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The experience of counseling the terminally ill and the best counseling practices

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THE EXPERIENCE OF COUNSELING THE TERMINALLY ILL AND THE
BEST COUNSELING PRACTICES

A Thesis

Presented to the

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and the

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In Partial Fulfillment
Of the Requirements for the Degree

Masters of Arts

University of Nebraska at Omaha

By

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THE EXPERIENCE OF COUNSELING THE TERMINALLY ILL AND THE
BEST COUNSELING PRACTICES

Helen Jackson Bleicher, MA

University of Nebraska 2011

Advisor: David Carter

As people approach the end of their lives, many experience anxiety throughout the dying experience. This research investigated the death experience of terminally ill patients and the best counseling practices among licensed mental health practitioners. The questions developed by the researcher served as the measure, which was developed specifically for this research. The questions were given to a small purposive sample of counselors (N=10) who work in hospice settings, private practice, and oncology clinics. This research found that counselors focus on the psychosocial and spiritual aspects of dying, and observe patients having less death anxiety when they are comfortable with who they are and what they believe in. The counseling approaches presented in this research help to enhance quality of life, maintain a purpose in life, and manage death anxiety.

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Chapter 1

Introduction

As people approach the end of their lives, many experience anxiety about death and dying. Like birth, death is an integral part of the life cycle; yet while birth is a cause for celebration, death is a subject that is often avoided in western society (Bowie, Curbow, Laveist, Fitzgerald, & Pargament, 2001). In order to live longer lives and maintain their youth, people engage in healthier lifestyles by eating special diets and doing exercises that decrease stress on the body and claim to reduce the aging process. In recent years, anti-aging drugs have become an area of increasing investigation and discussion in science (Stipp, 2004). People in western society share a common desire to avoid death. However, death is inevitable regardless of how healthy a person tries to be, so why, as humans in western society, do we avoid the subject of death? Why is it so hard to die, or to understand the concept of death?

In 2010 it is estimated that approximately 1,529,560 new cases of cancer will be diagnosed and reported (American Cancer Society, 2010). The American Cancer Society (2010) estimates that this year alone about 569,490 American patients will die from a form of cancer, which accounts for more than 1,500 people every day. With cancer being the second most common cause of death in the United States, it accounts for 1 out of every 4 deaths. Males will account for 299,200 deaths and females 270,290 (American Cancer Society, 2010). Thus, as a leading cause of death, cancer has been determined to be an appropriate choice in which to examine issues relating to end of life anxieties.

Terminally ill individuals often prolong life using aggressive treatments, hoping for a cure to a devastating illness. Today, death has become a challenge due to the

advancement of medicine and technology (Kyba, 2002). The literature suggests that patients' needs and wants often go unmet at the end of life. Dying patients' desire communication, support, control, and a caring environment that enables them to live with quality and reach peace at the end of life (Chibnall, Videen, Duckro, & Miller, 2002). One of the most difficult questions facing society today is how to help patients achieve these desires at the end of their lives.

Hospice is defined as an inpatient or outpatient program that provides a caring environment and meets the physical and emotional needs of terminally ill patients and their loved ones (Lair, 1996). Hospice programs define terminal illness as death that will be imminent within six months or less (Beresford, 1993). In order to qualify for hospice, a patient must have a terminal illness and choose to only receive care that offers him or her comfort and pain relief, not life support. Palliative care is defined as: "The active total care of patients whose disease is not responsive to curative treatment. Control of pain and other symptoms, and of psychological, social, and spiritual problems is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families" (Parkes, Relf, & Couldrick, 1996, p. 23).

Most of the money spent on a person's health care is spent at the end of his or her life (Komaroff, 2005). Although the hospice movement has brought tremendous improvements in the care of terminally ill cancer patients over the last 30 years, only about 20% of dying patients are referred to hospice in the United States (Larson & Tobin, 2000). The utilization of hospice services in the United States began in the 1970's as an outreach to patients suffering from significant emotional and physical pain and discomfort in the hospital setting (Carlson, Morrison, & Bradley, 2008). Statistics

estimate that 80% of terminal cancer patients will have psychological symptoms that go unrecognized and untreated (Williams, 2000). One quarter of all patients with terminal cancer will develop symptoms of depression and sixty percent of them will experience some type of psychological distress, such as anxiety or adjustment disorder (Block, 2000).

Mental disorders can be challenging to differentiate from appropriate sadness at the end of life (Block, 2000). Oncologists who listen to their patients needs through effective communication are able to screen for psychiatric disorders and refer their patients to mental health professionals (Miovic & Block, 2007). From a mental health perspective it is important to understand that depression, anxiety, fear, and grief are common in terminally ill cancer patients. Finding an appropriate balance between treatments of psychological illness and helping patients to process appropriate end of life emotions can help reduce patient suffering (Lander, Wilson, & Chochinov, 2000).

Patients with more severe psychological distress will require antidepressant and anxiolytic medications combined with individual counseling and support groups to help reduce their psychological distress, while patients with less severe distress may benefit from psychotherapy alone (Miovic, Block, 2007). Terminal cancer patients who struggle with psychological distress show a high correlation to poor quality of life, which impacts their ability to connect with others, experience pleasure, and find meaning in life (Block, 2000). Rasmussen and Johnson (1994) state that severe death anxiety has been linked to insomnia, psychosomatic problems, depression, and schizophrenic type symptoms. People may fear the dying process more than they fear actual death, as dying can cause

people to worry about pain, being a burden, losing control, weakness, separation from family members, and losing one's sense of purpose (Rasmussen and Johnson, 1994).

One way that people of many generations try to remove or lessen death anxiety is by using various forms of religion or spirituality to cope with the uncertainties of death (Powell, Shahabi, & Thoresen, 2003). Research suggests that religion has the potential to affect a person's perception and acceptance of death. Wink and Scott (2005) suggest several reasons why religion and death anxiety frequently have a negative relationship. Religion provides relief and comfort from suffering during times of stress (Pargament, Brannick, Adamakos, Ensing, Keleman, Falgout, Cook, Meyers, & Warren, 1987).

Stress at the end of life can bring up unresolved concerns for a patient, so counselors are becoming a significant member of the interdisciplinary cancer team and are helping to make positive contributions to the patient's quality of life (Robinson and Stiefel, 1985). Combining a counseling approach that involves emotional support, flexibility, recognizing of a patient's strengths, and listening to a patient review his or her life story helps the terminally ill come to a better acceptance of their impending death (Block, 2000). Patients often cope with terminal illness much like they coped with struggles in life, so counselors who become aware of their clients' coping skills can help them resolve their concerns and emotional pain using some of the same tools (Beresford, 1993).

Purpose of the Study

Previous studies report findings about the experience of death anxiety and end of life issues in terminally ill cancer patients (Lair, 1996). Research points out the phenomenon of death anxiety and its relationship to religiosity and spirituality (Johnson,

2003). Distinguishing the difference between intrinsic and extrinsic religiosity when studying attitudes toward death and religiosity is important for understanding death anxiety. Compassion and understanding are necessary components in helping people with different belief systems come to terms with their mortality and cope with death anxiety. The purpose of this research is to examine the experiences of counselors who counsel the terminally ill and determine the best counseling practices that help reduce death anxiety.

Statement of the Problem

By the year 2030, one in every five Americans will be 65 years or older (Centers for Disease Control and Prevention, 2010). As the population of older adults grows, the need for end of life care will become increasingly important. Medical advances continue to increase and contribute to the overall growth in older populations. Advanced technologies will enhance the quality of life for terminally ill patients (Duba & Magenta, 2008). Block suggests that it is difficult to differentiate between appropriate grief at the end of life and mental illness. Researching the issue of mental health counseling and death anxiety provides valuable information that would have significant implications in how counselors can better provide mental health services to terminally ill cancer patients and provide them with appropriate counseling methods to lower death anxiety and achieve a higher quality of life.

Research Question

What are the successful practices that counselors use to ease the death experience for terminally ill patients?

Importance of Study

End of life care is continuously becoming an issue of greater importance, given the increase in the aging population and medical advances. This study is important because it provides mental health counselors a guide to addressing end of life issues in terminally ill cancer patients. Concerns facing patients with a terminal illness are often overlooked due to the normal process of grief. This study addresses the different areas of grief terminally ill cancer patients face and the different ways in which they cope – among them religiosity, spirituality, meaning and purpose in life, and regret in life.

This study provides a review of current research, and addresses the significance of this subject as it helps patients towards a good death. Despite Kubler-Ross' efforts to promote greater awareness towards terminal illness and death, counselors have received limited attention and training to help patients in what Kubler-Ross called the “final stage of growth” (Johnson, 2003). It is imperative to conduct such a study to provide counselors with a guide to best practices for working with terminally ill patients.

Delimitations

This study is a phenomenological study that examines how counselors respond to terminally ill cancer patients. There are several delimitations that may have affected this study. First, this study was conducted by using an interview questionnaire developed by the researcher, who then identified and interviewed 10 licensed mental health practitioners who work with patients who have terminal cancer in the Omaha and Lincoln areas in Nebraska. This review focuses primarily on cancer populations and does not fully address the issues and needs of patients with other terminal illness. Different cultures have different perspectives on death and dying, and limiting this study to

interviewing counselors from only one region may reveal a biased point of view. Different religious and spiritual beliefs may not be accounted for in the counselor's practice, due to not randomly selecting counselors who work in diverse conditions. Religiosity and spirituality were defined differently in this study, yet they were used interchangeably in the results section. Also, the questionnaire was not standardized. Instead a small convenience sample of counselors (N=10) who work in hospice settings, private practice, and oncology clinics were interviewed to collect information based on counseling terminally ill patients. External validity may be affected by the absence of a random sample as the size of the sample holds implications for the power of the findings. Counselors who work with terminally ill patients in other settings may have different beliefs and approaches towards these issues.

Operational Definitions

The specific terminology that defines concepts for the purpose of this study is as follows:

1. Religiosity: The quality of being religious, pious, and devout. The focus is on religious doctrine, practices, and rituals (Harding, Flannelly, Weaver, & Costa, 2005).
2. Spirituality: A belief in an ultimate or immaterial reality. An inner path that enables a person to discover the essence of their being or the deepest values and meanings by which people live. Personal faith in something greater (Nelson, Rosenfeld, Breitbart, & Galietta, 2002).
3. Life purpose and Meaning: Assigning meaning and worth to life events and accomplishments (Rappaport, Fossler, Bross, & Gilden, 2001).

4. Life Review: The review of one's life to find meaning, understanding, and acceptance of one's life story (Fishman, 1992).
5. Life Regrets: Guilt, shame, and anxiety about not living up to one's potential (Tomer, Eliason, & Wong, 2008).
6. Mental Disorders: Health problems that are characterized by changes in thinking, feeling, or behavior associated with distress and impaired functioning (Gladding, 2006).
7. Terminal Illness: An incurable, progressive illness that will end in death despite treatment (Forbes & Roshdahl, 2003).
8. Cancer: Cancer is a group of more than 200 diseases in which cells begin to grow out of control (American Cancer Society, 2010).
9. Quality of Life: Refers to an individual's emotional, social and physical wellbeing, including their ability to function in the ordinary tasks of living. The ability to enjoy normal life activities, as well as the amount of happiness and contentment one enjoys in life (Byock & Merriman, 1998).
10. Licensed Mental Health Practitioner: An individual who has obtained at least a masters degree in counseling and who has completed a practicum of supervised experience and acquired a state license to practice psychotherapy (Gladding, 2006).
11. Hospice: Alternatives to hospital care, in which patients who have six months or less to live and choose non-curative comfort measures are cared for at home or in a homelike facility (Beresford, 1993).

12. Cancer Centers: A hospital type setting where patients seek treatment and support from the affects of cancer.

The rest of this research includes the following: a review of literature that provides the reader with additional information related to this study; a methodology section that explains in detail the intended research design, participant selection, interview questions, research procedures, data collection, and analysis of data; a discussion section that explains the study's findings and what implications these findings will have for counselors working with terminally ill cancer patients; and references.

