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UNDERSTANDING THE COUNSELOR EXPERIENCE WHEN WORKING WITH END OF LIFE CLIENTS

A DISSERTATION

Submitted to the Faculty of
Montclair State University in partial fulfillment
of the requirements
for the degree of Doctor of Philosophy

by

CONNIE S. DUCAINE

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Upper Montclair, NJ
2017

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UNDERSTANDING THE COUNSELOR EXPERIENCE WHEN WORKING WITH
END OF LIFE CLIENTS

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ABSTRACT

UNDERSTANDING THE COUNSELOR EXPERIENCE WHEN WORKING WITH END OF LIFE CLIENTS

by Connie S. Ducaine

This was a qualitative study exploring the experiences of counselors working with clients who are coping with an advanced illness and approaching end of life. The study focused on the risks and benefits of fostering relationships with end of life clients, with an emphasis on how these practitioners process their experiences. While supporting clients at end of life, these professionals often were impacted by the deaths of people who they had worked with for varying lengths of time.

The findings suggest that these counselors experienced many of the same issues that have been documented by other helping professions, and that they developed a means of sustaining themselves through emotionally turbulent times. The participants in this study leveraged their spirituality, connections and boundaries to meet their need for psychological safety, while using the experience to cultivate the unexpected gifts of the work. In the final analysis it was determined that a combination of psychological safety and unexpected gifts created a cycle of sustainability.
ACKNOWLEDGEMENTS

I would like to thank the members of my dissertation committee for their ongoing support and encouragement. I will be forever grateful to Dr. Dana Heller Levitt for exceeding my expectations as the chair of the committee; I can only hope, if I am ever in a position to support doctoral students in the future, that I am able to follow her example. I am also thankful to Dr. Kathryn Herr for challenging me to look for the deeper meaning in the stories that the participants shared with me; I am appreciative of her introduction to Gilligan’s Listening Guide as it was this method of analysis that helped me uncover the constructs outlined in this document. I offer my gratitude to Dr. Les Kooyman for his positive reinforcement throughout the process, and his encouragement which began with my first doctoral class. I express my thanks to Dr. Harriett Glosoff as she was the first person to help me to develop my research question, while encouraging me to explore my motivations for this study. As I reflect on individuals who have contributed to my success, I would be remiss if I did not acknowledge Dr. Catherine Roland, as she was the first faculty member to encourage me to consider entering a doctoral program.

I want to thank those who provided the much needed fortification during this journey which was both exhilarating and exhausting. This includes the members of the leadership team of my employer, Vital Decisions, who were accommodating during times when I need flexibility while offering ongoing support. I appreciate the students in the doctoral program that listened thoughtfully as I shared details of this study, asked provocative questions, and expressed a sincere interest. I hope they know that each time I was able to tell my story, my motivation to continue was elevated. I also appreciate my
cohort and I will fondly remember our orientation and our first semester in the doctoral program – how far we have come.

This study was only possible because eleven professionals gave me their time, told me their stories, and shared their emotions as I probed to understand their experiences. I hope that this dissertation helps the readers to appreciate these counselors and all that they do for people who are at a delicate time in their journeys. I feel I do not have the words to clearly express the depth of my gratitude so I will simply say to these amazing eleven people – thank you.
DEDICATION

This dissertation is dedicated to my husband, David, who has been a constant source of love, laughs, support, and encouragement throughout this entire journey. I am thankful to him for taking care of the details of our life while I dedicated a good portion of the past four years to the pursuit of my lifelong goal. I am happy to say I will no longer be the invisible wife!

I am also dedicating this work to my parents who instilled in me the work ethic that is needed to complete both a dissertation and a doctoral program. The belief that I can accomplish my goals was fostered during my childhood and has never wavered.

