The final HADS score measured depressive symptoms; the FACIT-Sp measured spirituality; the Brief RCOPE measured religious coping and the TDAS measured imminent death concerns. Patient characteristics and demographic items were taken directly from the EMR, which included age, race, gender, spiritual identity, and diagnosis.

Preliminary Analyses

All data analyses were performed on SPSS software. Preliminary analyses included descriptive statistics that showed the frequency distribution, central tendencies, and dispersion (standard deviations) of the four primary variables: imminent death

concerns, religious coping, spirituality, depressive symptoms, and for patient characteristics taken from the EMR: age, race, gender, spiritual identity, and diagnosis. Pearson correlation analyses were performed for normally distributed data to assess the degree and direction of linear relationships among the independent and dependent variables. The average hospice scores for each of the scales were compared to other populations using one-sample *t*-tests. A Cronbach's alpha test of reliability was conducted for each of the scales to evaluate the consistency of the participant responses.

Data Analysis

The research questions involved predictor and moderator variables, so regression analyses were the primary statistical method to test the hypotheses. Both a simple linear regression and hierarchical multiple (or moderated) regression were used to analyze data. Regression analysis measures a linear relationship between the independent variables and the dependent variable (George & Mallory, 2009). In the present study, imminent death concerns was the independent, predictor variable; depressive symptoms was the dependent variable. Spirituality and religious coping were the moderating independent variables. The role of moderator variables is to assess the direction or strength of relationship between the predictor and dependent variables (Frazier, Barron, & Tix, 2004). Moderating variables may change the relationship between the independent variables and dependent variable. In this study, age was a potentially confounding variable and was controlled in the regression analyses. Older hospice patients may feel more accepting of their own death since they have already lived a long life and have more

exposure to death from the loss of friends and loved ones (DeRaedt & Van Der Speeten, 2008; Missler et al., 2011).

The statistical plan was to conduct a multiple linear regression for the first research question, and hierarchical multiple regression for Research Questions 2 through 4 using the Stepwise procedure. The entry order was determined by each hypothesis, which in turn was derived from the theoretical and empirical rationale outlined in the literature review. The multiple regressions included centering the independent variables and creating an interaction term that represented the interaction between the predictor and moderator variables. Centering the variables was needed to reduce multicollinearity in the regression equation because the predictor and moderator variables are usually highly correlated with the new interaction term (Frazier et al., 2004). Centering involves subtracting from each variable score the mean of all scores on that variable, which is done through SPSS. The creation of the interaction term is also through SPSS which multiplies the predictor and moderator variables to create a new interaction variable. I interpreted the multiple regression results by using (a) the effects of the predictor and moderator variables, (b) the significance of the moderator effect, and (c) plotting the significant moderator effects as appropriate. The specific regression steps are outlined for each hypotheses set following restatement of the four research questions.

Research Question 1: Do imminent death concerns predict depressive symptoms in hospice patients after controlling for age?

$H_0$1: Imminent death concerns will not significantly predict depressive symptoms in hospice patients after controlling for age.

H_a1: Imminent death concerns will significantly predict depressive symptoms in hospice patients after controlling for age.

For this hypothesis set, I conducted a simple linear multiple regression predicting depressive symptoms. The input steps for the first regression were as follows. First, from the menu at the top screen of SPSS, I picked the linear regression analysis. Second, imminent death concerns was entered into the box as the independent variable. Third, depressive symptoms was entered as the dependent variable. Age was put into the first block. If there was no correlation, then age would be not be included in the following multiple regressions. Fourth, in the Method box, I selected 'enter,' then clicked on the Statistics button and selected the following: Estimates, Confidence Intervals, Model fit, Descriptives, Part and partial correlations, and collinearity diagnostics. Fifth, on the Options button, in Missing Values section, I selected 'exclude cases pairwise' then clicked 'continue' then 'save' to conduct the multiple regression.

Research Question 2: Does spirituality moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age?

$H_0 2$: Spirituality will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

$H_a 2$: Spirituality will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

For this analysis, I clicked Analyze on the SPSS menu screen, then selected Regression, then Linear. The hierarchical multiple regression included centering the means of imminent death concerns and spirituality. Then I created the interaction term by multiplying the centered predictor (imminent death concerns, or *IDC*) and moderator (spirituality) variables in SPSS, usually denoted by an asterisk, such as "IDC * spirituality." After the centered independent variables and interaction term were in place, I conducted the multiple regression with the following steps. First, the imminent death concerns variable was entered into the first block. Second, the interaction term (centered spirituality and centered imminent death concerns scores) was entered into the second block with the centered scores for spirituality. Depressive symptoms was placed in the dependent variable box. The original plan was to include age in the multiple regression. However, since it was not correlated with depressive symptoms it was excluded from this multiple regression and the ones that followed. I selected 'enter' for the Method button, and the following fields in the Statistics section: estimates, R square change, confidence intervals, model fit, descriptives, correlations, and collinearity diagnostics. In Options, I selected 'exclude cases pairwise' and clicked 'continue' and 'save' to conduct the multiple regression.

After the initial multiple regression was completed, I separated out the three subscales of spirituality: meaning, peace and faith, and examined each using one moderation on the relationship between imminent death concerns and depressive symptoms. The steps were the same for each subscale. First, imminent death concerns ("IDC") was entered into the first block. Second, the centered score for the subscale

(meaning, peace, or faith) along with the interaction term between the centered variable score and centered imminent death concerns score were added to the second block. When the variables were in place, I conducted the multiple regression each for meaning, peace, and faith.

Research Question 3: Does positive religious coping moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age?

$H_0$3: Positive religious coping will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

H_a3: Positive religious coping will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

For the multiple regression, the variables imminent death concerns and positive religious coping were centered. Then, the interaction term was created by multiplying the centered imminent death concerns predictor and moderator positive religious coping variables in SPSS. After the centered independent variables and interaction term were in place, I conducted the multiple regression. The first step was to enter the imminent death concerns variable into the first block. The centered positive religious coping scores and the interaction term between centered positive religious coping and centered imminent death concerns scores were entered into the second block. Depressive symptoms were placed in the dependent variable box. I selected ‘enter’ for the Method button, and the

following fields in the Statistics section: estimates, R square change, confidence intervals, model fit, descriptives, correlations, and collinearity diagnostics. In Options, I selected 'exclude cases pairwise,' and clicked 'continue' and 'save' to perform the multiple regression.

Research Question 4: Does negative religious coping moderate the relationship between imminent death concerns and depressive symptoms after controlling for age?

$H_0$4: Negative religious coping will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

H_a4: Negative religious coping will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

For the multiple regression, I centered the imminent death concerns and negative religious coping variables. Then I created the interaction term by multiplying the centered predictor (imminent death concerns) and moderator negative religious coping variables in SPSS. After the centered independent variables and interaction term were in place, I conducted the multiple regression. The first step was to enter the imminent death concerns variable into the first block. The second step was to enter the centered negative religious coping scores and the interaction term between centered negative religious coping and centered imminent death concerns scores into the second block. Depressive symptoms was placed in the dependent variable box. I selected 'enter' for the Method button, and the following fields in the Statistics section: estimates, R square change,

confidence intervals, model fit, descriptives, correlations, and collinearity diagnostics. In Options, I selected ‘exclude cases pairwise’ and clicked ‘continue’ and ‘save’ to conduct the multiple regression.

Data Cleaning and Screening

The study design was formulated to maximize data quality and minimize errors in data collection. It was expected that the solid psychometrics of the four scales would lessen the probability for significant outlier scores or odd patterns in the data. The scales were formatted with large fonts to enhance readability for the participants. Moreover, I was present while participants completed the survey to ensure participants answered all of the statements and to avoid missing or incomplete data. The demographic material was taken from the EMR, which was collected upon admission to hospice services. The primary hospice team ensured that demographic material was updated while patients were on hospice, so there were no expectations that demographics would be incorrect during data collection.

In the event that missing data, outliers or peculiar patterns are discovered, I planned to discuss the discrepancies and options with the dissertation chair. The optimal plan was to leave questionable data unchanged, and to document the findings in the results section. However, there were no peculiar patterns, outliers, or incomplete data in this study. Ranges for variables were put into the database to reduce error from data input (e.g. pressing wrong key on keyboard). Moreover, the researcher did random spot checks of at least 20% of the data to review data entry and ensure integrity of the results.

Threats to Validity

There were threats to external validity that would have impacted the degree in which this study's outcomes could be generalized to other populations. First, using a convenience sample from a specific medical institution, limited the context in which the results of the study could be generalized to all persons at the EOL. Second, the patients who agreed to participate in this research may not have represented the whole hospice population. Data collection with hospice patients can be challenging due to symptom management, death, and abrupt changes of condition (NHPCO, 2013). Due to data collection time constraints, all eligible participants who completed the consent forms were accepted into the study, and the final sample may not have been indicative of all persons who have faced their mortality. Another threat to validity was the location of the study: San Diego county, an area of California with its own geographic population distinctions. In San Diego County, 48% of persons are White, non-Hispanic, 32% are Hispanic or Latino, 11% are Asian, and 5% are Black (U.S. Census Bureau, 2012). Generalizations of findings may not be applicable to hospice populations where the demographics are different.

There were efforts to improve external validity for this study. In order to keep low dropout rates and minimize incomplete data, I provided clear explanations about the study and consent forms so participants knew what to expect in response to the survey items. Generalizations were limited to persons at the EOL in hospice care, and were not representative of how all populations might respond to their mortality. Chapter 5 will incorporate the theory of proximal similarity (Campbell, 1988) to describe the differences

and similarities of the present study in comparison to other contexts, groups, and settings related to the EOL.

There were two other threats to internal validity in this study. First, social desirability response bias may have posed a threat to construct validity. Participants completed the surveys independently, and may have provided socially desirable responses that made them look as good as possible (Donaldson & Grant-Vallone, 2002). For example, they may have underreported depressive symptoms, or over reported positive R/S experiences in efforts to portray strength and acceptance of their situation. Thus, the validity of the measures may have been impacted. To minimize self-report bias, the researcher reminded participants that all surveys were confidential, with numbers replacing names and other identifying information so they could respond as honestly as possible with no repercussions.