Chapter II

Review of the literature

Quality of Life

Assuring patients the promise of dying well is impossible, yet it is crucial counselors recognize the growth made in the final stages of life promotes and provides patients with a higher quality of life (Larson & Tobin, 2000). Quality of life is defined as a patient's ability to enjoy normal life activities, as well as the amount of happiness and contentment one enjoys in life. Contentment is viewed not just in the material sense, but also from a patient's spiritual and mental well-being. Quality of life can be difficult to explain as it is influenced by environmental, cultural, and social factors (Byock & Merriman, 1998), although patients from both western and eastern cultures report a higher quality of life when family members and health care professionals treat them with dignity and respect (Lo, Woo, Zhoc, Li, Yeo, Johnson, Mak, & Lee, 2001). Routine end of life conversations between dying patients and health care providers would promote a better understanding of patients' hopes and desires as they deal with the realities of their impending death, yet these conversations are often avoided in order to prevent the uncomfortable feelings and emotions of patients, family members, and health care professionals (Larson & Tobin, 2000).

The goal of standard medical care is to cure disease, and quality is often sacrificed to extend life. Unwanted medical treatments that cause uncomfortable side effects and prolong life are often provided to patients who have not informed others of their wishes. Death and dying are not easy topics to discuss, but communication with caregivers about end of life choices can improve patient care as life comes to an end. Hospice is not

concerned with extending life, but helping patients to live with the best quality in the present. People often view palliative care as giving up, or doing nothing, slowly ending life with a morphine drip, instead of embracing the supportive care hospice has to offer (Gawande, 2010). Patients who receive a form of palliative care at the end of life report less emotional discomfort and despair resulting in a higher quality of life before death (Lair, 1996).

Death Anxiety

In order to help people cope with death and dying, death anxiety needs to be better understood. The crisis of a terminal illness gives death a new and urgent meaning, which demands thought towards the concept of what a good death is (Parker, 2004). Death is defined “as good when there is an awareness, acceptance and preparation for death by all interactants who may include family, friends, and health professionals” (McNamara, Waddell, & Colvin, 1995, p. 223). A “good death” also encompasses important social, psychological, and philosophical elements, such as maintaining close relationships with loved ones during the final days, accepting one’s impending death, dying at the end of a long and fulfilling life, and not feeling like a burden to loved ones. Patients do not view death as good when they fear loss of dignity, being too dependent upon others, maintain a sense of being out of control (Emanuel & Emanuel, 1998), do not find forgiveness or reconcile differences with others, and feel they have not been forgiven for their wrong doings by God (Breitbart, Gibson, Poppito, & Berg, 2004).

Kubler-Ross (1969) suggests that most people go through five stages in order to come to terms with their death. As a society, we must begin to understand Kubler-Ross’ five stages better so that death will be approached with the tools necessary to make it a

less anxious time. The five stages are denial, anger, bargaining, depression, and acceptance. In the denial stage, Kubler-Ross explains that the dying person may continue to act like nothing is wrong, shielding him or herself from the truth (Kubler-Ross, 1975). Psychological denial occurs when patients become anxious about dying and use denial as a defense mechanism to avoid communicating the truth with their family and friends (Stedford, 1979). When the reality of death hits a person in the second stage, he or she may sometimes react with anger, questioning why it is their time to die (Kubler-Ross, 1975). Patients may displace their anger onto the medical team or family members who are taking care of them, causing relationships and communication to suffer (Stedford, 1979). The next stage, bargaining, is when a person bargains with him or herself, or with God, for a little more time by promising something in return in hopes of prolonging the inevitable (Snick, 1976). Depression is the stage when a person mourns for the past and then proceeds to lose interest in the present and future. The individual may withdraw from life and lose interest in the life going on around him or herself. Grieving allows a person to enter the final stage, which is acceptance and dying with peace (Kubler-Ross, 1975). Acceptance is not a time of happiness, or a celebration that patients have reached the end of their journey, it is a stage when patients are almost at a void of feelings. Patients begin to withdraw from the outside world and rest quietly as they contemplate their journey beyond the world they know (Kubler-Ross, 1969). Some patients do not reach the stage of acceptance and continue to fight and struggle to the end of life, preventing themselves from reaching the inevitable with peace and dignity (Beresford, 1993).

Although it is important for counselors to be aware of these stages and the guidelines Kubler-Ross provided, it is also important to be flexible and not overlook the many different ways patients cope with terminal illness (Stedeford, 1979). Counseling terminally ill patients involves asking them questions that will draw out their concerns about the death and dying process (Block, 2000). Death anxiety brings up unclear and uneasy feelings and emotions related to the fear of death itself and related fears (Backer, Hannon, & Young-Greg, 1994). It may occur when individuals fear no longer existing in their present life, or the unknown of being dead and punishment in the afterlife (Rasmussen & Johnson, 1994). Kubler-Ross felt strongly that a patient's physical needs must be met before focusing on his or her spiritual needs, so counselors who work with the terminally ill must be aware of the patient's physical comfort before approaching his or her emotional needs (Kubler-Ross, 1997). A patient's religious or spiritual needs usually surface after his or her physical needs have been met, so it is crucial that counselors first build trust and rapport with the patient and ensure he or she has the desire to explore end of life spiritual issues. Patients and family members often avoid conversations about impending death in order to protect each other from emotional pain and fear. Counselors can help to bridge the gap between them and encourage communication about emotional, spiritual, and religious beliefs. When counselors facilitate patients in exploring their religious and spiritual beliefs they help them remove their reservations over talking about death and help them to find hope and spiritual peace that extends beyond death (Johnson, 2003).

Religiosity and Spirituality

Death anxiety is a universal experience, yet the way different cultures use religion and spirituality to approach death and dying can predict levels of anxiety. Religion plays an important role in the lives of about 67% of Americans, of which 96% believe in God, and 42% are involved with religious services on a regular basis (Powell, Shahabi, & Thoresen, 2003). Religiosity is perceived, as practicing beliefs, rituals, and traditions in order to connect to a higher power, like God. It is an organized belief system that dictates how a person is expected to practice his or her religion (McClain-Jacobson, Rosenfeld, Kosinski, Pessin, Cimino, & Breitbart, 2004). In contrast to religiosity, spirituality is a universal concept that connects people to thoughts or beliefs above and apart from the material world. Spirituality helps people to search for a meaning and purpose to life (McClain-Jacobson et al., 2004). The Spiritual Care Work Group of the International Work Group has defined spirituality on Death, Dying, and Bereavement as “concerned with the transcendental, inspirational, and existential way to live one’s life as well as, in a fundamental and profound sense, with the person as a human being. Spirituality may be heightened as one confronts death” (Doka & Morgan 1993, p.11). A positive spiritual outlook in terminally ill cancer patients has been shown to prevent depression, hopelessness, and the desire for life to end quickly, so it is important to recognize when patients are suffering spiritually and find ways to help them address their issues (Breitbart, Gibson, Poppito, & Berg, 2004). Counseling professionals who respect diverse beliefs understand the importance of helping patients with spirituality and can provide interventions that address spirituality suffering.

The acronym LET GO, which stands for: Listening to a patient tell their story; Encouraging a search for meaning in the story; Telling of concerns and showing empathy for patients loss; Generating patient hope; and Owning counselor limitations is an intervention counselors can follow to provide patients with appropriate spiritual care and support (Rousseau, 2003). Religiosity and spirituality are sometimes linked, yet a person who is spiritual may not have a connection to a divine figure or higher being (McClain-Jacobson et al., 2004). Religious doctrine and beliefs can help some patients answer spiritual questions about existence and meaning in life, yet pious religious rules and philosophies may create anxiety and fear in those patients facing death (Rousseau, 2003). Religiosity and spirituality often predict whether a person will experience death anxiety, depending on his or her level of intrinsic or extrinsic religious or spiritual beliefs (McClain-Jacobson et al., 2004). Therefore, it is important that religious, spiritual and existential needs are assessed for all patients who are facing death (Byock & Merriman, 1998).

Intrinsic and Extrinsic Religiosity

Intrinsic religiosity is described as the full integration of religion into people's lives. Intrinsically religious individuals internalize and live by their religious beliefs. They have dedicated their lives to their higher power. In contrast to those motivated by intrinsic religiosity, those individuals motivated by extrinsic religiosity use religion as a means to a different end, such as meeting new people and participating in events through the social aspect of religion (Ardelt & Koenig, 2006). These individuals use religion to achieve security, social connectedness, social communication, social status, and comfort

when they are sad or disappointed. Ardel and Koenig believe that extrinsic religiosity serves as a source of comfort for individuals who are looking for social support.

Intrinsic religiosity might alleviate fear of death better than extrinsic religiosity, as research suggests religious belief predicts death anxiety, not behavior (Wink & Scott, 2005). Indeed several studies have found that intrinsic religion is related to lower death anxiety, whereas extrinsic religiosity has no relationship to death anxiety (Rasmussen & Johnson, 1994). Thus, intrinsic versus extrinsic religiosity is important to measure when evaluating how religiosity is related to an individual's level of death anxiety (Ardelt & Koenig, 2006).

Belief System and Death

A common assumption is that the more religious a person is, the less death anxiety that person should experience (McMordie, 1981). Indeed, religiosity predicts one's belief in the afterlife, and individuals who participate in religious services often discuss topics such as death and dying (Pinquart, Frohlich, Silbereisen, & Wedding, 2006). Pinquart et al. (2006) suggests that religiosity and death acceptance should positively correlate when a person has less death anxiety. They referred to several previous studies that have found negative correlations between death anxiety and religiosity, but they noted that the size of the correlations in these studies were small. In their own study, Pinquart et al. found a decreased level of death anxiety and a better acceptance among newly diagnosed terminally ill cancer patients who had no unfinished life tasks and high religiosity. They argued that terminally ill individuals might see death as a relief from their illness and present life situation. Also, Wink and Scott (2005) found that individuals who believe in a rewarding afterlife, but do not practice religious beliefs,

had high levels of death anxiety. Leming (as cited in Wink and Scott, 2005) found that individuals who are highly religious had the least amount of death anxiety because they understood death as personally comforting and meaningful. These highly religious individuals believed death meant seeing people who had died before them. In contrast, individuals who did not have religious views and who also had high death anxiety feared leaving loved ones behind.

Because intrinsic religious beliefs and not extrinsic religious behaviors predict lower death anxiety, researchers need to evaluate religious beliefs to determine what level of religiosity helps with death anxiety. McMordie (1981) suggests that the strength of an individual's religious or non-religious beliefs is important in determining death acceptance. Specifically, McMordie found those individuals who are devoutly religious as well as those who do not have any religious beliefs have less death anxiety than the people who are in between. Similarly, Koenig (1988) found that people who have medium religiosity, have the highest level of death anxiety. Perhaps individuals who are not certain about their religious beliefs question the existence of a divine figure and an afterlife (Koenig, 1988). Wink and Scott (2005) reported a significant curvilinear relationship showing that individuals who were moderately religious had more death anxiety than individuals who had high or low religiosity. Kubler-Ross (1997) believed that a person's religious beliefs were not the important factor in determining whether religiosity decreased death anxiety; she believed it was more important in the reduction of death anxiety for people to be genuine and authentic in whatever beliefs they had. More research is needed to determine the role religion plays in death anxiety.

Afterlife

The religious concept of immortality suggests a belief in an afterlife (Cohen, Pierce, Chambers, Meade, Grovine, & Koenig, 2005). The belief in life after death and being reunited with loved ones who have died brings people of Christian religious teachings comfort (Lemming, as cited in Wink & Scott, 2005). People who view death from certain Eastern perspectives believe in a rebirth of their soul, a reincarnation or continuation of their mind in this world. Both Eastern and Western religions believe in the spiritual self-continuing on, but the differences are resurrection for some people of Christian faiths and reincarnation for followers of some Eastern religions (Lair, 1996).