I feel it is also important to dedicate this study to my two furry feline friends, Chica and Brutus, because they reminded me daily that goals may be important but they are not more valuable than the connections I have with those who love me. I am glad that with the completion of this project I will have more time to dedicate to my relationships because they are more valuable than diamonds.
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Understanding the Counselor Experience When Working with End of Life Clients

Chapter One

Introduction

My personal interest in end of life issues began in 1982 when I composed my first essay on Elizabeth Kubler-Ross's perspective on grief and loss. My curiosity relating to the experiences of counselors who work with clients dealing with an advanced illness and approaching end of life was conceived in 2011. It is in the retelling of my story that I begin to narrate the issues that may be central to the experiences of others who work with clients who are critically ill. As is the case with many research topics, mine was born from my experience as both a caregiver and an end of life counselor.

It was in 2011 when I started training for the position as a healthcare/end of life counselor that I was introduced to this little-known counseling specialty. I accepted a counseling position knowing I would be working with clients (and the surrogates of clients) who were facing an advanced illness and were considered to be 12 months from end of life. As a result of the clients’ disease progression, it was understood that our relationships with the clients (and their surrogates) would be short term and would likely end with the client's death. The first week of the classroom training program was intense, and at the end of each day, I left feeling fatigued. As trainees, my cohort and I were challenged to consider what it might be like to have an advanced illness (or care for someone who does) and placed in situations similar to those our clients would experience (e.g., notifying our family that we had a serious illness and completing an advanced
directive). At the close of the fifth day of training, I was emotionally depleted, but another level of education was about to begin.

During my evening commute, I received a phone call from my boyfriend (now husband) with the news that his defibrillator (a small implanted electronic device intended to maintain heart rhythm) had discharged four times in a matter of minutes. He informed me that this occurrence would mean a trip to the emergency room when I got home. He was deceptively calm. I spent most of the sixty-minute journey reflecting on the week and what I had learned, wondering what it would be like to help people who are coping with an advanced illness or facing death.

Upon arrival at the hospital, we naively thought my husband would be in and out of the emergency department. The doctor tempered our optimism when he decided after monitoring my husband for several hours that he would be admitted as a precaution. Being uninformed, I had convinced myself this was a minor episode, and I assumed we would spend a single night in the hospital. Early Sunday afternoon, I realized we both would be spending another night in the facility, and it was evident I would miss the sixth day of my new job.

Late Monday afternoon we eagerly awaited the doctor, as we thought we were meeting the cardiologist to discuss discharge planning. Instead, the specialist efficiently presented us with the personal cell phone of the Director of Heart Transplant Unit at a local transplant hospital, while also informing us that discharge was not happening for at least 24 hours. In hindsight, I see that this conversation, this unexpected revelation, was a shift point in my experience. Nothing in my personal or professional history had
prepared me for the words “heart transplant.” The idea that we would be waiting for someone to die so my husband could have their heart is still something that is hard to grasp. The situation went from bad to worse, when my husband's defibrillator discharged as he was being examined by his cardiologist. Suffice it to say, the discharge was traumatic to witness.

My husband was admitted to the Intensive Care Unit (ICU). The stay in ICU lasted 36 hours during which my husband was appropriately medicated, and I was left to process what was happening. Seeing crash carts in corridors magnified my fears. The emotional strain was intense as I struggled to maintain a composed exterior so my husband would not worry. I was trying to maneuver through the situation with grace, but my collected composure was a complete façade. During my husband’s stay in ICU, I had one epic meltdown at the nurse’s station – no one could console me. However, by the time I walked back into his room, I had repackaged my emotions so as to protect my husband.

A week after the beginning of this life altering event, my husband had physically improved and was discharged. I, however, was emotionally and physically exhausted. Shortly after we returned home, I met with my employer to give them an update on my husband's situation and it is an understatement to say I was an emotional wreck during the entire meeting. The leaders were compassionate but adamant that I was not in an emotional place where I could work effectively with clients who were seriously ill. We shared concern about what could occur if I found myself working with a client who had a condition similar to my husband's or a surrogate in a situation similar to my own. We
agreed during that meeting that I would return to training when we felt I was emotionally ready; that ended up being more than four months after the trauma.