A second threat to internal validity involved the confounding variable of age. The relationship between the independent variables (imminent death concerns, spirituality, and religious coping) and the dependent variable (depressive symptoms) may be attributed to someone's age, particularly those who are elderly and expectant of their death. To minimize this threat to validity, the multiple regressions for each set of hypotheses were run with and without the confounding variable of age.

Ethical Procedures

The local hospice (IRB-13-6258) and Walden University (12-12-13-0140094) Institutional Review Boards provided approval to conduct the study. The permission

included access to hospice patients through the EMR database, data storage areas within the hospice offices, and use of the hospice consent forms and research materials.

I used a general recruitment script to explain the research study to potential participants. The script also addressed a potential ethical concern that participants would be recruited without going through proper screening, explanation, and consent procedures. There was always the ethical concern that individuals would be enticed to participate without full knowledge of the study content. The researcher explained details of the study content to potential participants over the phone so they were able to make an informed decision about whether to participate. Only legally competent patients with decision-making capacity were allowed to participate in the study. Moreover, the consent form for this study was long. There was an ethical concern that participants would not fully understand what they were consenting to. Care and attention was given to explain the consent form to participants with time for questions.

Protection of Participants

Conducting research with people at the EOL poses unique ethical considerations because the population is vulnerable and in need of special protection due to the medical and contextual issues surrounding their situation. Hospice patients often have cognitive impairments from disease progression and pain medications, and many patients experience emotional and psychological distress as they confront their mortality (Chochinov et al., 2009). In addition, to qualify for hospice care, the patient must have a life expectancy of 6 months or less if the disease follows its natural progression. With such a limited time frame left to live, some researchers argue that it would be an intrusion

to solicit hospice patients to participate research at such an important time in their lives (Casarett & Karlawish, 2000; Jubb, 2002). Nevertheless, hospice research has grown over the years and provided a valuable resource to enhance EOL care.

There are a variety of reasons hospice patients are willing to participate in research. Some view research participation as a way to give back to their families and communities, or as a contribution to their legacy (Chochinov et al., 2005). Others join research studies as a means to help health care workers and the greater public to understand the unique issues related to death and dying (Casarett, 2005). Moreover, many hospice patients experience their lives as meaningful and productive, and participate in research because it is a constructive way to use their time and stay connected with the greater community (Terry, Olson, Ravenscroft, Wilss, & Boulton-Lewis, 2006). There is consensus that doing research with hospice patients is ethical when patients have decision making capacity and willingly volunteer to participate, and when the research design contributes to quality improvement, benefits future patients, and minimizes risk (Casarett, 2005; Stanhauser et al., 2006).

The following care was incorporated for the protection of participants in this study (a) the ability to withdraw from the study at any time with no questions asked, (b) the ability to stop or reschedule the survey questionnaire with participants who demonstrated cognitive changes, pain, or distress, and (c) the availability of bereavement counseling or additional debriefing after the survey was completed. Study participants were reminded that their inclusion or withdrawal in the study would have no effect on the quality of care they received from hospice. The IDT continued to monitor the spiritual

and psychosocial status of participants after the study was administered. There were no adverse events with the patients who completed the study.

Confidentiality

The privacy of the participants was protected by taking measures to prevent the disclosure of protected health information. Procedures in the data collection protocol were compliant with the Health Insurance Portability and Accountability Act. In order to ensure the confidentiality of responses to the survey, each participant was assigned a unique study identification number as an identifying element. At no time will the participant's identifying information be used in presentations or scientific discussions pertaining to the results or research findings. Patient characteristics and demographics (age, race, gender, spiritual identity, diagnosis) were taken directly from the EMR and input anonymously into a data spreadsheet. The spreadsheet did not include items that identified specific patients.

Printed raw data is currently stored in a locked cabinet at the local hospice offices. Access to the raw data is limited to those the researcher and IRB. Electronic raw data is stored on a password-protected, encrypted, and firewalled computer server. Raw data is available for retrieval by request to the researcher. Raw and electronic data will be destroyed after 5 years.

Summary and Transition

This research study was conducted at a local hospice in San Diego, CA. The study was a quantitative, cross-sectional, survey design that examined the influences of imminent death concerns, spirituality, and religious coping on depressive symptoms in a

sample of 54 hospice patients. The survey was self-administered, and consisted of four validated scales that measured the variables. Demographic materials were taken from the participants' EMR. Participants completed the survey at their home residence. The researcher was present to assist with questions, explain the consent forms, and ensure the surveys were filled out completely. The data collection continued until 54 surveys were fully completed and collected. Data analysis included bivariate correlational analyses among the primary variables (imminent death concerns, spirituality, religious coping, depressive symptoms), and hierarchical multiple regression for each set of hypotheses using SPSS software. Ethical procedures were in place to ensure participants' safety and confidentiality.

In Chapter 4, the results of the data analysis will be presented. In addition, I review the study's purpose, research questions, and hypotheses prior to outlining the findings. The chapter includes a description of the study protocol and demographic characteristics of the sample as they relate to the larger hospice population. Essential tables are included as a visual representation of study findings.

Chapter 4: Results

The purpose of this study was to examine whether religious coping and spirituality moderate the relationship between imminent death concerns and depressive symptoms in hospice patients. TMT was the theoretical framework that determined the variables and influenced the discussion in Chapter 5. TMT is based on the hypothesis that people cling to and defend their established religious and or spiritual, cultural, and personal beliefs when they are confronted with their own mortality (Pyszczynski et al., 1999). The belief systems bolster self-esteem and provide a sense of meaning and immortality to peoples' lives, which in turn minimizes the threat of death (Schimel et al., 2007). The present study was designed to examine whether religious coping and spiritual beliefs moderate the relationship between imminent death concerns and depressive symptoms in hospice patients. The research questions and hypotheses were as follows:

Research Question 1: Do imminent death concerns predict depressive symptoms in hospice patients after controlling for age?

$H_0$1: Imminent death concerns will not significantly predict depressive symptoms in hospice patients after controlling for age.

H_a1: Imminent death concerns will significantly predict depressive symptoms in hospice patients after controlling for age.

Research Question 2: Does spirituality moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age?

$H_0$2: Spirituality will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

H_a2: Spirituality will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

Research Question 3: Does positive religious coping moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age?

$H_0$3: Positive religious coping will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

H_a3: Positive religious coping will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

Research Question 4: Does negative religious coping moderate the relationship between imminent death concerns and depressive symptoms after controlling for age?

$H_0$4: Negative religious coping will not significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

H_a4: Negative religious coping will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

This chapter is organized as follows. First, an overview of the statistical assumptions are reviewed, followed by an outline of the data collection process. Second, the baseline descriptive and demographic characteristics of the sample are presented and compared to similar populations. Third, I present reliability results for each of the scales. Fourth, the data analysis results for each research question and hypothesis are provided. Finally, there will be a summary of the overall findings and brief preview of the next chapter.

Statistical Assumptions

There were four major assumptions for multiple regression that were considered in the research design and reviewed again during data analysis to ensure the integrity of the analysis. First, sample size needed to be accurate for generalizability. The sample size for this study (n = 54) was determined using G*Power 3.1.1. (Erdfelder et al., 1996) and took into account the number of variables, effect sizes, alpha levels, and power values needed to run effective regression analyses. The second assumption involved relationship among variables. Errors can occur when independent variables are highly correlated (multicollinearity), or when one independent variable is actually a combination of other independent variables (singularity; Pallant, 2013). Multicollinearity and singularity among variables were examined prior to the regressions and were not an issue, evidenced by Table 4. Third, outliers can skew multiple regression output. There were no evident outlier scores on the residual plots provided with the multiple regression analyses. Finally, multiple regression is sensitive to the distribution of scores and the nature of the underlying relationship between the variables. The scores were checked from the

scatterplots generated as part of the multiple regression procedure and found to have normal distribution (normality), straight-line relationship with predicted dependent variable scores (linearity), and similar variance of predicted dependent variable scores (homoscedasticity).

Data Collection

Data collection took place over 5 months, from December 2013 until April 2014, and proceeded as planned with no discrepancies from the outline in Chapter 3. Ninety-seven eligible hospice patients were approached to participate in the research. The final sample size was 54 participants. Eligibility requirements included the following: (a) over 18 years of age; (b) ability to understand, speak and read English; (c) ability to sustain wakefulness and attention for several hours per day; (d) pain and symptoms that were well-palliated at the time of recruitment and survey delivery; (e) over 14 days since initial hospice admission; (f) no clinical or chart diagnosis of dementia, delirium, or any other overt cognitive impairments; and (g) clinical decision-making capacity without the use or need of surrogate decision makers. Participants were ineligible for the study under the following criteria: (a) under 18 years of age, (b) nonverbal, (c) comatose, (d) inadequate cognitive status by diagnosis or clinician report (dementia, Alzheimer's, confusion, agitation, delirium), (e) unable to speak or read English, (f) HIPAA consent not signed, (g) legally incompetent to make decisions or had a conservator, (h) lack of decision-making capacity, and (i) barriers approaching the patient (e.g., family gatekeeper).

Of the 97 hospice patients who were recruited to participate, 54 gave informed consent and completed surveys. Forty-three hospice patients did not consent or continue

with the study for a variety of reasons, the most frequent being a lack of interest in research or the study content (37%). Other hospice patients declined participation due to privacy reasons and did not want another person from the hospice organization coming into their home (30%). The remaining hospice patients approached for the study originally consented to be part of the research, but could not continue because escalated symptoms (28%) or death (4%) rendered them ineligible by the time the survey was to be administered. Table 1 outlines recruitment data.

Table 1

Recruitment Data

Potential Participants	*n*	%
Total Patients Recruited	97	
Completed Surveys	54	55
Declined/Unable to Participate	43	44
Not Interested	16	37
Privacy	13	30
Change of Condition/Symptoms	12	28
Death	2	4

Descriptive and Demographic Characteristics of Sample

The majority of participants were male (57%) and White (67%). The most frequently reported religion of participants was either Catholic (26%) or Christian (26%). Participants were most likely to be under hospice care because of a cancer diagnosis (43%) or heart disease (26%). Lastly, the most frequently reported age group of hospice patients was between 60 and 69 years (31%), followed by those aged 80 to 89 (20%). Complete demographic information is presented in Table 2.