Dying patients often have images of the world they will enter after life; they sometimes anticipate the people who died before them being in this other world (Callanan & Kelley, 1992). Patients of some Eastern religions may question the concept of Karma, which is a belief in how their soul will continue in their next life. Regardless of patient's different religious and spiritual beliefs, counselors must be prepared to listen and understand how death and the afterlife are perceived by patients who are dying, and support the meaning that death holds for them (Lair, 1996). Cohen et al. (2005) suggest that a belief in an afterlife should promote well-being, as it serves as a buffer against the fear of death. In contrast, Kubler-Ross (1997) believed that people who do not have a concept of immortality do not have a harder time with death anxiety than those that do. The conflicting literature needs to be looked at from the different views of death in order to understand patient's needs and support their different cultural and religious beliefs.

Views of Death

Death can be viewed in different ways including: viewing death as neutral, or an experience that patients feel is neither welcomed nor feared; viewing death as an approach oriented experience in which death is viewed and accepted as the journey between life and the eternal and happy afterlife; viewing death as an escape oriented acceptance in which death is welcomed, as it removes a person from a painful existence; fearing death and having death avoidance, in which an individual avoids thinking and talking about death at all costs (Gesser, Wong, & Reker, as cited in Harding, Flannelly, Weaver, & Costa, 2005). Klug and Sinha, (as cited in Neimeyer, Wittkowski, & Moser, 2004) found similar results as they believe death acceptance involves both a cognitive component, which is one's confrontation with his or her own death and acknowledgement of death's inevitability, and an affective component, which is the integration of one's death with a positive emotional evaluation.

Everybody has to die, and ultimately everyone will, but using affective expressions of emotion will encourage people to accept their own death and start living the life they have remaining (Kubler-Ross, 1997). Elizabeth Kubler-Ross, in her book *On Death and Dying*, helped society become aware of terminally ill patients and their needs. She made it her passion to teach the world that patients who are ending their journey here on earth are of course dying, but she insisted that until they are dead they are still living, and deserve to be treated with respect and dignity (Kubler-Ross, 1969).

Death Anxiety, Religiosity, and Aging Patients relationships

Religiosity may be especially meaningful to the elderly population in coping with death anxiety. Growing older means living through many stressful changes, which may

include loss of health and physical abilities, losses in important life roles, and the loss of loved ones (Koenig, 1988). According to Koenig, prayer and religious beliefs can provide emotional support and help to the elderly as they cope with the fears and stresses of old age. According to Fortner and Neimeyer, (as cited in Neimeyer et al, 2004), elderly individuals had more death anxiety when they had physical health problems, such as terminal cancer, a history of psychological problems, low satisfaction in life, low religious beliefs, or when they lived in a nursing home or institution. Fiefel (as cited in Neimeyer et al, 2004) found that elderly participants reported equally the view that death was the end of life and the view that death was a beginning of the afterlife. According to Wink and Scott (2005), religiosity is positively related to life satisfaction, which then relates to less death anxiety. Wink and Scott suggested that the elderly, who lacked a formed belief or philosophy about death, might have been individuals who had chronic anxiety or a low sense of self.

Life Satisfaction and Review

People that view life as meaningful might also perceive death as meaningful, which would increase their acceptance of death. Indeed, individuals who are able to accept their own death show higher religious beliefs and more life satisfaction (Neimeyer et al., 2004). Also, individuals who have a sense of meaning and purpose in life are less likely to view death as a welcome escape from a hard life (Pinquart et al, 2006). Pinquart et al suggest that a major challenge for terminally ill patients is perceiving death as a reality and accepting their lives as positive when reviewed. Quality of life includes functioning well in emotional, physical, social, and spiritual areas. Individuals consistently report spirituality as an important area of life, yet to define spirituality and

quality of life is difficult, as it is subjective to each individual. Patients who are unable to find meaning in their lives may experience deeper spiritual pain as they view their lives as empty (Doka & Morgan, 1993). A biopsychosocial-spiritual model is an appropriate measure that allows researchers to measure and understand a patient's quality of life, with spirituality being a core dimension (Brady, Peterman, Fitchett, Mo, & Cella, 1999).

Erik Erickson's psychosocial theory is an eight-stage model of personality that focuses on explaining attitudes and feelings towards self and others. As a person ages or prepares to die they must resolve the last crisis in the model, integrity versus despair. The theory shows that resolving the integrity versus despair crisis relates to a decrease in death anxiety (Fortner & Neimeyer, 1999). When patients feel positive about the life they have led and their accomplishments, they are able to complete Erikson's last stage successfully. Understanding and recognizing the choices they made in life and feeling a sense of accomplishment and acceptance help these patients gain wisdom and peace. Those who are unhappy with the life they led or choices they made in life feel a sense of bitterness, regret, and despair (Broderick & Blewitt, 2010). Life review allows patients to resolve unfinished conflicts and accept past regrets in order to live more fully in the present. This acceptance improves their quality of life and lessens their fear of death (Fishman, 1992). Patients who avoid end of life conversations can have difficulty coming to terms with their impending death, which can cause the quality of their remaining life to be greatly diminished (Larson & Tobin, 2000). Counselors who actively listen to terminally ill patients, by reviewing their memories and processing their life stories can help them to facilitate growth at the end of their patients' lives (Fishman, 1992).

Counseling the Terminally Ill

In his book, *Cancer as a Turning Point*, Dr. Lawrence LeShan, a psychologist who works with cancer patients, writes about the importance of helping patients lead their best lives and find what is meaningful to them (LeShan, 1994). He believes psychological and spiritual concerns come together to guide both the patient and the counselor in understanding what life and death mean to the patient (Carni, 1988). Kubler-Ross recognized the importance of allowing patients to be the experts in their own death, as she believed patients know their strengths and weaknesses (Wright, 2003). When counselors keep an open mind and recognize this, they can help their patients to discover the tools they have relied upon in past challenges to cope with their present problems. Some patients are secure enough that they can adapt and continue to try new ways to cope with problems at the end of life however, patients who are less secure cling to familiar ways, as they are unable to tolerate changes to improve their quality of life (Stedeford, 1979).

The purpose of the counselor working with the terminally ill is to listen to the patients with empathy and understanding, helping them to find psychological and spiritual peace. Carl Rogers (1940) was an influential psychologist in America who founded client-centered therapy. He believed counselors should show clients unconditional positive regard, which is an empathetic understanding and total acceptance of where the client is on his or her journey (Corsini & Welding, 2008). Treating mental illness and helping patients fix their problems are not a counselor's focus when working with terminally ill patients. The goals of both individual and group counseling are to help facilitate patients on their last journey in life by creating an environment where the

patient feels comfortable examining how they perceive their impending death and the options available to them (Lair, 1996). Because dying patients experience death anxiety, counselors must build a therapeutic alliance with the patient and encourage good rapport. When a patient believes the counselor is listening to them in a non-judgmental way, they feel encouraged to talk openly about their fears (Stedeford, 1979).

Patients who are facing death often lose control over much of their lives. They are forced to give up their independence due to illness, and rely upon family members and health care teams to help them (Chochinov, 2010). When faced with the death of a loved one, emotions of anxiety, fear, resentment, and anger can come to the surface. Family members who fear the death of loved ones often make decisions based on emotions instead of what is best for the patient (Bloche, 2005). Professional care teams may face ethical dilemmas when patients do not have advanced directives (Kyba, 2002). Advanced directives are legal documents that state what kind of care a person would like to receive if he or she becomes unable to make medical decisions for him or herself. If a person becomes permanently unconscious, then having an advanced directive allows the medical facility to honor the patient's decisions, which ensures the patient they have control over their own death (Fine & Mayo, 2003). Advanced directives provide patients with peace of mind, and prevent families the burden of making difficult and emotionally intense decisions at the end-of-life (Kyba, 2002).

Patients who perceive themselves as a burden on others often experience depression and anxiety, which can produce a lower quality of life (Lair, 1996). In order to prevent patients feeling like a burden, Frankl suggests they find meaning or purpose in life (Tomer, Eliason, & Wong, 2008). Victor Frankl, a famous psychiatrist who wrote

Man's Search for Meaning, a book about his personal experiences in Nazi concentration camps, talked about the importance of people setting their intentions of how they were going to perceive and respond as human beings in a crisis. Even in the worst of situations, Frankl believed people still had power - the power to choose their thoughts (Frankl, 1963). The crisis of a terminal illness forces patients to not only search for meaning in their life, but also look for meaning in their death through emotional and spiritual growth (Lair, 1996). Frankl (1963) believed that humans could find meaning in life up to the last possible moment in the face of death. A main concern commonly listed for terminally ill cancer patients is existential suffering. In a study, 61% of terminal patients in the United States reported having an opportunity to discuss their concerns with death and the meaning of death as important for a good death (Hirai, Morita, & Kashiwagi, 2003). Three of the main goals of existential therapy are to help clients to 1) engage and be fully present and authentic in life, despite their situations; 2) confront and acknowledge the concerns of human existence; and 3) develop ways to cope with their fears and anxieties surrounding these concerns (Frankl, 1963). Existential therapy may help the terminally ill find meaning in their life, illness, and death. Addressing such issues as meaning, peace, and hope while facing advanced cancer may help patients reduce their death anxiety to a more manageable level (Breitbart, Rosenfeld, Gibson, Pessin, Poppito, Nelson, Tomarken, Timm, Berg, Jacobson, Sorger, Abbey, & Olden, 2010).

Counselors who are aware that patients hold different meanings of life and death can respond to them with understanding and compassion, helping them live their best life until they die (Chibnall, Videen, Duckro, & Miller, 2002). As patients focus inward to

find their own personal meanings toward death, counselors can create an environment that encourages them to explore their transformation from life to death (Lair, 1996). Faith is a spiritual term that has a similar meaning to the psychological word hope. Patients who have faith depend upon their inner beliefs to help them find hope and meaning in their lives. Counselors offer comfort when they listen to patients talk about these beliefs and understand how patients use faith and hope to give meaning to their experiences (Carni, 1988). Sometimes, patients have desires to remove barriers that prevent them from finding peace at the end of their life, requests that are difficult for counselors to satisfy. They may wish to heal a difficult relationship, fulfill a regret they have in life, or complete an unfinished task (Callanan & Kelley, 1992). Some people face a discrepancy in their actual self and ideal self, especially when the ideal self will not be met due to illness and an early death. Self-concepts are important factors in helping patients lessen death anxiety (Tomer & Eliason, 2001). Counselors can help patients find new hopes as they work through their unmet needs to find peace with what they cannot control or reconcile (Callanan & Kelley, 1992). Counselors must use different approaches with different patients depending upon their level of human development and religious and spiritual beliefs.

One of the most difficult trials humans must face is loss, and with death comes the loss of oneself. Some terminally ill patients turn to religious and spiritual beliefs in order to understand their experiences and answer difficult existential questions about life and death (Tomer, Eliason, & Wong, 2008). Counselors who create an accepting environment can use the transpersonal model to help facilitate growth to a higher level of development in patients at the end of life. This approach encourages dying patients to

explore the meaning of their death and reach a higher level of consciousness, increasing their knowledge of self. A continuation towards growth and wholeness is crucial in helping patients understand the meaning of their life and their impending death (Lair, 1996). Higher death anxiety is expected when patients have regrets about the past or future, or if death is viewed as meaningless (Tomer, Eliason, & Wong, 2008).

Counselors can encourage patients to live in the present moment to help them become more aware of their emotions. Openness and awareness of these emotions help counselors to facilitate patients as they work through their fears of death (Lair, 1996).

Dignity Therapy

In the twenty-first-century, hospital professionals are trained to heal and promote wellness. Patients who are dying are often perceived as a failure on the part of the health care professionals, which can promote a feeling of inadequacy. Medical science and advances can influence the death and dying process preventing some individuals and their families from experiencing death with dignity (Kubler-Ross, 1975). Chochinov (2010) found that terminally ill patients were more concerned with loss of dignity than they were with pain and symptom control. Dignity therapy addresses some of the issues that dying patients identify as being most important to them as they face their death.

Issues such as: maintenance of pride, purpose and meaning in life, becoming a burden on others, remaining independent, maintaining a sense of self, and demeaning attitudes of others (Chochinov, Hack, Hassard, Kristjanson, McClement, & Harlos, 2005). Death with dignity can be defined as patients receiving honor and respect at the end of life (Chochinov, 2010). A person's physical, emotional, and spiritual sides complete them and make them a whole person. Each part is important and should be

respected and appreciated (Kyba, 2002). One challenge for counselors who work with terminally ill patients is helping them to maintain a sense of dignity (Bloche, 2005). Although it can be difficult for patients to achieve dignity when they are facing the challenges of a terminal illness, it is important for counselors to recognize and treat patients who are sick and dying with the same dignity and respect as those who are healthy (Bloche, 2005).

Dignity therapy is an intervention that encourages terminally ill patients to address psychosocial and existential issues in two to three counseling sessions (Chochinov, Hack, Hassard, Kristjanson, McClement, & Harlos, 2005). Counselors invite patients to talk about things that matter most to them both in the present moment and from their past, and for what they want to be remembered for. They ask specific questions to encourage dying patients to tell their stories, and then give patients time to think about and reflect upon their answers. The questions pertain to the patient's life history, emphasizing areas of importance such as: roles, accomplishments in life, hopes and dreams, and any advice or information they want to pass on to family and loved ones. Some of the routine questions include: 1) Tell me about your life history and the parts you feel were the most important. At what point in your life did you feel like you were the most alive? 2) Do you want your family to know specific things about you and what things do you want them to remember about you? 3) What have you learned about life? 4) What words do you wish to pass onto your loved ones? (Chochinov et al, 2005).

The session is audio recorded then transcribed verbatim by the counselor who edits the information for clarity, sequencing of life events, and organization of important information. In the next session the counselor reads the document out loud to the patient

for accuracy and feedback allowing him or her to edit any changes (Ando, Morita, Okamoto, & Ninosaka, 2008). When patients hear their words repeated back to them they often become emotional, yet they believe they maintain their dignity, and achieve a better sense of purpose and meaning in life, which can be empowering. Patients also report less anxiety and despair about their impending death after sessions of dignity therapy (Chochinov et al, 2005). Terminally ill patients are able to ensure Erickson's seventh psychosocial stage of generativity, where strength comes through care of others and production of something that contributes to the betterment of society, by leaving their created document to family and loved ones as a lasting reminder of who they were and their hopes and dreams for their families future (LeMay & Wilson, 2008). Chochinov et al. (2005) conducted a qualitative research study on 100 terminally ill cancer patients to determine the impact of dignity therapy on psychosocial and existential concerns. The results of the study showed that 91% of the patients reported feeling satisfied with dignity therapy. Participants reported that dignity therapy helped them to communicate their thoughts, feelings, and memories to their loved ones and the document they created allowed them to perceive life as more meaningful. Results also showed that dignity therapy had a positive impact on overall quality of life, and was an effective intervention in addressing psychosocial and existential concerns for many patients at the end of life.

Group Counseling

Group counseling is a cost effective and efficient alternative to individual therapy, which promotes an increase in member's quality of life. Studies report less psychological distress, death anxiety, and coping skills for terminally ill patients who attend group therapy (Breitbart, 2001). A study conducted by Spiegel (1989) found that women with

terminal breast cancer who received group therapy survived significantly longer than women who did not receive group therapy (Greer, 1994). Kosoff (2003) conducted a qualitative study that showed the benefits of support groups that met for a single session. Single session groups provide patients who are terminally ill with the support necessary to ensure growth and change at the end of their lives. The groups were organized and structured like groups that meet longer, but the stages of the group progressed quickly and could be completed in one hour, which worked well for terminally ill patients whose energy was often compromised. The dying patients complained they often felt isolated and disconnected from others who were healthy. This study showed that group members who were nearing death found comfort and support within each other, as they could share similar experiences with someone who could relate to them and what they were going through. Members were also able to learn from each other, and teach each other how to handle situations that arose with family, pain, medical concerns, and other areas of difficulty that surfaced (Kosoff, 2003).

Universality can help dying patients feel a sense of belonging, giving meaning and purpose to their lives (Breithart, 2001). Counselors must guide members through the beginning, middle, and end stages of a group, knowing when to move to the next stage. Providing each member the opportunity to share is important, so group leaders must make sure that certain members do not overpower the group and all members have an opportunity to share. Group cohesion is encouraged during and outside the therapy sessions, as it allows members to empower each other and develop trusting relationships quickly, providing continued support to each other when the group session is over (Kosoff, 2003).

Breibart studied the benefits of Meaning Centered Group Therapy (MCGP) compared to Supportive Group Therapy (SGT). MCGP is an 8-week group intervention developed by Breitbart and colleagues. Sessions are held weekly for 90 minutes to provide terminally ill cancer patients with a better sense of meaning, peace, and purpose as they face the end of their lives. The intervention is based off of Viktor Frankl's existential theory and teachings and is designed to convey information to patients through experiential learning. Supportive Group Therapy (SGT) is the traditional style of group therapy for cancer patients, which is based on an educational format that provides patients with information about their disease and its process. It also teaches patients coping skills, and provides a support network. The results showed greater benefits with MCGP, as the intervention provided terminally ill patients with more emotional support. MCGP enhanced spirituality and helped patients understand their meaning and purpose in life better, which promoted a better quality of life (Breitbart, Rosenfeld, Gibson, Pessin, Poppito, Nelson, Tomarken, Timm, Berg, Jacobson, Sorger, Abbey, & Olden, 2010).

Breibart & Heller, 2002, believe learning that is connected to an emotional experience is more effective, so they developed MCGP to help those suffering from terminal illness find meaning, purpose, peace, spiritual well-being, and hope as they approach the end of their lives. The MCGP approach utilizes a variety of techniques including; experiential group exercises, open-ended discussions, existential readings, assigned homework, and feedback from the group facilitators. These techniques help patients reach the goals of MCGP, which is to encourage self-awareness and promote a search for deeper meanings in life despite their situation. The intervention helps patients prioritize and maintain a sense of purpose or meaning in life.

Complementary Therapies

Complementary therapies are not considered a part of conventional medicine used in the United States. The American Cancer Society suggests that complementary therapies are those therapies that can be integrated and used along with conventional medicine (American Cancer Society, 2010). Increasing numbers of patients are using complementary therapies as they face the end of their lives. Demmer (2004), an assistant professor at the department of health services in New York, explains complementary therapy as “a broad domain of healing resources that encompasses all health systems, modalities, practices, and their accompanying theories and beliefs, other than those intrinsic to the politically dominant health system of a particular society or culture in a given historical period” (Demmer, 2004, p. 510). Studies by Demmer, (2004), and Hilliard, (2005) have observed that complementary therapies can help improve the quality of a patient’s life by helping them to cope better with the stresses caused by their illness.

Different therapies can help a patient have more control over their life, give them an improved mood, and help with the pain and discomfort caused from their illness (Demmer, 2004). Patients acknowledge the benefits that complementary therapies offer by expressing that they feel less anxious, have a decrease in pain, less nausea, and less fatigue (Kuebler, Berry, & Heidrich, 2002). Complementary therapies encompass many different therapies including massage therapy, touch therapy, music therapy, art therapy, aromatherapy, reiki, meditation, relaxation, breathing exercises, and hypnosis (Demmer, 2004). Demmer, believes that patients with terminal illness benefit physically, psychosocially, and spiritually from complementary therapies. Patients who practice

meditation, breathing exercises, and relaxation techniques are able to relax their bodies and minds. Relaxation allows them to face their circumstances in a more positive fashion, which allows them to cope better with end-of-life concerns by finding meaning in their illness and death. Counselors trained to use relaxation techniques can help themselves and patients release built-up stress and tension to improve the patients' quality of life (Callahan & Kelley, 1992).

Self-Care of the Counselor

The needs of the dying are complex and working with terminally ill patients' places counselors in situations where they may question their own emotions and responsibilities. Counselors who follow the American Counselor Associations (ACA) guidelines and code of ethics strive to provide terminally ill patients with the best standards of practice and provide the highest quality of care (Duba & Magenta, 2008). Counselors may have challenges with their own death and dying concerns, so it is important for them to seek professional help to discuss the history of their own losses, countertransference, self-awareness, and mortality. Counseling the terminally ill can be frustrating when efforts to help patients heal difficult relationships do not work or their life regrets cannot be fulfilled. Counselors who are aware of their limitations and process their grief appropriately can prevent emotional stress and burnout (Worden, 1991). Counselors need continued education, knowledge, and skills in the areas concerning death and dying in order to provide terminally ill patients and themselves the best possible care. Not all counselor education programs offer students a comprehensive study of death related issues, so counselors must seek out opportunities for growth, self-reflection, and training in areas of death (Duba & Magenta, 2008). Counselors are

encouraged to seek mentors who can share their knowledge and support, as well as provide them with additional skills and confidence. Supervision with someone who has skills and experience working with the terminally ill allows counselors the benefit of processing their work and reflecting upon their emotions (Parkes, Relf, & Couldrick, 1996).

Kay Ryan, co-founder and facilitator of the cancer support group “A Time to Heal” in Omaha, Nebraska believes performing rituals such as lighting a candle, saying a prayer, journaling, or attending the funeral of a patient can help counselors to process their own grief in a healthy way (personal communication, July 9, 2010). Working with dying individuals can be both challenging and rewarding for counselors. Gary George of Hospice House in Omaha, Nebraska, finds counselors and hospice staff report having a greater appreciation of friends and family, and a more spiritual life from the rich experience of working with people who are at the last stage of life (personal communication, July 3, 2009).

Chapter III

Methodology

Research Design

This study adopts a qualitative approach using a phenomenological stance. In basic terms, phenomenology is the examination of phenomena, or “things” (Annells 1999). Likewise, Benner and Wrubel (1989) see phenomenological research as a philosophical approach based on a study of things perceived by individuals. The purpose of phenomenological research is to study an experience as it is lived, including descriptions of the meanings that these experiences have for individuals (Omery, 1983). In the human realm, this simply means gathering meaningful or “deep” information through qualitative methods such as interviews (Cresswell, 2007). Phenomenological research stems from the philosophies of Husserlian, whose goal was to understand the significance of human perception, and Heideggerian, who viewed context and preconceptions as important to any interpretation (Husserl, 1965).

Data Collection

Utilizing the phenomenological approach, the goal of the study was to explore the meaning of counseling from the perspectives of Licensed Mental Health Practitioners (LMHP) who work with terminally ill patients. The researchers’ role was to develop two qualitative questions (Appendix A) and ten face-to-face interview questions (Appendix B) in order to gather information from ten counselors. The interview questions and the two qualitative questions did not represent standardized measurements. The semi-structured conversational interviews were conducted first, at the subjects’ convenience and location of choice. The interviews were intended to take about 60 minutes to

complete. About one month after the initial interview, the two qualitative questions were sent to the subjects by electronic mail without any directions. Although the interview questions are referred to as semi-structured, they were conducted in an open style, which permitted participants to speak freely about their views, hence ensuring the richness of the collected data. The same questions were asked in the same order for all interviews. The interviews were audiotaped and transcribed verbatim. Within two weeks of each interview, a transcription of the interview was sent to each subject by electronic mail. A follow up electronic mail was sent to each subject asking for approval or clarification of conflict for example accuracy. The researcher read the transcripts and identified recurring themes found in response to the interview questions. Field notes gathered by the researcher provided data not available in the audio recordings, such as facial expressions, gestures, physical expressions of the subject's work place, and the subject's responses to the interview experience.

Data Analysis

The researcher reviewed the transcripts, recordings, and field notes numerous times in order to break down the data into types of responses. The researcher utilized the phenomenological research design and analyzed the data by reducing the information acquired from the subjects to significant statements or quotes and combined the statements into common themes, key phrases, and demographic information. The researcher then developed a textual description of the experiences of the subjects (what participants experienced while counseling the terminally ill client), a structural description of their experiences (how they experienced it in terms of the conditions,

situations, and context), and a combination of the textual and structural descriptions to convey an overall essence of the experience.