Table 2

Frequencies and Percentages for Demographic Variables

Variable	*n*	%
Gender		
Male	31	57
Female	23	43
Ethnicity		
White-Non Hispanic	36	67
White-Hispanic	8	15
Black	6	19
Asian-Pacific Highlander	4	13
Diagnosis		
Cancer	23	43
Heart Disease	14	26
COPD (chronic obstructive pulmonary disease)	8	15
Liver disease	4	7
Kidney disease	2	4
ALS (amyotrophic lateral sclerosis)	2	4
HIV-AIDS	1	2
Age		
20-29	1	2
30-39	0	0
40-49	2	4
50-59	9	17
60-69	16	30
70-79	10	18
80-89	12	22
90-99	2	4
100-109	2	4

(table continues)

Variable	*n*	%
Spiritual Identity		
Catholic	14	26
Christian	14	26
None	8	15
Spiritual	3	6
Jewish	2	4
Baptist	2	4
Mormon	2	4
Buddhist	2	4
Protestant	2	4
Agnostic	1	2
Religious Science	1	2
Pentecostal	1	2
Muslim	1	2

Note. Percentages may not total 100 due to rounding error.

The sample population was representative of the larger hospice population in race, ethnicity, and primary diagnosis. On a national level, most hospice patients are White, non-Hispanic (93.1%), followed by White, Hispanic or Latino (6.9%), Black (8.6%), and Asian-Pacific Highlander (2.8%). The majority have a cancer diagnosis (37%) followed by heart disease (11.2%; NHPCO, 2013). The sample was less representative of the larger hospice population for gender and age demographics. Nationally, most hospice patients are female (56%), whereas the sample demographics included more male (57%) than female (43%) participants, and 68% of the sample were over the age of 65, compared to 83% of hospice patients in the U.S. (NHPCO, 2013). Thus, results of this study may not be generalizable to hospice patients who are women and those who are over 80.

Analyses

The survey consisted of four validated scales to quantify the primary variables. The FACIT-Sp quantified the spirituality variable. Immanent death concerns were measured with the TDAS, and depressive symptoms with the HADS. The negative and positive religious coping scales were quantified with the Brief RCOPE. For the first set of analyses, I measured the central tendencies of the hospice sample total scores for each scale and conducted independent sample t-tests to compare the data to samples with advanced illness.

Spirituality scores in the sample included the meaning, peace, and faith subscales of the FACIT-Sp, as well as a composite of the three. There are no cut-off scores that determine levels of spiritual well-being for the FACIT-Sp. Higher scores are indicative of higher quality of life and spiritual well-being (Peterman et al.,2002). The range for the three subscales of meaning, peace, and faith is 0 to 16. The sample had an average meaning score of 12.30 (SD = 3.45), a mean peace score of 10.81 (SD = 3.27), and a mean faith score of 11.41 (SD = 4.03). There was no significant difference between the faith score of the hospice sample and advanced cancer patients from Murphy et al., 2010 (M = 11.70, SD = 4.3). However, there were significant differences between the two samples for meaning t (292) = 2.95, p = .0035 and peace t (292) = 2.3, p = .0035. The range for the total spirituality score, a composite of meaning, peace and faith, is 0 to 48. The sample had a mean total spirituality score of 34.04 (SD = 8.27). There was a significant difference in the spirituality scores for the hospice sample and patients with the advanced cancer patients (M= 37.35, SD = 8.60); t (53) = 2.82, p = .005.

Likewise, imminent death concern scores of the hospice patients were lower compared to other populations. Scale scores for the TDAS range from 0 to 15. A total score between 4.5 and 7.0 denotes a normal level of death anxiety (Templer & Ruff, 1971). The mean imminent death concerns score of the hospice patients was 5.31 (SD = 2.94), which falls within the normal range of death anxiety, but was significantly different than the normative mean scores for cancer patients (Gonan et al., 2012); 6.12, SD = 3.4; t (53) = 2.02, p = 0.05 and healthy populations (Lester, 2006); M = 6.19, SD = 0.72; t (53) = 2.19, p = 0.03.

Average positive and negative religious coping scores for the hospice sample were lower when compared to other samples with life-limiting illness. The total score range for both negative and positive religious coping is 1 to 28. A moderate level of negative religious coping includes scores from 8 to 14. The mean hospice sample score of 1.50 (SD = 2.44) indicated a low level of negative religious coping, and was significantly different from advanced cancer patients (Pargament et al., 2011); M = 9.0, SD = 3.5; t (53) = 22.5, p < .001 and end-stage HIV-AIDS patients (Pargament et al., 2011); M = 10.7, SD = 4.3; t (53) = 27.7, p < .001. Moderate positive religious coping scores range from 17 to 21. The mean positive religious coping score for the hospice sample was 10.35 (SD = 6.59), a low level of coping, and substantially lower than patients with advanced cancer (M = 18.1, SD = 6.4); t (53) = 8.64), p < .001 and end-stage HIV (M = 17.7, SD = 6.4), t (53), = 27.7, p < .001.

Average depressive symptom scores were 6.69 (*SD* = 3.84), which fall within the HADS normal depression severity level score of 0 to 7 (Snaith & Zigmond, 1994).

However, the scores were significantly lower than those of advanced cancer patients (Castelli, Binaschi, Calder, Missa & Torta, 2011); M = 8.9, SD = 5.4; t (151) = 2.76, p = .006. Table 3 has the complete list of means and standard deviations for the continuous variables.

Table 3

Means and Standard Deviations

Variable	*Min.*	*Max.*	*M*	*SD*
Imminent death concerns	0.00	12.00	5.31	2.94
Positive religious coping	0.00	21.00	10.35	6.59
Negative religious coping	0.00	10.00	1.50	2.44
Depressive Symptoms	1.00	19.00	6.69	3.84
Spirituality Composite	15.00	47.00	34.04	8.27
Meaning	4.00	16.00	12.30	3.45
Peace	4.00	16.00	10.81	3.27
Faith	3.00	16.00	11.41	4.03

Next, I conducted a Pearson correlation matrix to identify the variables' relevance in the multiple regression analyses. Each variable of interest was assessed for correlations with the others as an exploratory analysis, as well as to assess for multicollinearity in the following regression analyses. According to Tabachnick and Fidell (2012), significant correlations with a coefficient of .80 or greater may contribute to a violation of the assumption of multicollinearity. Although there were significant correlations, none of these had a correlation coefficient of .80 or greater, and the assumption was met for all following regression analyses.

Imminent death concerns was significantly negatively correlated with both age (r = -.27, p = .05) and peace (r = -.27, p = .05). Meaning was significantly correlated with peace (r = .45, p < .01) and negatively correlated with depressive symptoms (r = -.51, p < .01). Peace was significantly correlated with faith (r = .37, p = .01) and negatively correlated with both depressive symptoms (r = -.41, p = .002), and negative religious coping (r = -.29, p = .03). Faith was significantly correlated with positive religious coping (r = 68, p < .01). Depressive symptoms were significantly correlated with negative religious coping (r = .30, p =. 03). Results of the Pearson correlation matrix are presented in Table 4.

Table 4

Pearson Correlation Matrix between Variables of Interest

	1	2	3	4	5	6	7
Imminent death concerns	-						
Age	-.27*	-					
Meaning	.13	-.18	-				
Peace	-.27*	-.06	.45**	-			
Faith	.11	-.22	.21	.37**	-		
Depressive symptoms	.03	-.02	-.51**	-.41**	-.07	-	
Positive religious coping	.21	-.23	.00	.16	.68**	.00	-
Negative religious coping	.25	.09	-.25	-.29	-.12	.295*	-.01

Note. * p < .05, ** p < .01. (1) imminent death concerns, (2) age, (3) meaning, (4) peace, (5) faith, (6) depressive symptoms, (7) positive religious coping

Reliability

I conducted Cronbach's alpha test of reliability to determine how consistently participants responded to each scale. Results of the Cronbach's alpha test of reliability were interpreted using the guidelines suggested by George and Mallery (2010) where > .9

Excellent, > .8 Good, > .7 Acceptable, > .6 Questionable, > .5 Poor, < .5 Unacceptable. The coefficient alpha for the overall FACIT-Sp scale was α = .76, an acceptable level of reliability. The TDAS scale had a questionable level of reliability, α = .69, though the level of reliability for this scale was borderline acceptable. I will discuss the implications of the TDAS reliability in Chapter 5. The RCOPE positive religious coping scale had the highest alpha coefficient, α = .92, which corresponded to an excellent level of reliability for this scale. The RCOPE negative religious coping scale had acceptable reliability, α = .77. The HADS scale was evaluated as acceptable reliability, α = .79. Results of the analysis are presented in Table 5.

Table 5

Cronbach's Alpha Reliability for Scales of Interest

Composite	α	No. of items
Overall Spirituality	.76	12
TDAS	.69	15
Positive Coping	.92	7
Negative Coping	.77	7
HADS	.79	7

Regression

Results of the multiple regression analyses conducted on each of the research questions are as follows.

Research Question 1: Do imminent death concerns predict depressive symptoms in hospice patients after controlling for age?

H_a1: Imminent death concerns will significantly predict depressive symptoms in hospice patients after controlling for age.

In the first multiple linear regression (predicting depressive symptoms) the predictor variable, age was to be entered into the first block as well as imminent death concerns. However, because age was not significantly correlated with depressive symptoms, it was not included in the regression model or any that followed. The results indicated that the overall model was not significant F (2, 51) = 0.03, p = .972 R^2 = .00. Imminent death concerns was not a statistically significant predictor of depressive symptoms. The results of the regression analysis on depressive symptoms in hospice patients are presented in Table 6.

Table 6

Multiple Linear Regression Using Death Concerns to Predict Depressive Symptoms

Source	*B*	*SE*	β	*t*	*p*
Imminent death concerns	0.04	0.18	0.03	0.23	.816

Note. Block 1: $F(2, 51) = 0.03$, $p = .972$, $R^2 = .00$

Research Question 2: Does spirituality moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age?