Participants

Demographic information was gathered from a purposive sample of subjects. The population interviewed involved nine female and one male mental health practitioners, who all met the criterion of the study, which was to have experience counseling terminally ill patients. The majority of the participants had been counseling the terminally ill through the death experience for three to five years. Only one of the subjects had been counseling the terminally ill for less than three years, and two of the subjects had been counseling the terminally ill for more than 30 years. The subjects were all licensed mental health practitioners in Nebraska, and nine of 10 participants were raised in smaller Midwestern cities. Subjects ranged in age from 30 to 60, with the mean age being 45.2 years. In the category of religious affiliation, diversity was absent as all ten of the subjects reported practicing a Christian based religion. Another demographic area that lacked diversity among the subjects included race, as all subjects classified themselves as Caucasian.

Ethics

Prior to recruiting the subjects to participate in the study it was necessary to show that the study provided the ethical values of beneficence, justice, and respect to the subjects.

The subjects remained anonymous and all data was kept confidential during the analysis process. Providing the subjects with pseudonyms, so no responses or demographic information could provide any identification in the data protected confidentiality. A list

of subject's names and corresponding pseudonyms were archived and kept in a locked cabinet and destroyed when the study was completed. Pseudonyms were used in the findings section of this paper. The researcher submitted an application to the University of Nebraska Medical Center Institutional Review Board for an exempt research and received approval (IRB # 602-10-EX). The purposes of this study were explained to potential subjects who were told they could withdrawal from the study at any time and had the right to ask questions about the study or refuse to take part. Written informed consent was obtained from those who agreed to participate in this study (Appendix C).

Validity

This study relied upon the phenomenological process of validating the questions for the interviews with experts in the field of counseling. The interview questions were administered to a preliminary pilot sample of licensed mental health practitioner's (N=8) to illicit feedback determining consistency regarding clarity of the questions. The feedback from the preliminary sample determined how the counselors could possibly interpret each question. The validity of the interview questions specifically addressing the research question in the study allowed the preliminary expert sample of counselors to provide necessary feedback for the content of each question. The questions were sent to the preliminary sample of counselors by electronic mail and dialogue through electronic email helped the researcher to critique the questions in order to present them to the participants in the most valid and reliable way. Three of the participants followed the specific directions of the researcher and critiqued the questions. Five of the participants reviewed the questions and critiqued them, but in addition they also answered the questions based on their own experiences. This gave the researcher an understanding of

how the questions were received and the responses the questions could elicit. Originally there were 11 questions, but the Institutional Review Board suggested eliminating one question, which asked the counselors to rate their own death anxiety. The review board was concerned with the outcome if the counselors rated themselves high in death anxiety, so the question was eliminated. The interview questionnaire was not a standardized measure that had been tested long term to determine the outcomes outside of this study.

Chapter IV

Results

Terminally ill patients need to experience comfort in their own way as they struggle with the physiological, emotional, and spiritual distress experienced through the death experience. These issues are addressed within the key themes found from the 10 interviews and two additional questions. Two hundred and Fifty significant statements were extracted from the transcripts and reduced to 21 meaning units that did not repeat or overlap. Similar patterns and themes emerged and were identified along with supporting participant quotes. The researcher arranged the meanings into nine common themes located in Table 1.

TABLE 1 Common Themes

Theme	Indication
Religiosity & Spirituality	Co-researchers agreed that religious and spiritual beliefs are central to life experiences and typically promotes a decrease in death anxiety.
Fear	Co-researchers report fear being related to the uncertainty of the afterlife, the actual pain involved in the death process, and the fear of leaving loved ones behind.
Control	Co-researchers indicated that patients who have less control at the end of life experience increased death anxiety
Life Review	Co-researchers agreed that the experience of telling ones' story provided patients with comfort and purpose at the end-of-life.
Forgiveness	Co-researchers reported facilitation of forgiveness when possible to help patients who are dying with regrets or guilt for past behaviors.
Family	All co-researchers indicated family meetings to help patients and their families communicate their needs.

Mental Health	Patient history can provide vital insight into prior mental health issues, which co-researchers agreed can provide them with treatments that were previously successful.
Comfort	Co-researchers indicated the benefits of incorporating complementary therapies to help patients find comfort and cope better with the death experience.
Grief	Co-researchers indicated the importance of managing their own personal grief when a patient dies in order to maintain balance and self-care.

Religiosity

Co-researchers agreed that religious and spiritual comfort are about “relief of the emotional anguish” and the various ways in which patients can “express their religious and spiritual beings” as they approach death. Debra reported that it is “appropriate” for patients at the end of life to “question their religious and spiritual beliefs,” yet she feels there are no “definite answers” to give to patients, as different religious and spiritual beliefs require different responses. Jo does not direct her patients in their religious and spiritual beliefs, she assesses where they are on their view and encourages and supports them in exploring their beliefs. She said, “I can tell my patients what I know as a professional as far as what goes on when the end nears and what I have seen or worked with, but I have no concrete answers to the afterlife.” Similar to all of the other co-researchers who report that when patients are “struggling with religiosity and spirituality” they “recruit the help of a clergy member,” as religious and spiritual leaders have the education and training to help answer the patient’s questions, Jo encourages her patients to explore their beliefs further with her, their “family or support system, and their clergy”.

Shelly believes people who are “estranged from their faith, have had a bad experience with their faith, or never really had a faith” have the worst experiences with the death and dying experience. She noted this is a real “delicate situation,” because, as a counselor, she knows she is not supposed to “impose her beliefs on anyone,” but as an individual, she really hates to see someone “die in fear,” so she tries hard to find a “compassionate pastoral care person” of their faith to help them feel like they were “absolved from whatever they feel bad about.” Co-researchers believe patients are sometimes religiously and spiritually “fraught” from their past experiences, so “supporting the patient in a comfortable and safe way” is important to Paula. She observes that patients who have a “strong religious and spiritual connection” experience “less fear and death anxiety.” Molly agreed, as she reported, “a patient’s religiosity and spirituality is central to their life experience.” She tries to engage family members in talking with patients about their beliefs, and she finds the “patients who have a strong connection to their religious or spiritual beliefs have less death anxiety”. Paula notices for the most part that people are comforted by their religion and spirituality, but she thinks some patients who have a “stronger religious tie and less of a spiritual tie may experience more fear and death anxiety.” She said, “Some patients believe religion can be punitive and they fear hell.” Paula believes it is better to help patients find a balance between religion and spirituality, and she observes talking with her patients about their beliefs can help them “process through some of their fears”. Jackie talked about the importance of faith, as many times she notices patients find the courage and strength to deal with their “impending death through religion and spirituality”. She reported, “I have

a patient who recites quotes from the bible, sings hymns to me, and whenever I ask him how he is coping with the end of life, he refers back to his religion and spirituality.”

Jackie believes everyone “questions faith” at the end of life however, she thinks many of her patients go on the “faith or the religious beliefs and miracles” they have been “taught and the ones they have lived their lives by”. Amanda observes patients who are “comfortable with who they are” and the things they have done in their lives as having “more spiritual peace”. She said, “there seems to be two continuums, as for some reason the patients I talk with who are of the Catholic faith are either very afraid because of the guilt and confession mentality that has been ingrained in them, or they are so faithful and feel so supported that they are comfortable with death and dying.” She observes Catholic patients who have “absolute faith” in their religion and belief in an afterlife to be less anxious. She believes these patients who have “unquestionable faith” know they are going to heaven when they die. Interestingly, when discussing working with atheists she said, “I observe a similar comfort level with death, as atheists don’t have any questions or worries about the end of life.” She believes they know that death is the “end of the cycle of life” and they do not believe in any type of afterlife. Amanda said, “it is about being sure of yourself and who you are as a person, and knowing you lived the life you wanted or could live.” However, she reports that she has only worked with a small number of actual atheists. According to Shelly, when people believe they have been a good person in their life by whatever criteria they use, many of them are not afraid of death. She observes patients who are afraid of suffering and being out of control, but they do not really fear death when they believe in an afterlife where they will be “reunited with loved ones and with God.” On the other hand, she has witnessed patients who have a negative

belief in God or an “agnostic view of God” as terrified to die. Patients who see “God as mean and punitive” have lots of questions, and Shelly actively listens to them, which helps them to process their thoughts and work through the obstacles that prevent them from experiencing a peaceful death.

Caroline allow her patients to talk about their “spiritual concerns” and tries to help them “process their questions” so they can find some sense of peace. Many patients experience “anger as part of grief,” and she helps them work through this by having them “talk about their feelings.” In her experiences, Caroline has observed people who have a “strong belief system,” no matter what it is, to have more “acceptance” with end of life concerns and worries. She reported, “people who have no religion or faith are not necessarily precluded from accepting their death, but in my experience they tend to ask less questions and have a more difficult journey.” Shelly believes it is normal for people to question their faith at the end of life, even if they never questioned it before, and believed they were “absolutely going to heaven.” When death is “imminent,” Shelly feels that “patients can get cold feet,” questioning their beliefs in the afterlife. She reported, “I think there is a lot of fear at the end of life, so many times I try to accommodate different religious beliefs by finding rituals or ceremonies that the community or pastoral care team can perform to bring comfort and reassurance to the dying patient. I have observed clergy from the Catholic Church performing a ceremony called the sacrament of the sick, which is where a priest anoints the dying person with oil. I have also observed Native American leaders perform rituals with different spirits and symbols to bring emotional healing at the last stage of life.”

Jackie is really sensitive to what her patients say, and she is careful “not to challenge their thoughts and values.” She thinks exploring their beliefs with them and asking “relatively probing questions” can help patients to express themselves more easily, and together they can process any “irrational beliefs” that prevent a peaceful “death journey.”

Fear

Co-researchers identified patient education as an effective technique they utilize when patients report fear of the dying experience. Angela identified “education as a tool” to help her patients to understand the death process better. She works with a lot of people who are “afraid of how they are going to die.” Patients often ask her if they are going to “suffocate to death.” Angela works with them on their fears and encourages them to talk with a medical professional about the “physical side of death” to comfort them, as medicines and procedures are available to help ease this pain. Caroline agreed that education is key in helping patients to understand the dying process, and she notices that education allows patients to “understand and anticipate” what they can expect to happen as their “body begins to shut down.”

Co-researchers identified that fear is often associated with pain and suffering, and patients who are in emotional pain are often unable to find peace and comfort. Co-researchers spoke at length of the “terror people experience” as they come to terms with the “terminal nature of their disease.” They believe it is difficult for their patients to find comfort when their “minds are troubled.” Shelly identified that her patients are often concerned about “pain and suffering” before they are actually at the state where they are experiencing pain. She described that by asking her patients “what pain and suffering

means to them” and what it is that they fear, she is able to understand if it is “suffering of a physical or emotional nature.” She talks to them about the “medications” that are available to them and gives them information on the end of life; but if they are worried about being “alone,” then she helps them to determine what kind of help they want and how they can keep enough family and friends around them. Co-researchers reported that it is difficult for patients to achieve a state of comfort when they are fearful of “loneliness, isolation, and leaving loved ones behind.” Shelly noted that it is important to “listen to the patients” and understand what they mean by the words pain and suffering, and not “jump to conclusions” that the patient has the same understanding of the words as she does. She said, “If I am aware of how patients understand the words, then I will more likely be able to figure out something to help them.” Paula identified that when patients know they are going to die, their dying process can fill their days with “apprehension and anxiety.” She understands that the dying process can produce a “huge discomfort” for some patients, so she tries to help them by bringing “calmness to their storm of emotions,” and attempts to lessen their fears so they can find comfort and lead a better quality of life.

Control

Co-researchers stressed the importance of patients remaining in control of some aspect of their life and death. They each explained their definition of control in different ways; however, they agreed that when patients feel a “loss of control, their death anxiety dramatically increases.” Jackie described how she offers patients “choices” for remaining in control. She believes giving patients the option of what “tasks they want assistance with” allows them to remain in control in meaningful ways and “reframes their

definition of independence.” Patient choices also involve advanced directives. Co-researchers encourage patients to have an advanced directive in place to assist with decreasing anxiety and guiding the patient’s family in decision-making. Caroline has witnessed many family members struggle with anxiety, because they don’t know what their loved ones wishes are at the end of their life. She believes the process of filling out the advanced directive is beneficial to both patients and their family, as the dialogue puts everyone on the same page, which can prevent “irrational decision making” at the end of life.