H_a2: Spirituality will significantly moderate the relationship between death concerns and depression in hospice patients after controlling for age.

In the first hierarchical multiple linear regression, imminent death concerns was entered into the first block. In the second block, the centered scores for total spirituality as well as the interaction term between centered total spirituality scores and centered imminent death concern scores were entered along with imminent death concerns in the

first block. The overall model was significant, F (3, 50) = 6.22, $p < .001$, $R^2 = .27$. Therefore, total spirituality scores, and the interaction between total spirituality and imminent death concerns in addition to imminent death concerns accounted for approximately 27% of the variance in depressive symptoms of the hospice patients. The total spirituality score was a statistically significant predictor $B = -0.24$, $p < .001$, indicating that as spirituality scores increased by one, depressive symptoms decreased by 0.24. Importantly, the interaction term between total spirituality and imminent death concerns that indicates a moderating effect was not statistically significant, $B = -0.01$, $p < .617$. No other predictor variables were statistically significant. The results of the regression analysis on depressive symptoms are presented in Table 7.

Table 7

Hierarchical Multiple Linear Regression with Total Spirituality Moderating Relationship between Death Concerns and Depressive Symptoms

Source	*B*	*SE*	*β*	*t*	*p*
Block 1					
Imminent death concerns	0.04	0.18	0.03	0.23	.816
Block 2					
Imminent death concerns	0.04	0.46	0.03	0.26	.795
Total Spirituality	-0.24	0.06	-0.51	-4.19	<.001
Imminent death concerns*total spirituality	0.01	0.02	0.06	0.50	.617

Note. Block 1: $F(1, 52) = 0.06$, $p = .816$, $R^2 = .00$; Block 2: $F(3, 50) = 6.21$, $p < .001$, $R^2 = .27$

To further examine the effect of spirituality on depressive symptoms and the relationship between imminent death concerns and depressive symptoms, the construct of spirituality was broken into three discrete subscales. These three subscales included

meaning, peace, and faith. In the following analyses, these subscales were examined using one moderation analysis on each, where each subscale of spirituality was examined for moderating effects on the relationship between imminent death concerns and depressive symptoms.

First, the meaning subscale of spirituality was assessed. In this second hierarchical multiple linear regression (predicting depressive symptoms) imminent death concerns was entered into the first block. In the second block the centered scores for the meaning subscale of spirituality as well as the interaction term between centered meaning and centered imminent death concern scores were entered with imminent death concerns as in the first block.

The overall model was significant, F (3, 50) = 6.06, $p < .01$, $R^2 = .27$. An R^2 value of .27 suggests that the inclusion of the meaning spirituality scores, and the interaction between meaning spirituality and imminent death concerns in addition to imminent death concerns accounted for approximately 27% of the variance in depressive symptoms. Notably, the interaction term between meaning and imminent death concerns that indicates a moderating effect was not statistically significant. The only statistically significant predictor of depressive symptoms was the main effect of meaning spirituality scores, $B = -0.57$, $p < .001$. No other predictor variables were statistically significant. The results of the regression analysis on depressive symptoms are presented in Table 8.

Table 8

Hierarchical Multiple Linear Regression with Meaning Moderating Relationship between Death Concerns and Depressive Symptoms

Source	*B*	*SE*	β	*T*	*p*
Block 1					
Imminent death concerns	0.04	0.18	0.03	0.23	.816
Block 2					
Imminent death concerns	0.13	0.16	0.10	0.84	.404
Meaning	-0.57	0.14	-0.52	-4.13	.001
Imminent death concerns*meaning	.007	0.05	0.02	0.14	.886

Note. Block 1: $F(1, 52) = 0.06$, $p = .816$, $R^2 = .00$; Block 2: $F(3, 50) = 6.06$, $p < .001$, $R^2 = .27$

Next, the peace subscale of spirituality was assessed. In this hierarchical multiple linear regression (predicting depressive symptoms) imminent death concerns was entered into the first block. In the second block the centered scores for the peace subscale of spirituality as well as the interaction term between centered peace and centered imminent death concern scores were entered with imminent death concerns as in the first block.

The overall model was significant, $F(3, 50) = 4.44$, $p < .001$, $R^2 = .21$. The combination of the inclusion of imminent death concerns, peace, and the interaction between peace and imminent death concerns accounted for 21% of the variance in depressive symptoms of hospice patients. Notably, the interaction term between peace spirituality and imminent death concerns that indicates a moderating effect was not statistically significant. The only statistically significant predictor of depressive symptoms was the main effect of peace spirituality scores, $B = -0.53$, $p < .001$. No other

predictor variables were statistically significant. The results of the regression analysis are presented in Table 9.

Table 9

Hierarchical Multiple Linear Regression with Peace Moderating Relationship between Death Concerns and Depressive Symptoms

Source	*B*	*SE*	β	*t*	*p*
Block 1					
Imminent death concerns	0.04	0.18	0.03	0.23	.816
Block 2					
Imminent death concerns	-0.04	0.18	-0.03	-0.25	.804
Peace	-0.53	0.15	-0.45	-3.40	<.001
Imminent death concerns*peace	0.08	0.05	0.20	1.53	.132

Note. Block 1: $F(1, 52) = 0.06$, $p = .816$, $R^2 = .00$; Block 2: $F(3, 50) = 4.44$, $p < .001$, $R^2 = .21$.

Finally, the faith subscale of spirituality was assessed. In this hierarchical multiple linear regression (predicting depressive symptoms) imminent death concerns were entered into the first block.

In the second block, the centered scores for the faith subscale of spirituality along with the interaction term between centered faith and centered imminent death concern scores were entered with imminent death concerns as in the first block. The overall model was not significant, $F(3, 50) = 0.23$, $p = .873$, $R^2 = .01$, indicating that none of the predictor variables significantly contributed to depressive symptoms in hospice patients. The results of the regression analysis on depressive symptoms in hospice patients are presented in Table 10.

Table 10

Hierarchical Multiple Linear Regression with Faith Moderating Relationship between Death Concerns and Depressive Symptoms

Source	*B*	*SE*	β	*t*	*p*
Block 1					
Imminent death concerns	0.04	0.18	0.03	0.23	.816
Block 2					
Imminent death concerns	0.06	0.19	0.05	0.35	.732
Faith	-0.07	0.14	-0.07	-0.51	.610
Imminent death concerns*faith	0.03	0.04	0.09	0.62	.541

Note. Block 1: $F(1, 52) = 0.06$, $p = .816$, $R^2 = .00$; Block 2: $F(3, 50) = 0.23$, $p = .873$, $R^2 = .01$

Research Question 3: Does positive religious coping moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age?

H_a3: Positive religious coping will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

In the fifth hierarchical multiple linear regression predicting depressive symptoms (Table 11), imminent death concerns was entered into the first block. In the second block the centered positive religious coping scores as well as the interaction term between centered positive religious coping scores and centered imminent death concern scores were entered with imminent death concerns as in the first block. The overall model was not significant, $F(3, 50) = 0.02$, $p = .996$, $R^2 = .00$, indicating that none of the predictor variables significantly contributed to depressive symptoms in hospice patients.

Table 11

Hierarchical Multiple Linear Regression with Positive Religious Coping Moderating Relationship between Death Concerns and Depressive Symptoms

Source	*B*	*SE*	β	*t*	*P*
Block 1					
Imminent death concerns	0.04	0.18	0.03	0.23	.816
Block 2					
Imminent death concerns	0.05	0.19	0.04	0.25	.804
Positive religious coping	-0.01	0.08	-0.01	-0.07	.943
Imminent death concerns*positive religious coping	0.00	0.03	0.01	0.08	.940

Note. Block 1: $F(1, 52) = 0.06$, $p = .816$, $R^2 = .00$; Block 2: $F(3, 50) = 0.02$, $p = .996$, $R^2 = .00$

Research Question 4: Does negative religious coping moderate the relationship between imminent death concerns and depressive symptoms after controlling for age?

H_a4: Negative religious coping will significantly moderate the relationship between imminent death concerns and depressive symptoms in hospice patients after controlling for age.

In the sixth hierarchical multiple linear regression (predicting depressive symptoms) imminent death concerns were entered into the first block. In the second block, the centered negative religious coping scores and the interaction term between centered negative religious coping and centered imminent death concern scores were entered with imminent death concerns as in the first block. The overall model was not significant, $F(3, 50) = 2.58$, $p = .064$, $R^2 = .13$, indicating that none of the predictor variables significantly contributed to depressive symptoms in hospice patients. The results of the regression analysis on depressive symptoms are presented in Table 12.

Table 12

Hierarchical Multiple Linear Regression with Negative Religious Coping Moderating Relationship between Death Concerns and Depressive Symptoms

Source	*B*	*SE*	β	*t*	*p*
Block 1					
Imminent death concerns	0.04	0.18	0.03	0.23	.816
Block 2					
Imminent death concerns	-0.08	0.18	-0.06	-0.47	.643
Negative religious coping	0.63	0.23	0.40	2.71	.009
Imminent death concerns*negative religious coping	-0.13	0.08	-0.23	-1.61	.114

Note. Block 1: $F(1, 52) = 0.06$, $p = .816$, $R^2 = .00$; Block 2: $F(3, 50) = 2.58$, $p = .064$, $R^2 = .13$

Summary

The intent of the present study was to contribute to TMT and examine whether spirituality and religious coping (positive and negative) influence the relationship between imminent death concerns and depressive symptoms in hospice patients. Four research questions were presented that explored the relationships among the variables. Higher spirituality was significantly correlated with lower death concerns, and together the two variables helped to explain how participants responded to the depressive symptoms questionnaire. Moreover, two subscales of total spirituality (meaning & peace) were significant predictors of depressive symptoms. Higher meaning and peace scores were significantly correlated with lower depressive symptoms. Spirituality and religious coping were not moderators of the relationship between imminent death concerns and depressive symptoms.

In Chapter 5, findings from the data analyses are examined within the framework of TMT to see how the hospice sample responses fit into the existing body of TMT

literature. The results will also be interpreted within the larger body of hospice and palliative medicine research. Chapter 5 includes a review of the limitations of the study, and recommendations for clinical practice and further TMT research to expand the findings from this study.