The co-researchers also stressed that not every aspect of the end of life can be controlled, and they assist the patients in “determining the difference.” Rose described that when patients have items that are uncontrollable, the focus of counseling becomes working toward “letting go.” Rose stated, “Control what you can, and the other things you have to let go of. We all want to think we are in control and none of us are.” Shelly identified that she works with patients on “letting go of their worries” in order to ease their death anxiety, and she finds this helps them “regain control” of their emotions. Molly described patients who have “anticipatory grief,” and she believes it is important to facilitate them through the “stages of grief,” so that they feel they have better control over their emotions. Rose observes her patients going through “Kubler-Ross’s five stages of grief,” and reports that most patients reach the final stage of acceptance before they die. She is aware that her patients may “struggle with different stages,” but ultimately, if they are open to counseling and prepared to work hard in their “final journey,” they arrive at acceptance and peace. Shelly said, “I know patients want to bury their heads in the sand and stay in denial, as the initial fear and shock of the dying experience is overwhelming

for them, but they eventually gain back some control of their emotions and come to a new acceptance.”

Life Review

The co-researchers identified life review as a beneficial technique for counseling terminally ill patients through the death experience. Jane utilizes life review as a tool to identify information about her patients. A lot of times, she said, “it’s just about starting from the beginning and going through, and it’s amazing to me what you find out about people.” Jackie thinks life review is the most helpful technique for counselors as it is “non-invasive and non-threatening.” She also believes it is an effective tool that encourages patients to evaluate their life.

Paula and Angela both start their counseling sessions with life review. They ask open-ended questions to help their patients tell their life story. Angela described her first questions as “personal life events.” She asks her patients if they are “married, and if they are, how they met,” and she observes that this usually “spurs an entire conversation” about their life.

Angela believes it is important to ask her patients questions in an “open format” then “actively listen” to their answers, as this shows her patients that she is engaged in their story. She observes that when she is non-judgmental, the patients feel safe to tell her whatever they want and need to.

Molly also utilizes life review, as she observes this technique to be “the most effective in helping patients evaluate their lives.” She does a lot of “guided review,” which she thinks from a counseling standpoint helps patients to reveal a lot of information about their lives in a

non-threatening way. Rose agrees that life review is an important “counseling method” that helps patients who are dying evaluate their lives. She asks her patients the following questions: “What has been important in your life? What are the things in your life that you are most proud of? What impact do you think your life has made on the world?” Rose described the practice of life review as listening to her patients tell their stories about their lives, and then finding out about their milestones or the areas in their lives they have “regrets” about from their stories. She said, “From this conversation, I am able to help my patients talk more about specific things and events that may be holding them back from finding peace.” Jane concurs that life review helps to uncover some of those problems patients have that are not solved, and may not be resolved. Jane believes allowing her patients to tell their story helps them to reach a better understanding of their lives, so they can move forward on their “final journey.”

Shelly encourages patients to tell her what they have “done right in their life” instead of what they have “done wrong.” She asks them to explain to her what they have learned along the way and what their purpose in life is. She feels it is important to frame the questions in a way that “elicits positive answers.” She asks questions such as: “what are you most proud of in your life, have you made a difference in somebody else’s life, and who have you loved in your life.” Shelly observes that if you ask patients to tell you about their lives, a lot of times they will give you a chronological order of the main events in their lives, such as when they were born and where and when they went to school. She also thinks patients’ answers depend upon their “frame of mind” at the moment she asks the questions. She notices when “patients are in a negative frame of mind” they may tell her every “bad thing” that ever happened to them. So she said, “I

ask them specific questions to promote positive responses.” She encourages patients to talk about their spouse when she knows they have a healthy marriage, and she asks them to tell her “how they met their spouse, and how they knew they were in love.” She believes these specific types of questions “distract the patient” and help them “focus on the good” they experienced in life.

Jo identified the importance for many patients who have been in the military to process through their experiences. She observes that they tell stories that they have been unable to share before, but understands that they have a need to talk about this “chapter in their life and find closure.” Often they talk about the friends they “lost during war times” and some of the events they witnessed during their military years. She listens and tries to help them “find meaning and an understanding” of their military years. Debra asks her patients to describe themselves to her, and tell her what makes them the unique person they are. She stated, “There is usually one outstanding feature that has given the patients’ life purpose and meaning. It is like Victor Frankl,” she continued, “who found meaning in the concentration camps. I try to help my patients find meaning in where they are on their death journey.”

The majority of the co-researchers give their patients the option of making a video, audiotape, or a book about their life. The co-researchers find that when they counsel patients who have children, the patients want to leave their children something to remember them by. During the life review process, patients are able to “record their thoughts and wishes” for their families and leave a legacy behind. Angela prefers it when her patients are with her for longer, as she feels she gets to know them better, and she is able to help them “prepare a meaningful legacy” for their families. She shared a story

about a patient whom she worked with that was able to “audiotape” and “write a book about her life,” which she was able to give to her family before she died. She believed the project gave the woman a purpose at the end of her life, and observed that the patient felt a sense of “peace processing her memories” and leaving them behind as a legacy for her children.

Rose asks her patients what legacy they would like to leave behind for their children. She recalled, working with a woman 30 years ago who was a musician and singer. She recommended to the woman that she “record her voice” on an audiotape and sing to her children, as this idea was a simple way for this woman to leave her children a wonderful and “lasting memory” of their mother. Rose recognized that technology has come a long way today and the possibilities for recording are endless. Paula and Debra talked about making “plaster hand molds” of their patients. They feel their patients enjoy leaving this type of legacy to their families, as the hand molds are a “visual piece” that families can “treasure” for years to come.

Rose utilizes life review not only for past events, but also looking forward to the “future important occasions” that the patients will not be present for. She talked about having her patients “write cards or letters” for their families “significant birthdays, weddings, graduations, and other special occasions.” She believes this practice helps parents of younger children come to terms with knowing they will not be present for their children’s future special events, and although they are saddened, the cards and letters allow them to “voice their feelings” to their children. She also observes that writing the letters can be emotional for patients, but it helps them to “process their death” and helps

them to feel like they have a purpose. She identified that writing cards can be a time of healing for patients and allows them to participate in their families' future.

Shelly agrees that leaving children and families a legacy can help patients “maintain a purpose.” She recalled working with a young woman who was afraid her young children would not remember her. Shelly discussed with the patient what she could do to help them remember her. She described how the young mother came up with a “scrapbooking idea.” She observed the patient as she went on a “scrapbooking crusade” and found people to help her finish the project. The patient took pictures of herself “reading to her children, tucking them into bed at night, playing outside with them, and picking them up at school.” She wanted the scrapbook for her children, so they would “remember that she loved them.”

Debra discussed how many times husbands want to make sure “all the finances are in order” and taken care of for their family. She encourages them to “write down all the financial information” for their spouse, and she believes this helps to “alleviate some of their concerns.” She also helps them to write lists and instructions for their families on how to take care of the home in regards to such things as when to “change the oil in the car, how to run the snow blower,” and other household jobs and repairs. Debra said, “I remember working with one woman who was dying, and she was concerned with how her husband would send out Christmas cards. The woman was worried as her husband had never sent out a card, and probably didn't know where the Christmas card list was.” Debra tries to help her patients look at different things that they think they need to share before the end of their life, and she “reassures them that if something is forgotten” that the spouse will figure out a “new method” on how to accomplish the task.

Forgiveness

The co-researchers identified “facilitating forgiveness and reconciliation” as an effective method in helping terminally ill patients with “regrets or guilt” for past behaviors. They agreed that it is important to help patients with forgiveness and self-acceptance when reconciliation is not possible. Debra believes it is important not to judge patients for their past mistakes, but to accept’ them. Jo encourages people to seek forgiveness or reconciliation when they have regrets for something they perceive they did wrong to someone else. She believes “family feuds” happen, and she tries to help her patient’s process through the “family discord”, which allows her patients to bring “closure to their problems” at the end of life.

Debra tries to facilitate meetings with people when patients want to find “closure in a situation.” The reality is that the other person sometimes says no, so she has to help her patients “process their emotions” and find an acceptance. Debra worked with a man who had not seen his children in many years, and he wanted to see them before he died. She reported, “when I called the children and told them their father was dying and wanted the opportunity to say goodbye to them, they refused to come and see him.” Debra worked with the patient on his regrets and helped him to understand how he had “changed,” and she asked him what he had “learned along the way.” Shelly agrees that reconciliation is not always possible. She tries to help her patients to “accept the fact that they were not perfect”. She sometimes works with people who regret what they have done because they are afraid they are going to die and go to “hell and will be punished forever.” She helps her patients process their regrets and find a way to “make amends,”

so they can find closure and die with peace, but unfortunately some patients are unable to reach this stage. She said, “This is when I am grateful for anti-anxiety medications, as they can help patients to feel and cope better.” According to Angela, when reconciliation is not possible, it can “require a team effort” to help a patient find peace at the end of life. She observes that patients who do not “achieve reconciliation” or have an “outlying problem” as having a more difficult time with the dying process. Angela observes that when patients are struggling with past regrets and have “not found forgiveness,” they are unable to let go. She notices that even when they are unable to respond anymore their “subconscious continues to fight” and they show that they are “agitated to the end.”

Family

Co-researchers identified the use of family meetings to help patients communicate their needs. Jane observes that often times patients believe that their family is “concerned about something specific,” and unable to communicate their worries to the patients because they don’t want to upset them. Co-researchers recommended “facilitating family meetings,” so family members can “communicate openly” to each other about what concerns they have. “Just giving the patients’ family the okay or the encouragement to tell their loved one that they can die now”, a subject often avoided by families, is often all that is needed, according to Jackie.

Rose reported working with a “young patient who had metastatic breast cancer on how to tell her “children goodbye.” She helped her patient work through her own “anticipatory grief” for the last year of her illness, yet the patient was unable to tell her family she was dying. Rose knew the patient’s purpose was to see all four of her children “graduate from high school and begin college,” and when this purpose was “fulfilled” she

would be ready to die. Rose conducted a family meeting so she could help the patient to tell her family goodbye. She also worked with the “father and the children on helping them tell their wife and mother that it was okay for her to go,” reassuring her that they would be okay. Although this was a difficult family meeting, Rose believes the family was able to “communicate their needs” to each other and take the next step of enrolling the patient in a hospice program. Rose identified how the family had resisted hospice, as they felt like it was the “final straw, expecting that their loved one would die right away.” She used the experience as a teaching moment with the family, and explained that “hospice is a philosophy of care” and that it did not mean you would “die right away.” She stated, “It was wonderful to see the patient and her family communicating with the support of the hospice team.” She observed the patient’s husband tell her probably two or three times that “he would be okay, the kids would be okay, and that it was okay for her to let go.” The patient was a wife and mother until the very end, according to Rose. She said, “Until she took her last breath, she was a mom.”

Shelly recalled a story about a patient she worked with for a couple of years. She could see the patient was getting sicker and sicker and not going to live much longer. The patient had a young daughter who was in her early twenties, and she was getting married. Shelly did not believe the daughter understood how sick her mother was and how close she was to her death. The patient was able to tell Shelly how disappointed she was that she would not see her daughter on her wedding day. During a family meeting, Shelly was able to help the patient convey this sadness to her daughter and they were able to work out a plan to please them both. The daughter went out and bought her wedding dress even though the wedding was not for another year. She came home and put it on

for her mother with her hair fixed and her makeup on. Shelly said, “As emotional as this scene was for the mother and daughter, it helped them to both come to terms with the mothers’ death, and not have regrets.”