Chapter 5: Discussion, Conclusions, and Recommendations

The purpose of this study was to add knowledge to psychological and palliative care research by exploring how existential concerns related to symptoms of depression at the EOL. Specifically, the study used quantitative analyses to determine whether religious coping and spirituality significantly influenced the relationship between imminent death concerns and depressive symptoms in a sample of 54 hospice patients. The variables were examined within the framework of TMT (Greenberg et al., 1986), which was influenced by Becker's (1973) notion that people are fundamentally fearful of death and experience measurable anxiety when confronted with their mortality. In order to assuage the anxiety, people cling to their belief systems: religious, spiritual, cultural, or other deeply ingrained beliefs that serve a psychological function to buffer them from the threat of death (Solomon et al., 1991). The beliefs provide a sense of meaning, security, and immortality and foster feelings of equanimity that balance out the conflict between a strong survival instinct and the inevitability of death (Pyszczynski et al., 1999).

Most TMT studies involved participants who were healthy and had to imagine their impending death, whereas hospice patients by definition are expected to die within 6 months or less. Moreover, there was little empirical research on how patients felt about their impending death and how religious and spiritual beliefs influenced their psychological well-being at the EOL. The present study was developed to bridge the gaps in literature and highlight relationships among variables that are important to EOL care and research (Puchalski et al., 2014).

In this study, total spirituality, meaning, and peace (two subcategories of spirituality) were significant predictors of depressive symptoms in hospice patients. Imminent death concerns were not a predictor of depressive symptoms, and spirituality and religious coping did not moderate the relationship between imminent death concerns and depressive symptoms. Moreover, age was not significantly correlated with depressive symptoms. The analyses revealed several significant correlations among the variables: (a) imminent death concerns were negatively correlated with age and peace; (b) meaning was correlated with peace and negatively correlated to depressive symptoms; (c) peace was negatively correlated with depressive symptoms and negative religious coping; (d) positive religious coping was correlated with faith, and (e) depressive symptoms were correlated with negative religious coping.

Interpretation of the Findings

There was confirmation in this study that religious coping and spirituality had roles to play at the EOL. In addition, some hospice patients facing their imminent death are not as depressed or concerned about their mortality as previously thought (Hales, Zimmerman, & Rodin, 2010; Pyszczynski et al., 2006; Rao et al., 2011). The finding that total spirituality, which included subscales for faith, peace, and meaning, was a predictor of depressive symptoms validated work by Kandasamy et al. (2010) and Neimeyer et al. (2011), who found a significant relationship between spirituality and depression in persons with advanced illness. Hospice patients in this sample who reported greater peace and meaning experienced fewer depressive symptoms, while those who scored higher in negative religious coping experienced more depressive symptoms. These correlations

were expected, as there is a well-documented link between religiosity, spirituality, and depression in both medically ill and healthy populations (Abu-Raiya & Pargament, 2014; Koenig et al., 2001).

However, spiritual beliefs have to be internally motivated or considered intrinsic R/S beliefs in order to have an effect on depressive symptoms (Peselow et al., 2014). People with intrinsic R/S beliefs experience a strong, often unyielding sense of meaning and purpose to life (Allport, 1966; Donahue, 1985). The beliefs are intimately intertwined with one's deepest value system and help guide behavior (Donahue, 1985). In contrast, extrinsic R/S beliefs are more socially motivated. They are not considered deeply ingrained worldviews and are often used to obtain safety, comfort, and social status (Allport, 1966; Jonas & Fischer, 2006). Extrinsic R/S beliefs are not associated with decreased depression in advanced illness (Chaudoir et al., 2012; Johnson et al., 2011). The distinction between intrinsic and extrinsic R/S orientation is important in order to determine under what conditions R/S beliefs have a protective role in managing the threat of death (Soenke et al., 2013). In this study, individuals with high spirituality and positive religious coping scores and low negative religious coping had fewer depressive symptoms. Depression has been linked to existential distress (Pargament, 2011), suffering, and pain (Waccholtz, 2014) at the EOL. Thus, the results indicated that R/S beliefs have a protective role in managing depressive symptoms and ultimately minimizing pain and suffering at the EOL.

The FACIT-Sp measures an intrinsic orientation to spiritual beliefs through its subscales of faith, meaning, and peace (Peterman et al., 2014). In this study, the meaning

and peace scores were inversely correlated with depressive symptoms, supporting previous research that associated intrinsic spirituality with effective coping in persons with advanced illness (Dose, Leonard, McAlpine, & Kreitzer, 2014; Johnson et al., 2011). People who have a story or context in which to place their illness and life experiences may not need the cognitive struggle to try to make sense of what is happening to them. They can experience greater acceptance of their physical limitations (Selman et al., 2014) and focus their waking hours on pursuits that are life giving and significant (Best, Butow, & Olver, 2014; Cozzolino & Blackie, 2013).

Moreover, the emotional state of peace suggests a serene, accepting affect that is contrary to the unsettled, discordant feelings of depressive symptoms. Best et al. (2014) found that patients who knew what to expect throughout their disease process and were well informed about their illness progression and medication side effects felt more peaceful at the EOL. For hospice patients with a strong intrinsic R/S orientation, spiritual peace and meaning provide increased self-worth and control over their experiences (Selman et al., 2014) and help them to retain a sense of normalcy in their daily activities with less need to focus on mortality when doing so increases anxiety (Milberg et al., 2014).

The correlation of negative religious coping with depressive symptoms and peace is also consistent with existing research that negative religious coping is related to lower quality of life (Pedersen et al., 2013) and increased emotional distress and pain in persons with terminal illness (Alcorn et al., 2010). However, most people do not engage in negative religious coping as much as positive religious coping on a routine basis

(Pargament et al., 2011), a view that was supported by the findings in this study. The religious coping scores of the hospice patients were significantly lower than other populations with life-limiting illness. The lower religious coping scores for the hospice sample are interesting because patients with life-limiting disease frequently employ religious strategies to help cope with their prognosis (Pedersen, Pargament, Pedersen, & Zachariae, 2013; Rand et al., 2012). Religious coping is multimodal (Pargament et al., 2011) and involves behaviors such as going to church, praying, and staying connected with a religious community. It also includes active cognition and emotion in how one thinks and feels about God and life. The low negative religious coping scores for the hospice patients might be due to their decreased physical activity levels, increased fatigue and sleepiness, and an overall withdrawal from the outside world as death nears (Hospice Foundation of America, 2011).

While it is difficult to pinpoint the reason for the differences without further research, it is also possible that the Brief RCOPE scale was not appropriate for this sample. I was present while each respondent completed the survey and observed many of the participants make offhand statements that some of the Brief RCOPE statements were not applicable to them. For the negative religious coping scale, the majority of respondents marked *never* for most of the statements. Perhaps religiousness was not as important for the hospice respondents and other coping strategies were more prevalent. Further study using the Brief RCOPE with hospice patients might yield more information about its relevance for individuals at the EOL.

The finding that spirituality and religious coping were not correlated with imminent death concerns, nor did they moderate the relationship between imminent death concerns and depressive symptoms, was in contrast to other research where inverse correlations between R/S beliefs and imminent death concerns were found (Daaleman & Dobbs, 2007; Henrie & Hicks, 2014; Morris & McAdie, 2009). One explanation for the contrast that will be discussed in the TMT section below is that R/S beliefs and practices minimized the threat of death (Vail et al., 2010). Instead of thinking about one's mortality, R/S beliefs became the focus of cognition and death concerns were pushed into the unconscious. Thus, it is possible that imminent death concerns would not be a source of worry or distress with hospice patients as thoughts of mortality were not in the forefront of their minds and they were not preoccupied with their imminent death (Farokhpay et al., 2014). Moreover, many patients who sign onto hospice services have been living with serious illness for a long time and may equate their EOL with the end of suffering (Karlsson, Friberg, Wallengren, & Onlen, 2014) or an acceptance of death (Goodwin et.al., 2013).

Findings and TMT

In this study, there were results that both supported and contrasted with TMT. The correlations between total spirituality, meaning, peace, negative religious coping and depressive symptoms support the TMT concept that belief systems, including one's own R/S beliefs can make a difference in how people psychologically manage the threat of death. According to TMT, depression is associated with death anxiety (Solomon et al., 1991), and stems from losses that interfere with one's inner protective resources that help

manage threats to existence (Maxfield, John, & Pyszczynski, 2014). The losses include everything from threats to personal security and serious illness to the loss of faith or an important relationship. R/S belief systems are inner protective resources that help individuals cope with the losses through increased meaning and value to life, greater self-esteem, stronger interpersonal connections and symbolic and literal feelings of immortality (Maxfield et al., 2014; Vail et al., 2010). Interpreted within a TMT perspective, participants in this study with higher total spirituality, meaning and peace scores experienced fewer depressive symptoms because the protective benefits of the R/S beliefs shielded them from fears of death.

Likewise in a TMT framework, when R/S beliefs break down (often called 'religious struggle') they no longer provide a protective barrier against the threat of death (Edmondson et al., 2008). In this study, negative religious coping was significantly correlated with depressive symptoms. This is consistent with other findings in TMT research that higher levels of religious struggle are associated with greater depression (Schimel et al., 2007; Vail et al., 2010). Individuals who use negative religious coping and struggle with their religious beliefs lose their sense of security, protection and fellowship within their religious community, and experience greater guilt, vulnerability, and lower self-esteem (Maxfield et al., 2014). The death concerns rise to the surface of consciousness and contribute to existential and psychological distress, and increased depression (Arndt et al., 2007; Maxfield et al., 2014). The psychological protection of R/S beliefs no longer works because the belief system has broken down.

Findings that were in contrast to TMT were that total spirituality, its subscales of meaning and peace, positive and negative religious coping did not correlate with imminent death concerns. In TMT, the link between R/S beliefs and death anxiety is supported in a wide breadth of literature (e.g., Ardelt & Koenig, 2006; Soenke et al., 2013; Vail et al., 2010). Reminders of death can increase defense of and commitment to one's R/S beliefs and practices. There are several possible explanations for the lack of relation between R/S beliefs and imminent death concerns in this study. First, the hospice patients may have already accepted and prepared for their death. The inclusion criteria included an explanation of the study contents and the need to answer questions about their feelings related to death and dying. Participants were aware of their prognosis and willing to talk about their mortality. In semi-structured interviews of hospice patients, Vig et al. (2010) found that patients receiving hospice care acknowledged and accepted their life-limiting prognosis and impending death, whereas those who had a prognosis of less than 6 months to live but were not with hospice emphasized that "hospice means death," and were not ready to die (p. 1009).

Second, other worldview beliefs my have been more integral than R/S in helping the hospice patients manage the threat of death. For example, nationalism (Morgan, Wisneski & Skitka, 2011), political ideology (Burke et al., 2013), and one's legacy or contribution to society (Wojtkowiak & Rutjens, 2011) are all beliefs that mitigate mortality salience and minimize the threat of death within a framework of TMT.

A third explanation comes from Pirutinsky (2009) who suggests that the terror management role of R/S beliefs can change over a lifetime. R/S beliefs and practices can

fluctuate in response to aging and new life experiences, becoming stronger or less important as people develop (Abu-Raiya & Pargament, 2015). For some individuals, R/S beliefs may be used as a template for living and self-actualization and have nothing to do with death and dying (Cohen & Hill, 2007). It may be that the R/S beliefs and practices of hospice patients functioned to help them manage the day-to-day limitations imposed by serious, life-limiting illness rather than help them prepare for death. Moreover, R/S beliefs serve a variety of functions for people (Vail et al., 2010). In a study of predominantly Christian men and women, Wink (2006) found no relation between spirituality and the fear of death. The focus of the respondents' spirituality was on creative endeavors, personal searching, and reminiscence. Further study using qualitative measures may help delineate the role of R/S beliefs within a TMT framework in hospice patients.

Fourth, death concerns and spirituality can be difficult to measure accurately, despite the strong psychometrics of the TDAS and FACIT-Sp used for this study. In a meta-analysis of the association between death anxiety and religiosity that showed 32 out of 108 research findings had no significant correlation, Ellis and Wahab (2013) suggested the TDAS may be too complex and obtuse to accurately measure death concerns in a wide variety of individuals. Likewise, spirituality is difficult to operationalize due to the subjective quality of the variable (Koenig, 2012; Neimeyer et al., 2011). Both the FACIT-Sp and TDAS had force-choice options for responses, so there was no opportunity for individuals to offer their own specific perspective as to what was measured. Thus, what may look like an extrinsic R/S belief on the outside might actually

involve some deeper nuances of faith that can only be revealed from more qualitative measures. Replication of this study using different scales and a longitudinal design may clarify outcomes.

Hospice patients and death concerns. As noted in Chapter 4, the mean imminent death concerns scores of the sample were significantly lower than the normative means scores for cancer patients (Gonen et al., 2012) and healthy populations (Templer et al., 2006). The lower imminent death concerns scores are contrary to a TMT perspective that mortality salience increases death anxiety among individuals. Are hospice patients not so terrified of death even though they are faced with dying within 6 months or less? It may be that hospice patients are not fearful of death, and in some cases, welcomed it as an end of suffering from a long, debilitating disease process. Most of the patients have been living with illness for years, and have had time to psychologically adjust to the limitations and outcome of the disease process. A recommendation for further study is assessment of death concerns in individuals with a recent diagnosis of terminal disease and a prognosis of 6 months or less to live. Moreover, the inverse correlation between age and imminent death concerns found in this study is consistent with the view that older adults are not as concerned with death than younger populations (Bozo et al., 2009; Templer et al., 2006). It could be that patients who are older are more accepting of death as a natural part of life. One 98-year old man with heart disease told the researcher that he had lived a "good, long life with a wonderful family," and he had "no complaints" and was "ready to die." Perhaps not all individuals are as terrified of death as purported in TMT.

Another contrast to TMT was that imminent death concerns did not predict depressive symptoms as hypothesized in Research Question 1, and spirituality and religious coping did not moderate the relationship between imminent death concerns and depressive symptoms as hypothesized in Research Questions 2 through 4. Within a terror management framework, there would be a relationship between imminent death concerns and depressive symptoms, and R/S beliefs and coping would have some moderating impact between the two variables. An explanation mentioned earlier is that tenets of TMT were at work: the R/S beliefs and coping assuaged imminent death concerns so they were not evident as predictors or moderators of depressive symptoms. According to TMT, there is no need to focus on mortality when one's belief systems are functioning appropriately to increase self-esteem and a sense of immortality.

Limitations

This study needs replication with larger, more representative samples of hospice patients that represent greater demographic diversity. The majority of respondents in this study were White, Christian males with an average age of 71 living in one county of Southern California. Nationally, most hospice patients are White females with an average age over 80 (NHPCO, 2013). Therefore, the findings from this study may not be easily generalized or valid for more diverse hospice populations, such as women, non-Christians, and individuals over 80. Moreover, participants had volunteered to be part of this study and may have been biased about the study content. Thus, the study results may not be valid to all persons who are confronting their imminent death.

Another limitation of this study was the reliance on patient self-reported data from a survey. Survey responses are hard to verify, and have to be received at face value and evaluated as truthful. In addition, there may have been a social desirability response bias at work. Patients completed the survey in the presence of the researcher who assisted with questions and ensured there were no missing data. There was always the possibility that patients over-reported their feelings of R/S well-being, or underreported depressive symptoms to portray strength and acceptance of their situation, which may have impacted the internal reliability of the measures.

Methodological Limitations

The cross-sectional design of the study limited the measurement of variables to a singular place and time, and may not accurately gage the fluctuations of experience related to R/S beliefs and coping, death concerns and depressive symptoms. Longitudinal designs are difficult in hospice research due to rapid change of symptoms, persistent functional decline, and sudden death (Chen et al., 2014; Steinhauser et al., 2006). Time constraints limited the time frame for data collection and the sample size. The sample size was also impacted by the 55% response rate for this study (54 participants out of 97 hospice patients approached during 5 months), which was average given the challenges of hospice research (Lynch et al., 2013). Hospice patients are a vulnerable population primarily due to the burden of disease at the EOL, and some researchers argue that it is intrusive to invite hospice patients for research (Casarett & Karlawish, 2000; Jubb, 2002). The researcher was mindful of the vulnerable status of hospice patients and careful not to

impose a sense of burden during study recruitment. Thus, 16% of potential respondents declined to participate due to lack of interest, and 13% due to privacy issues.

Moreover, another limitation of the study involved the medical status of participants. Hospice patients often experience varying levels of pain throughout their disease process (Lysene & Wachholtz, 2011), and pain is associated with lower levels of perceived spiritual support and decreased religious coping (Kandasamy et al., 2011; Mystakidou et al., 2007). Fourteen percent of hospice patients approached for the study agreed to participate but were unable to continue due to increased symptoms or death prior to survey administration. The participants' pain had to be well-palliated in order to complete the survey, so inclusion criteria may have left out potential subjects who may have responded differently to the survey.

As noted in Chapter 4, the reliability of the TDAS scale was questionable, and participants may not have responded consistently to its statements. It was difficult to find the right measure for imminent death concerns for hospice patients, as the TDAS and most other death anxiety and or death concern scales were designed for healthy participants and not validated with hospice patients. Moreover, several of the statements in the TDAS scale were awkward or irrelevant as they referred to occurrences that the hospice patients already experienced, which may have contributed to a 'floor' effect with the scores. For example, items that talked about dreading cancer or being fearful of a heart attack may not have evoked a meaningful response about death, and in turn, may have impacted responses for subsequent questions. One participant with heart disease replied in response to the heart attack statement in the TDAS, "Well, I've had five heart

attacks already. It's not a big deal at all." The response reflects a need for a death anxiety scale developed specifically for individuals who are directly facing their imminent death.

Finally, age was a potential confounding variable that was anticipated to hinder validity and therefore was used as a control variable for each analysis. The assumption was that elderly hospice patients would not be as concerned about their own dying as younger patients in a different stage of life. The assumption was correct as age was inversely correlated with imminent death concerns. However, age was not a significant predictor of depressive symptoms and not a confounding variable.

Recommendations

The primary gap in the literature that prompted this study was the lack of research related to TMT, spirituality, and EOL using hospice patients as participants. There is an abundance of research on spirituality and hospice care with caregivers (Delgado-Guay et al., 2013), family members (Exline et al., 2013), volunteers (Planalp et al., 2011) and clinical staff (Montross et al., 2013) as participants, but little direct research has been conducted with the hospice patients themselves (Lynch, Payne, Reeve, & Lloyd-Williams, 2013). A recommendation is to develop more targeted research with hospice patients. The challenges in working with a vulnerable hospice population have been well documented (Chen, 2014; NHPCO, 2010) but do not outweigh the valuable insights hospice patients can provide to improve EOL care. For TMT research, a recommendation is to develop more studies with participants who are directly facing their death, such as hospice patients, who may provide more reliable data about how people respond to threats of actual death rather than a fabricated or imagined death.

A methodological recommendation is to incorporate more qualitative and mixed methods to learn about hospice patients' lived experience in both TMT and EOL research. This project was modeled after the majority of TMT quantitative studies. Additional sources of data from qualitative designs could be used to strengthen conclusions drawn from the study and add context to how patients confront dying. Moreover, longitudinal designs could be valuable in clarifying relationships among imminent death concerns, R/S beliefs and depression, and monitoring how the variables fluctuate as disease progresses.

One of the challenges in working with spirituality as a research variable is identifying what it is. The FACIT-Sp scale used in this study included a well-validated 3-factor model for spirituality: meaning, peace, and faith (Canada et al., 2008; Murphy et al., 2010). In this study, meaning and peace were predictors of depressive symptoms. A recommendation is to examine more fully the roles of meaning and peace at the EOL. Spirituality may be of special importance at the EOL as many patients search for a meaning or purpose to their illness (Edwards et al., 2010). Additionally, given the combative terms such as "battle," "fight," or "struggle" that are used when treating disease or in the presence of existential or psychological distress, examining "peace" at the EOL may add nuance to outcomes of how dying persons feel as they confront death. Another recommendation is to explore different measures for death concerns, death anxiety, and depression in hospice patients. The lack of association between imminent death concerns and depressive symptoms in the hospice sample was in contrast to TMT.