Mental Health

Co-researchers agreed that it is important to distinguish between appropriate sadness at the end of life and actual mental health disorders, such as depression and anxiety. The co-researchers confirmed that if patients “continually rate themselves as sad or anxious,” and the symptoms continue for a “prolonged period of time,” it might be an indicator of “mental health disturbances” versus appropriate sadness at the end of life. Determining whether patients have depression or anxiety is a team effort, not just the responsibility of the counselor, according to Jane. She said, “I ask patients to provide me with their mental health history and a current personal rating of how they feel, but physicians or psychiatric nurses are often consulted to complete assessments on the status of a patients’ mental health.” Rose assesses her patients’ to collect a mental health history, as she believes learning about the patients past conditions can provide her with “vital insight” into their present concerns. The information she gathers allows her to determine what coping mechanisms were previously used successfully.

Paula talks to her patients, she asks them to “rate on a scale of one to five,” with five being the highest, how they are doing and how much their life is being affected by the sadness or anxiety they are experiencing. She gives them the “opportunity to talk” through their concerns and “process their thoughts” to see if it helps alleviate some of their symptoms. Shelly identified that patients being hopeless about their recovery isn’t necessarily depression. According to Shelly, patients can know that there is no chance

that they will recover “shy of a major miracle” and still not be depressed. Co-researchers discussed that during the death experience, many “medications are discontinued or decreased,” but reported that psychotropic medications might need to be increased or added. If I know patients have some sort of mental illness diagnosis, she continued, then that “gives me and the team a clue” as to what needs to be done in regards to “treatment of medications.”

Co-researchers identified how physiologic symptoms such as breathing, heart rate, and pain scales assist with identifying true anxiety. Molly observes that behaviors, such as “withdrawal, attention seeking, or suicidal ideations and planning” can also be useful tools in determining the patients’ mental health status. Angela reported, “anxiety is a little easier to figure out, I can observe when patients show physical symptoms, their breathing gets more difficult, if they’re at a facility they’re on the call light all the time, we can see concrete things with anxiety.” Shelly reviews “normal behavior patterns” for the patients and identifies variances. She said, “These patterns include sleeping amounts, interacting with the outside world, eating patterns, and communication style and quantity.” Jo reports that she always assesses her patients for “suicidal ideations,” just asking my patients questions, while “reminding them that it’s normal to have some of those thoughts and feelings,” especially when end of life is near. If her patients are having suicidal thoughts, Jo assesses at what level. She asks them if the thoughts are “fleeting or if they are continually happening.” She asks her patients if they are “creating a plan,” and if they are, she believes this is a “good indication of depression.”

Comfort

Co-researchers identified complementary therapies as “important additions to conventional medicine” at the end of life. Angela reports that she finds the use of relaxation techniques and other alternative therapies as good distractions for patients who are struggling with past regrets, as it helps them find ways to “cope with their guilt” and die a more peaceful death. Co-researchers identified music therapy as beneficial to their patients. Jo believes “music is huge,” as many people find it soothing. She observes when patients are religious they often want to listen to “hymns or church music.” One of her patients wanted to listen to the Gregorian chant. Angela noted that 90 percent of her patients report music as a comfort, which can distract and soothe their “triggered emotions and fears.” She believes music is helpful for most people, but she has observed a few patients who are “irritated by any type of music,” because they like it to be really “quiet and serene.” She feels it is important to get to know a patient and know what their music tastes are, because if a patient “likes rock and roll when they are healthy,” then they will probably be “comforted” by it when they are dying. She emphasized, “People don’t change because they are dying.”

Co-researchers identified comfort touch and massage therapy as alternative approaches. Paula and Molly both identified that “comfort touch and massage therapy” are “calming and comforting” to patients. Rose and Jo observe comfort touch being used more often than massage, as many people are unable to “tolerate massages due to increased pain.” Both Rose and Jo believe massage is a wonderfully relaxing tool if patients can handle it. Rose also identified “any kind of touch” as important and sometimes just “being present” with patients and “holding their hand” is all that is

necessary to bring comfort.” Caroline reports that she finds “aromatherapy combined with massage therapy and comfort touch” to be beneficial to patients, but sometimes patients can have a heightened sense of smell at the end of life. She likes to burn a candle in her office while doing counseling, but she always checks with her patients first to make sure the scent will not bother them. Shelly also utilizes aromatherapy in her counseling sessions with patients along with relaxation techniques, as she thinks aromatherapy adds another “dimension to the relaxation.”

Co-researchers identified Reiki as a complementary therapy that is beneficial during the end of life. Angela and Shelly both reported, “The positive energy received during Reiki treatments is effective in helping some patients relax.” Jo described meditation or relaxation techniques like Reiki as a valuable tool with patients who are of the “mystical type” and can provide them a welcome escape from their anxiety. Jane does not use relaxation techniques such as Reiki, and thinks it is important for her to look at “who her patients are.” She said, “In the Midwest, I am not going to try and help a farmer with relaxation techniques, as most of them would look at me like I was crazy. I try to find what it is my patients like. If they are huge sports fans and they watch basketball or football games, I try to talk to them about recent games or scores.” She reports that this helps her to build a better rapport with her patients and helps her to find ways to “distract or bring them comfort.”

Co-researchers identified prayer as an effective coping skill for those patients who have faith. Shelly and Molly both agreed that when they “read scriptures or prayers” with their patients, they observe how “powerful and comforting” this tool can be. Shelly reports that she thinks it really helps her to have her own faith, so when she prays with

her patients she is able to understand how prayer is able to bring them a “sense of peace.” Rose finds that her patients are “strengthened by their faith,” and prayer allows them to find comfort and peace within their “rituals and traditions.”

Co-researchers identified pet therapy as beneficial to patients going through the death experience. Angela believes pet therapy can be “comforting and reassuring” to patients who are dying. She said, “Patients talk about their pets and I can see the joy that their pets bring them.” Rose described that pets have a sense that their loved ones are dying, and she has witnessed the bond between her patients and their pets, and the comfort they bring to each other. Co-researchers talked about how important it is to find ways to help ease their patients’ discomfort, and find distractions to bring comfort at the end of life. Debra reports that many times her patients will have a “wish list of places” they would like to visit before they die. If patients are unable to physically make the trip, Debra helps them to “process their regrets” by talking to them about what the “place meant to them” and how it would “feel to visit it.” Sometimes she is able to help the person go on the trip using visualization techniques, looking at pictures and talking about the place. Angela sometimes recommends her patients receive manicures and pedicures, as she said, “it boosts a patients spirits,” and helps them to feel better, which is my goal.

Grief

Working with terminally ill patients can be emotionally taxing and counselors can experience grief when their patients die. Co-researchers identified that it is critical for them to take care of themselves to “prevent emotional problems and burn out.” Following the death of their patients, co-researchers must manage their own personal grief in order to effectively help other current and future patients. They report that

working with the terminally ill can be both “challenging and rewarding.” Co-researchers identified that working with dying patients causes them to face their “own mortality,” which gives them a “greater appreciation for life, family, and friends.” They believe that their experiences working with the dying cause them to have a “stronger faith and spiritual life.” Co-researchers reported that they often attend the patient’s funeral or memorial service, as this helps them to bring “a sense of closure” to the patient’s death.

Co-researchers identified that “weekly meetings with peers” help them to remember the patients who have died and process through their own grief. Molly said, “For patients who I have known for a while or have become close to, I seek out one of my peers to talk with on a one-to-one basis, or I talk to my supervisor about patients that were particularly difficult.” Jackie is still working on her own grief, as she tends to “take things very personally.” Talking to others sometimes is not enough for her, so she has to “step away” from it for a bit. She reminds herself that this is hard emotional work. Shelly described when she first started doing this work; she went to her mentor one day practically in tears and asked her how she could do this work because one of her patients was dying. Her mentor looked at her and gave her the “best advise, which sticks with her today.” Her mentor said, “If you want to stay in this work, you have to find some balance, so find other things to distract you.” She looked at me and stated, “When somebody dies, cry your tears and then go home, eat a really good dinner, drink a glass of wine, and make love to your husband. Her last words to me were to remember that I am still alive.”

Angela reports that she learns so much from all of her patients and their families, and they influence her on a daily basis. She reports that it is hard when her patients die,

but she takes what they have taught her and “integrates these skills into her practice to teach others” in both her professional and personal life. Rose stated, “I have experienced sadness and grief over patients who have died, yet I have also experienced relief for patients who have endured a significant amount of suffering to finally be at peace.” She has mixed feelings at times, but she always “feels privileged and honored” to be the one who is working with patients and their families at one of the most “vulnerable times” of their lives. Molly has derived enormous satisfaction from counseling terminally ill patients and their families, and feels like she “companions people through a universal life task.”

The co-researchers mentioned strategies for dealing with the intensity of emotions involved in losing their patients. They talked about distracting themselves and finding a balance in their lives when patients die. Co-researchers discussed the spiritual aspects of counseling the terminally ill, and the effects their work had on their lives. They identified their own faiths being an important factor in helping them to cope with the loss of their patients. Shelly relies upon her own “spiritual beliefs, prayer, and meditation” to help her grieve and appreciate what she has learned from her patients. Jackie identified that it is important to be aware of “treading the thin line between empathy and over involvement” when patients die. She acknowledged that if she were devastated every time her patients died then she would burn out, so she believes “balance is key.”

Chapter V

Discussion

This research study's primary goal was to explore the successful practices counselors utilize to ease patients through the death experience. The information gathered from the ten co-researchers who facilitate counseling to terminally ill patients supports previous research studies. As reported in the findings section, co-researchers of this study identified with many of the effective counseling techniques found in previous research, yet the names of the techniques were sometimes reported differently. When referring to the practice of having a patient tell their story, previous research used the term dignity therapy, whereas the co-researchers used the term life review.

Unlike the research of Breibart (2001), Kosoff (2003), and Spiegel (1989), who found the use of group counseling to be effective in helping terminally ill patients cope better with psychological distress and death anxiety, the co-researchers in this study did not report the use of group therapy as a counseling technique they utilize at the end of life. This finding may be due to the researcher's lack of specific questioning on support groups and group counseling.

As demonstrated by the research findings of Bloche (2005), who found that family members who fear the death of loved ones often make decisions based on emotions rather than what is best for the patient, co-researchers found family members were unable to communicate their worries to the patient because they did not want to upset them. Previous research findings focused specifically on individual and group counseling, whereas the interviewed co-researchers recommended facilitating family meetings, so family members can communicate openly to each other about what concerns

they have. As indicated by the co-researchers, family caregivers now operate as integral parts of the health care system and provide services to their loved ones that were once only performed by health care providers. Therefore, addressing the impact of stressors at the end of life on both caregivers and patients is crucial.

Similar to the research findings of Emanuel & Emanuel (1998), who suggest that patients do not view death as good when they have a sense of being out of control, co-researchers agreed and stressed the importance of patients remaining in control of their lives and their death, as death anxiety increases dramatically when patients feel out of control. The research findings of Fine & Mayo (2003) found that advanced directives ensure patients that they have control over their own deaths. The co-researchers agreed with previous research and they encourage patients to have an advanced directive in place to assist with end of life decisions, which decreases death anxiety. Kyba (2002), like the co-researchers, agrees that having an advanced directive provides patients with peace of mind, and alleviates the burden of making difficult and emotionally intense decisions at the end of life. The previous research of Lair (1996) found patients who perceive themselves as out of control, and a burden on others, often experience more death anxiety. The co-researchers also observed that patients who feel a loss of control in their lives have a dramatic increase in death anxiety.

The previous research of Corsini & Welding (2008) noted that counselors working with the terminally ill must not be overly concerned with treating mental illness and helping patients fix their problems. The co-researchers agreed that distinguishing between sadness at the end of life and depression and anxiety is a team effort, and utilizing the help of physicians and nurses is appropriate. The co-researchers, like

Fortner & Neimeyer (2004), suggest that patients have more death anxiety when they have a history of psychological problems. As demonstrated in the previous research of Breitbart, Gibson, Poppito, & Berg (2004), who found that a positive spiritual outlook in terminally ill patients has been shown to prevent depression and hopelessness, co-researchers in the current study agreed that it is important to find ways to help patients address their issues.