It would be advantageous to confirm findings using other scales that might yield different results and identify other aspects of spirituality.

Finally, a recommendation is to develop research with more diverse samples of hospice patients to avoid demographic homogeneity, and to identify any differences based on culture and R/S beliefs. An outcome of the study was that participants were open and willing to speak about their mortality. However, not all cultural groups support open communication about death. Some Latinos are more wary about death conversations and prefer to act as if patients are getting well (Kreling, Selsky, Perret, Huerta, & Mandelblatt, 2010). Some Black Americans are highly mistrustful of the health care system and have a fatalist 'if you speak it, it will happen' attitude toward death; many also prefer aggressive treatment until death (West & Hollis, 2012). Asian Americans attitudes are mixed: older adults are more willing to have EOL conversations and die naturally (Akechi et al., 2012), while some younger populations believe it is bad luck to speak about death (Thomas, Wilson, Justice, Birch, & Sheps, 2008). The cultural differences highlight the importance of asking patients or family members what they want to know about their condition, and to explore their belief system before imposing one's own beliefs onto their treatment plan. The study recruitment and consent process included specific details about the topics the survey covered in the survey, so participants were willing to speak openly about their imminent death concerns. Incidentally, 33% of study participants were Latino, Black or Asian/Pacific Islander and willing to speak openly about EOL.

Social Change Implications

There are several implications from the findings of this study for positive social change in research and society. First, it extends research that endorses religion and spirituality as relevant clinical variables that influence health outcomes at the EOL. Only 10% of clinicians address R/S beliefs and practices as part of their clinical assessments, yet 77% of patients at the EOL want support for spiritual and existential needs (Cobb et al., 2012; NQF, 2007). The use of validated R/S scales for clinical assessments could be valuable in identifying what issues are important to patients in the hospice setting and have a direct impact on their quality of life. Knowledge that R/S beliefs are related to depressive symptoms can promote more inquiry, respect, and interventional support related to R/S coping at the EOL. Moreover, non-pharmacological interventions such as dignity therapy (Chochinov, 2005) that provides terminally ill patients an opportunity to share their values, regrets, and achievements can be employed when there is evidence of spiritual or existential distress. Understanding the role of R/S in psychological well-being at the EOL can result in greater sensitivity to imposing conversations about religion, spirituality, death, and dying on vulnerable patients (Neimeyer et al., 2008).

Second, from a societal standpoint, life expectancy in the U.S. continues to rise (Centers for Disease Control and Prevention, 2014). There is increased demand for specialized EOL care and review of the treatment of death and dying in the U.S. (Institute of Medicine [IOM], 2014). The IOM outlined several issues that hamper high quality, person-centered care at the EOL: (1) lack of understanding, education and utilization of palliative and hospice care; (2) increased unnecessary hospitalizations; (3) a fragmented

health care system; and (4) lack of access for underserved and minority populations. In addition, there is a pervasive attitude and fear among many health care professionals that death ought not to be discussed with patients because it might increase their anxiety and diminish hope (Clabots, 2012; Gawande, 2014). Many physicians admit that they do not have the time or communication skills to discuss EOL with patients (Granek, Krzyzanowska, Tozer, & Mazzotta, 2013), and they often view death as a failure to adequately treat disease (Bowron, 2012; Tucker, 2009). Given that the majority of participants in this study openly discussed their death concerns or lack thereof, a positive social change from this inquiry is that it can be perfectly acceptable to discuss mortality with persons facing the EOL if they express a willingness to discuss the topic. There may additional support at the national level for EOL care discussions. By mid-2015, the Centers for Medicare and Medicaid will decide whether to reimburse physicians for advance care planning and EOL discussions. The move is a significant change from 2009 when such discussions were considered by some groups as 'death panels' rather than conversations that focused on options for care with people who have life-limiting disease (Belluck, 2014).

Moreover, new medical technologies and treatments with a "do everything" attitude can prolong the dying process and decrease quality of life (Gawande, 2014; McDermid & Bagshaw, 2009). Death does not have to be feared or viewed as a failure as evidenced by the findings of this study. In fact, people at the EOL can live with a deep sense of meaning and purpose until their final breath (Cozzolino & Blackie, 2013). There is wide speculation that the 76.4 million baby-boomers in the U.S. will change EOL care,

focusing more on quality of life rather than length of life, and wanting more control of how they die (Gawande, 2014; Goodwin et al., 2014; Kadlec, 2013). Considering that most of the participants in this study were "baby-boomers" in their 60s and not overly depressed or concerned with their mortality, they may represent a positive societal shift in how people face death with courage and equanimity. Baby-boomers are more apt to discuss EOL concerns, and prefer quality of life and comfort care to complex and expensive treatments that prolong life and extend suffering (Becker, 2009; Sade, 2012).

Individuals who feel more secure about their health care options, finances, and personal or social relationships are more likely to experience greater self-efficacy and peace when facing death (Milberg et al., 2014). Lung cancer patients equated a good death with being at peace with their illness, dying quickly, and having symptoms well controlled (Hughes et al., 2008). EOL conversations can help individuals better prepare financially, emotionally and psychologically for a more positive, self-determined life closure (Niemeyer et al., 2010; IOM, 2014). Patients may feel more confident and in control of their illness, and focus on aspects of life that are meaningful and generative as they approach death, rather than ruminate in despair and loss (Vail et al., 2012).

Theoretical/Empirical Implications

The sample of 54 hospice patients in this study were not overly depressed nor concerned about their impending death. In addition, the majority of participants had greater spiritual well-being than non-medically ill populations (Hooker, Grigsby, Ross, Master, & Steffen, 2013). Could it be that hospice patients are not as distressed as originally thought, and are actually psychologically and spiritually stable? According to

TMT, most people experience debilitating terror when faced with death. It may be that terror management protections were in place: participants were shielded from the terror of death as they had an opportunity to bolster their R/S beliefs while completing the survey. While further experimental research is warranted, an implication from this study is that death may not be "the worm at the core" that terrifies all humans (Schimel et al., 2007, p.789). Such an implication would undermine the basic tenet of TMT.

A more likely scenario within the scope of TMT is that there are positive aspects of coping when directly facing death, especially if there is a limited amount of time left to live. Experiences that involve an intensified awareness of one's mortality may motivate efforts to restructure or realign the beliefs and values that buffer the threat of death and provide meaning and significance to life (Vail et al., 2012). For example, conscious awareness of death can lead to more prosocial behavior and greater emphasis on positive interpersonal experiences (Cozzolino et al., 2009), less concern for extrinsically-oriented goals such as status or wealth (Vail, et al., 2012), and an acceptance of limitations and psychological growth (Morgan, Wisneski & Skitka, 2011). The impact of reorganizing goals and or values depends on how individuals perceive intrinsic goals as a way to increase their sense of meaning in life (Soenke et al., 2013). In terror management, when certain R/S values are active in conjunction with the threat of death, there is increased motivation to uphold values and behaviors (Vail et al., 2012). For example, if the values of compassion and prayer are relevant in one's R/S belief system, responses to death will be guided by those values. Moreover, individuals who exhibit resilient coping styles, high levels of self-efficacy, and high trait mindfulness can avert harsh reactions to their

mortality (Soenke et al., 2013; Vail et al., 2012). Such individuals have a stronger sense of control over life's problems (Rasmussen et al., 2006), an openness to new ideas Florian et al., 2001), and a tendency to evaluate stressful events as opportunities for growth and self-actualization (Niemiec et al., 2010). Thus, individuals may embody wisdom that stems from their shared worldviews, with a focus on contributing and receiving value to life rather than dwelling on its ending.

Whether the interpretation is that hospice patients are not terrified of death or that their R/S beliefs assisted them in coping with mortality, a highlight of this study was the important role of R/S beliefs and how they interact with depressive symptoms and imminent death concerns at the EOL. An implication of the findings is that clinicians ought to inquire about R/S beliefs in a manner that is respectful of individual differences. Additionally, the use of TMT as a framework to understand how hospice patients face their death provided an opportunity to integrate terror management insights into hospice and palliative care research. A TMT interpretation adds a more nuanced view to a simplistic notion that hospice patients are neither depressed nor overtly concerned with their death.

Recommendations for Clinical Practice

A first recommendation for clinical practice mentioned earlier is to ask patients their preference for EOL discussions: are they willing to talk openly about death or are they apprehensive? The inquiry can be part of a larger advanced care planning discussion where patients and families can openly talk about how they envision 'a good death' and how clinicians can respect their preferences for treatment. A focus of EOL discussions

ought to be centered on people's lives and belief systems: how they have lived, what they've learned, what they believe and why, and the stories they have to share. How people live their lives is a good indicator of how they approach death (Byock, 2007).

A second recommendation is a call for more specialized care that includes psychological support at the EOL. The APA (2005; 2014) identified how psychologists could contribute their expertise to EOL through research, collaboration with hospitals and hospices, and therapy. Given the strong emphasis in TMT on people's cultural, spiritual, and religious belief systems as a psychological defense to death anxiety, psychologists are well-trained to work with deeply-held beliefs that support or hinder adjustment to disease processes. Moreover, psychologists can help patients feel more secure by providing them an opportunity to discuss their imminent death concerns and fears as they arise in a safe, therapeutic setting. Greater security is associated with decreased anxiety, lower symptom intensity, and higher quality of life in patients nearing the EOL (Milberg et al., 2014). However, psychologists ought to undergo special training that includes their own self-reflective process about death prior to working directly with individuals at the EOL (APA, 2014).

A third recommendation is to incorporate the tenets of TMT into hospice and palliative care interventions. There are over 400 studies from researchers who have tested the TMT hypotheses with positive results, yet elements of TMT have not been incorporated into hospice and palliative research, or interventions with persons at the EOL. For example, the positive terror management properties of self-esteem and heightened life meaning as outlined in the mortality salience hypothesis of TMT can be a

framework for clinicians to understand the internal processes that contribute to psychological and existential distress at the EOL. To help measure internal processes, a recommendation is that clinicians use validated spiritual assessment tools such as the FACIT-Sp or Brief RCOPE as useful indicators of spirituality and religious coping, and to discern whether spiritually-based interventions are needed for hospice patients. In TMT, R/S beliefs provide a central function to help people manage anxiety related to death and dying, or views that life is meaningless (Soenke et al., 2013). Appropriate spiritual assessment and useful interventions can increase quality of life in hospice patients (Puchalski, 2014).

Conclusion

The central focus of this study was to outline the existential challenges among hospice patients who are confronted with imminent death by examining relationships among imminent death concerns, spirituality, religious coping, and depressive symptoms within the framework of TMT. Spirituality, meaning, and peace predicted depressive symptoms in hospice patients, and age was inversely associated with imminent death concerns. Imminent death concerns was not a statistically significant predictor of depressive symptoms. Moreover, an important finding was that the hospice patients were not significantly depressed nor concerned about their imminent death.

Spirituality may have a special role at the EOL as individuals grapple with the pursuit of meaning, the importance of relationships, the desire to maintain dignity, and according to TMT, the need to manage anxiety that arises with the knowledge of inevitable death. R/S beliefs can offer hope and a sense of comfort that one's life was

worth living, and that death need not be feared. Moreover, this study's outcome that R/S beliefs predicted depressive symptoms may help clinicians identify a source of psychological distress in hospice patients who are struggling with existential issues at the EOL. The findings of this study contribute knowledge to TMT research on the role of R/S beliefs in individuals who are directly facing their imminent death. It is my hope that more hospice and palliative care researchers incorporate TMT as a framework for understanding the psychological processes that influence depression at the EOL in efforts to improve patient care.

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Appendix A: Sample EMR

Patient Information as of 06-26-2012

Code: 87351 **Name:** [redacted] **DOB:** [redacted] **Sex:** F **M/S:** M

Address: [redacted]

Directions: [redacted]

Latest Admit Date: **SSN:** [redacted] **Age:** 69

Date	Class	Acuity	Status		Associated Facility
06-26-2012	HO	P	P01	Referred to Program	

Race/Ethnicity	White - Non-Hispanic	**Pt saw Military Service?**	Not Evaluated
Living Status	Pt lives with family/friend/other	**Release of Gen Info?**	Yes
Spiritual Identity	Unknown	**How hear of SDH?**	Healthcare Worker (non-physician)
Primary Language	English	**Kids affected by illness**	Not Evaluated

Caregiver: Family/Friend - Full Time Live in **Ref:** [redacted] **W:** [redacted]

SNF: **Team:** Unassigned

Directives:
Allergies: Unk
Safety:
Diet:
DME/Supplies:
Functional Limits:
Activities Permitted:
Mental Status:
Prognosis: < 6 months

MD#1:
Addr:
W: **F:**
MD#2:
Addr:
W: **F:**
MD#3:
Addr:
W: **F:**

Family & Friends
[redacted] EC
H: [redacted]
W:

Active Pay Sources

Code	Source	Plan	Insurance ID	Group	Rel	Other Insured	S	F
[redacted]	[redacted]		[redacted]		01		P	N

Assignment	Name	Work Phone
Team Manager	[redacted]	[redacted]
Primary Aide		
Primary SPC		
Primary MSW		
Primary Nurse		
Nurse Practitioner		
Team Physician		
Crisis Care Nurse		
Volunteer-Notify Homemaker		
Funeral Home #1		
Pharmacy		
Regional Manager		
Physical Therapist		
Admitting Nurse	[redacted]	[redacted]

Appendix B: Recruitment Script

Hello, my name is Janine Siegel. I am a student researcher. I am doing a research study with hospice patients to see how religious and spiritual beliefs, death concerns and mood are related. I was wondering if you would be interested in participating in the study. Participation would include: reviewing and signing a consent form, and filling out a survey that has questions and statements on it that have to do with your religious and spiritual beliefs, death concerns, and feelings. I would be present with you while you fill out the survey to help with questions. If should take no more than an hour to complete the survey, and you can drop out or stop participating at any time. No matter what you decide, your hospice care will continue without interruption. Is this something that interests you?

Appendix C: Consent Form

CONSENT TO COLLECT MEDICAL INFORMATION FOR RESEARCH

Title: Spirituality, Religious Coping, and Depressive Symptoms in Hospice Patients: A Terror Management Perspective

Principal Investigator: Janine D. Siegel, MA

Person to Contact: Janine Siegel, [redacted]

RESEARCH SITE: [redacted] Hospice

Why is this research being done?

To learn more about whether religious and spiritual beliefs make a difference in how hospice patients feel about death and dying and their overall mood. The researcher wants to collect information from hospice patients who are willing to complete a survey that asks questions about their religious and spiritual beliefs and practices, their mood, and feelings about death and dying. Ultimately, there is hope the information can help us to better care for patients and their families at the end of life. You have been asked to participate because you are physically able to complete the survey, are able to speak and read English, and expressed a willingness to be part of the research process.

How long will you keep my information?

The information will be kept for 5 years. The data collection is expected to be completed by June, 2014, and the whole research project is expected to be finished by December, 2014. This signed consent form will be kept in your electronic medical record.

What will happen to me?

If you agree to take part in this study, the researcher will review your medical records for the following information: *primary hospice diagnosis, age, spiritual identity, gender, and race.* You will also be asked to complete a survey that has 48 yes/no questions or statements on it.

Can anything bad happen to me?

The main risks are to your privacy. They are discussed below under the heading "What about Confidentiality?" There is a small chance that the survey questions or statements might bring up some uncomfortable emotions. If that happens, we will make sure that

you have the appropriate spiritual, emotional, and psychosocial support from your primary hospice team, or from our bereavement department.

Will I benefit from providing my health information to researchers?

There may be no direct benefit to you for being in this study. However, other people may benefit from the information that is learned in this study. Your participation will greatly help our knowledge of how religious and spiritual belief and practices affect your health at the end of life. The findings may prove useful for hospice teams to include more spiritual and religious support in their care of patients, and may help clinicians better understand some of the emotional and spiritual concerns people have at the end of life.

Will I get paid?

No, you will not be paid.

Will it cost anything to be in the study?

No.

What if I decide I no longer want to provide information?

You can change your mind and the researcher will stop reviewing your hospice medical record, and will not contact you again.

What other treatments could I take?

This study doesn't involve treatment. You can decide not to do the study at all.

What are my rights?

- You can call your hospice team or the primary researcher to ask any questions about this study. The telephone number is listed at the top of this form.
- You can decide not to be in this study or you can quit after starting. Whatever you do, your medical care at hospice will not be affected.
- You do not have to be in this study. You still have all your legal rights whether you join the study or not.
- You will be told any new information that might make you change your mind about staying in the study.

What about confidentiality?

The primary researcher will keep your personal information confidential as much as possible, however there is always small chance that some of your health care information might be disclosed. To protect confidentiality, you will be assigned a study number. Your study number will be used on the survey and demographics sheet, so your name will not be attached to any information related to the study (other than this consent form). You will not be identified by name or other identifying features in any publication resulting from this research. Your private health care information will not be shared with anyone other than the primary researcher and [redacted] committees that review research to help protect people who join research studies.

Who do I contact if I have questions?

If you have any questions about this research study or if you believe you have been injured as a result of participating in this research study, you can contact the primary researcher, Janine Siegel at the hospice. If you need medical or urgent care during the study, it will be provided by your primary hospice care team.

What if I change my mind?

Your participation in this study is voluntary. You don't have to be in this research study to obtain treatment. You can agree to be the study now and change your mind later. Your decision will not affect your regular medical care or the benefits to which you are otherwise entitled.
At any time should you decide to withdraw from the study you may do so by contacting the primary researcher at the telephone number listed above. The primary researcher can stop the study at anytime for any reason.

Will hospice, the study researcher, or sponsor benefit from this study?

There are no financial benefits for the hospice or the study researcher. However, study results can contribute information that may help all clinicians in the medical system (social workers, nurses, doctors, and chaplains) to better understand issues that patients face at the end of life.

I agree to participate.

I have read the explanation of the study and understand it. The study has also been explained to me by ***Janine Siegel****. I have had a chance to ask questions and have them answered to my satisfaction. I agree to take part in this study. I have not been forced or made to feel obligated to take part. I have read the attached* ***Authorization to use my Private Health Information****, which contains important information about research studies.*

I must sign this consent form and the ***Authorization to use your Private Health Information****. I will be given a signed copy of each to keep.*

_____
Printed Name of Subject

_____ _____
Signature of Subject *Date*

_____ _____
Signature of person conducting the informed consent discussion *Date*

_____
Role of person named above in the research project

Authorization to use your Private Health Information

Name of Study: Spirituality, Religious Coping, and Depressive Symptoms in Hospice Patients: A Terror Management Perspective
Principal Investigator: Janine D. Siegel **IRB Study Number:** 13-6258

What is private health information?
Private health information is any information that can be traced back to you. We need your authorization (permission) to use your private health information in this research study. The private health information that we will use and share for this study includes: *age, spiritual identity, primary diagnosis, gender, and race.*
Who else will see my information?
In addition to the Principal Investigator, this information may be shared with:

- Health Care committees that review research to help protect people who join research studies.

Once we have shared your information we cannot be sure that it will stay private. If ***you*** share your information with people outside the research team, it will no longer be private. Your name will not be used in any report that is written.
How long will hospice use and share my information?

- Your information will be used and shared until the research is completed, which we think will be in August, 2014.

What if I change my mind about sharing my research information?
If you decide not to share your information anymore:

- The researcher can continue to use any of the private information that she already has.
- You will no longer be a part of the research study.
- You will still get the same medical care that you've always had.
- You must write to the investigator and tell her that you no longer want to share your information. Write to the investigator at:

  Janine Siegel, % [redacted] Hospice
  [redacted]

Do I have the right to see and copy my research information?
You cannot see your research information while the study is going on, unless it is also being used for your health care. Once the study is over, you can ask to see any research information that is in your Medical Record.

If you agree to share your information you should sign this form below. You will be given a copy of this form.

****

I agree to share my information as described in this form

_____
Print your name

_____ _____
Sign your name Date

If you have questions or concerns about your privacy and the use of your personal medical information, contact the investigator at the telephone number listed in the consent form.