Frankl (1963) believed that humans could find meaning in life up to the last possible moment in the face of death; co-researchers agreed, and try to help patients find meaning in where they are at on their death journey. According to the research findings of Chochinov, Hack, Hassard, Kristjanson, McClement, & Harlos (2005), who utilized dignity therapy to encourage dying patients to tell their stories, the co-researchers reported the use of life review with their patients to help them evaluate their lives. Ando, Morita, Okamoto, & Ninosaka (2008) suggest the technique of audio recording the patients' story. The co-researchers support this technique and give their patients the option of making a video, audiotape, or book about their lives. The co-researchers perceptions are consistent with the research of LeMay & Wilson (2008), who found that by leaving their created documents to family and loved ones, terminally ill patients are able to leave a lasting reminder of who they were and their hopes and dreams for their families' futures. Chochinov et al. (2005) suggest the importance of dignity therapy, as it empowers patients and allows them to perceive life as more meaningful. The co-researchers agree that life review can help patients process their death and maintain a purpose at the end of life.

As demonstrated in previous research by Wink & Scott (2005), who found that individuals who are highly religious had the least amount of death anxiety, current co-researchers report observing patients who have absolute faith in their religion and a belief in an afterlife to be less anxious. McMordie (1981) and Koenig (1988) found people who have medium religiosity have the highest level of death anxiety in previous research, and in this research study the co-researchers believe people who question or are estranged from their faith have the worst experiences with the death and dying experience. The co-researchers agree with the research of McMordie (1981), who found people who did not have any religious beliefs have less death anxiety. Similarly, the co-researchers find that when working with atheists they observe less death anxiety, as in their experience, atheists view death as the end of the cycle of life and do not question any type of afterlife. According to Breitbart, Gibson, Poppito, & Berg (2004), patients have a more difficult time with death when they fear God has not forgiven them for their wrong doings. Similarly, the co-researchers observe some Catholic patients who are afraid during the death experience because of the guilt and confession mentality ingrained in them.

Kubler-Ross (1997) noted death anxiety is reduced when a person has the ability to be genuine and authentic in whatever beliefs they have. The co-researchers also observe that patients who are sure of themselves and know who they are as a person have less fear of the death experience. Kubler-Ross (1997), like the co-researchers, thinks it is important to explore and support her patients' beliefs, and believes it is important to understand people's needs and support their different religious and spiritual beliefs. Carni (1988) found that counselors who offer comfort and hope to their patients by listening to them and trying to help them find meaning to their experiences, is consistent

with the co-researchers who agree that listening to patients helps them to reach a better understanding of their life experiences and allows them to move forward.

Callanan & Kelley (1992) suggest that sometimes patients have desires to remove barriers that prevent them from finding peace at the end of their life. The co-researchers agree, and suggest facilitating patients with forgiveness and reconciliation when possible, in order to help them with regrets or guilt for past behaviors. Similar to Callanan & Kelley (1992), who found that patients might wish to heal a difficult relationship, fulfill a regret they have in life, or complete an unfinished task, the co-researchers encourage patients to seek forgiveness or reconciliation when they have regrets for something they perceive they did wrong to someone else. The co-researchers agreed with the research of Callanan & Kelley (1992), who support the concept that counselors can help patients find new hopes as they work through their unmet needs to find peace with what they cannot control or reconcile. As shown in the previous research of Tomer, Eliason, & Wong (2001), who believe it is important to find meaning in experience, the co-researchers find that when reconciliation is not possible, they help the patient process their feelings to find an acceptance and help them to understand what they have changed and what they have learned through their mistakes.

Demmer (2004) found that different complimentary therapies could help a patient have more control over their life and give them an improved mood. The co-researchers agree and report the use of alternative therapies as good distractions for patients who are struggling with past regrets to help them cope better with their guilt and achieve a more peaceful death. Co-researchers agreed with the research of Demmer (2004), who suggested that patients with terminal illness benefit physically, psychosocially, and

spiritually from complimentary therapies. The co-researchers supported most of the complimentary therapies suggested by Demmer (2004), which include massage therapy, touch therapy, music therapy, aromatherapy, reiki, and relaxation; however, they did not report using breathing exercises, meditation, or hypnosis. The co-researchers also included pet therapy, prayer, life review, manicures, and hobbies as alternative therapies to ease patients' anxiety at the end of life. One explanation for some of the different complimentary therapies mentioned by previous research and the current research may be availability of local therapists who provide alternative therapies.

The current research supported the research of Duba & Magenta (2008) and Worden (1991), who suggested it was important for counselors to practice good self-care. The co-researchers utilized education, mentors, and peer support to cope with their grief appropriately when a patient dies, which is recommended to prevent emotional stress and burnout according to previous researchers Worden (1991), and Duba & Magenta (2008).

Limitations

This research study is presented with limitations. One limitation is the lack of diversity among the counselors who participated in this study. All of the participants consisted solely of Christian Caucasians who may not be aware of different cultural issues when addressing concerns of patients who are experiencing the process of dying. The study may have been limited by nine of the ten counselors being female. Another limitation is that all of the participants were from the Midwest and their practice and techniques may have been centered on the local culture and values of Midwestern people.

Chapter VI

Conclusions and Implications

A sample of ten counselors cannot provide a definite description of end of life counseling experiences. Additional studies involving counselors and uncovering their experiences and meanings are needed for developing a more in depth understanding of the best counseling practices at the end of life. However, some basic premises can be derived from this study and the experiences of the co-researchers for beginners working with the terminally ill, as well as for counselors in other areas who will inevitably have patients with grief issues. The results of this study have several implications regarding how counselors facilitate patients through the death experience.

The terminally ill have to deal with death anxiety, accepting one's impending death, leaving loved ones behind, religious and spiritual beliefs, pain and suffering, and life satisfaction and review. To summarize, both previous and current research found that counseling can improve the quality of life for patients who are terminally ill. Helping patients to find purpose and meaning in their life is beneficial in reducing death anxiety. Current research also agreed with previous research and found religiosity and spirituality to be positively related to life satisfaction.

Counselor education programs should offer students a comprehensive study of death related issues, so they are more prepared to work with the terminally ill. Counselors must continue to educate themselves on the dying experience and seek out opportunities for personal growth, as well as training in the areas of death and dying counseling. In order to provide the patient with the best possible care at the end of life, health care providers, counselors, and caregivers must collaborate regarding the patients'

needs. Although hospice utilization is on the rise in the United States, the average length of stay is decreasing, which suggests patients are being referred to hospice closer to their death and not receiving the full physical and emotional benefits hospice teams can offer. This study provided useful knowledge in determining the emotional experiences and needs of the terminally ill, and the best counseling practices to facilitate end of life concerns.

Future researchers should use more diverse samples of counselors to understand the best counseling practices for use with different groups going through the death experience. Counselors who have a more diverse ethnic background may help to determine the affective practices for working with those patients who practice non-Christian religions and atheists who do not have a belief in an afterlife. Diversity may also provide further insight of cultural beliefs surrounding the death experience. Creating a better questionnaire that reviews a counselor's own death anxiety, religiosity, and end of life experiences may help to better understand the techniques counselors utilize to help patients going through the death experience. A question that assesses counselors' use of group counseling and support groups would determine if counselors find group therapy to be effective in helping terminally ill patients cope better with psychological distress and death anxiety. Future researchers should also assess the benefits of family counseling at the end of life, as the majority of co-researchers utilize this method to help patients communicate their needs at the end of life. Further research should also focus on the benefits of hospice and palliative care and question why only about 20% of dying patients are utilizing these services in the United States. In closing, this work contributes to a

better understanding of best counseling practices for working with terminally ill patients who are going through the death experience.

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Appendix A

Generalized qualitative questions:

- A. What have you experienced in terms of counseling terminally ill patients?
- B. What context or situations have typically influenced or affected your experience of counseling.

Appendix B

Interview Protocol

1. How many years have you been counseling people who are terminally ill through the death experience?

- A. 1-3
- B. 3-5
- C. 5-10
- D. 10-15
- E. 15 +

2. Please rank in order from highest to lowest the emotional symptoms you observe in patients going through the death experience most frequently.

- A. Anxiety
- B. Depression
- C. Anger
- D. Denial
- E. Rationalization
- F. Bargaining
- G. Other

<p>3. Please describe some of the methods you have found to be the most effective when patients have the following concerns?</p> <ul style="list-style-type: none">A. Leaving their children and family behindB. Pain and sufferingC. Unfulfilled ambitionsD. Regrets or guilt for past behaviorsE. Concern for family's well-beingF. Questioning their spiritual or religious views or afterlife
<p>4. From your observations how does a patient's religiosity and spirituality affect their death experience?</p>
<p>5. What counseling methods help you to differentiate between appropriate sadness at the end of life and mental health disorders such as depression and anxiety?</p>
<p>6. What alternative or complementary therapies have you observed to be effective during the death experience?</p>
<p>7. What counseling methods do you observe to be effective in helping patients evaluate their life?</p>
<p>8. What counseling methods do you find help patients maintain purpose at the end of their life?</p>
<p>9. What practices are effective in helping you process your own grief when a patient dies?</p>
<p>10. If you have death anxiety of your own what practices are effective in helping you to cope?</p>

Appendix C

IRB # 602-10-EX

University of Nebraska – Omaha

Counseling Department

Informed Consent

Project Title – The Death Experience of Terminally Ill Patients and Best Counseling Practices

PURPOSE

This is a research study. The purpose of this research is to investigate the most effective practices used by counselors serving terminally ill clients. You are invited to participate in this research study because you are a counselor working with this population.

PROCEDURES

If you agree to participate, your involvement will last for approximately 50 minutes. The following procedure is involved in this study. You will be asked to confirm your consent to participate. You will then be interviewed and asked 10 questions. The interview will be taped and then transcribed verbatim. A transcription of the interview will be sent to you by electronic mail. A follow up electronic mail will be sent to you asking for approval or clarification of conflict for example accuracy.

There are no foreseeable risks for participating in this study.

BENEFITS

There are no foreseeable personal benefits that may occur as a result of your participation in this study. The researcher anticipates that the field of counseling may benefit from the study by obtaining information to use in the daily occupational experiences within this profession, thereby making recommendations to strengthen the field as a whole.

COSTS AND COMPENSATION

There are no costs for participating in this research study. Participants will receive no compensation for participating in this research study.

CONFIDENTIALITY

Records of participation in this research study will be kept confidential to the extent permitted by law. However, federal government regulatory agencies and the University of Nebraska Institutional Review Board (a committee that reviews and approves research studies involving human subjects) may inspect and copy records pertaining to this research. It is possible that these records could contain information that personally identifies you. In the event of any report or publication from this study, your identity will not be disclosed. Results will be reported in a summarized manner in such a way that you cannot be identified. Confidentiality will be protected by numerically coding your responses, so no participant or agency identification will be obtained or recognized through the data. A list of names and corresponding code numbers will be archived and kept in a locked cabinet and destroyed when the study is completed.

VOLUNTARY PARTICIPATION

Participation in the study is voluntary. You may choose not to take part at all. If you agree to participate in the study, you may stop participating at any time. When completing the interview, you may skip any question that you prefer not to answer. You can choose to stop participating at any time. Any data collected from you prior to the withdrawal will not be included in the study. Research will take place at the site of your

choice and if a clinical office is chosen, the participant is expressing permission to conduct research at this location by signing the consent form.

By signing this consent form you have indicated that this research study has been explained to you, that your questions have been answered, and that you agree to take part in this study. You may print a copy of this form if you wish.

Participant signature

DATE _____

Agency Representative (if necessary)

Date _____

Principal Investigator – Helen Bleicher - Masters student in school of counseling

QUESTIONS

Questions are encouraged. If you have any questions about this research project, please contact the Principal Investigator Helen Bleicher at HJBleicher@mac.com or by phone at (402) 681-3520. If you have questions about your rights as a participant, please contact the University of Nebraska Institutional Review board at irbora@unmc.edu.