As I worked with clients dealing with an advanced illness, I realized I frequently thought about death. I never asked them, but I was curious if my colleagues thought about it, too. Based on my experience with my husband, I also wondered how my colleagues were affected by the intersection of personal trauma or loss, and their work with clients who were seriously ill. I know my colleagues were facing their own (or familial) medical challenges, and I continued to wonder how they were impacted by the ongoing exposure to discussions of illness and death. My supervision often included conversations about countertransference. I had many unanswered questions, but one in particular continued to nag at me: What is it like for my colleagues as they work with clients who are dying? What is the impact on counselors as they talk about issues related to end of life?

**Statement of the Problem**

My experience suggests that counselors are required to embrace a unique body of knowledge when supporting end of life clients. Drawing from the literature we might infer that counselors must understand the implication of advanced illness on quality of life (Avis, Crawford, & Maneul, 2005; Cheng & Lee, 2011), the role of religion at end-of-life (Dorf, 2005; Engelhardt & Smith, 2005; Firth, 2005; Kemp & Bhungalia, 2002; Keown, 2005; Sachedina, 2005), and the role of race and culture when an individual faces an advanced illness (Giger, Davidhizar, & Fordham, 2006; Noah, 2012; Stein,
Sherman, & Bullock, 2009). These topics are significant and when incorporated into practice have the potential to enhance the therapeutic relationship.

The Code of Ethics for both the American Counseling Association (ACA, 2014, B.2.b. - Confidentiality Regarding End of Life Decisions) and the American Mental Health Counselor Association (2015, Section 8. - End of Life Care for Terminally Ill Clients) highlight end of life issues. This illumination of a particular life stage in the professional ethical codes suggests the topic is significant, but this importance is not mirrored in the literature. This gap underscores the value of understanding the experiences of the counselors who are currently meeting the needs of those who are dying. Without exploration, we are only assuming we understand the experiences and the implications of these experiences for the counselor.

Over the years, end of life experts have authored manuscripts and texts documenting important considerations when providing end of life counseling, while making recommendations as to how one should approach the work. However, what are not identifiable in the literature are the implications of the work for the counselor. A PsychInfo database search using the terms counselor, end of life, and experience uncovered a total of 25 sources dated between 1995-2015, with none communicating the experience of the counselor and most providing "how to" information. This lack of research suggests little (or nothing) has been written about the experience of end of life counselors. This paucity of information may simply reflect the rarity of practitioners in this specialty. Many counselors may find themselves working with a single client who has a life-limiting illness, but far fewer counselors have chosen to make this the core of
their practice. Many counselors, despite their type of practice, are likely to support clients who are facing end of life either as it directly impacts the client or as a surrogate who is caring for another as they face an advanced illness.

The end of life specialty requires both expertise in counseling techniques and a unique knowledge set that includes topics such as advanced directives, Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders, physician-assisted suicide, and related topics (Doka, 2014). The literature may contain information that will help the counselor to do the work more effectively, but there is no information as to why one chooses to do the work or how the work impacts the counselor’s quality of life. Werth and Crow (2009) identified no more than 50 manuscripts published over a 12-year period in the counseling journals relating to end of life. This dearth of both research and conceptual writings targeted toward counselors suggests there is an opportunity to investigate the intersection of end of life and counseling. It is difficult to comprehend how we can develop and support practitioners who are working in an area of specialization we do not understand.

Counselors who work with clients at end of life are not represented by an ACA division or an interest network, and as noted earlier, the professional journals do not reflect their experiences. This absence of information and support systems should not suggest that the specialty area is insignificant. In fact, the need for this specialty is likely to increase as people age and we continue to experience serious illness in our culture. Researchers have determined that an individual will be diagnosed with cancer every 2.5 minutes (National Cancer Institute, 2014) suggesting the number of people who could
benefit from counseling is significant. The lifetime cancer statistics also reinforce the need when one considers that one in three females will hear the devastating words, "you have cancer," and approximately one in two males will receive a similar diagnosis (American Cancer Society, 2014). These statistics imply it is a virtual certainty that even counselors, who are not working in this specialty, will find themselves supporting clients who are processing the issues associated with a chronic or life-limiting illness. Despite this inevitability, the counseling literature offers little insight into how counselors experience working with a population that is contemplating issues regarding advanced illness, dying, and death. There is a lack of information in the counseling literature that documents what it is like for a counselor to work with clients around end of life issues when they have a comparable experience. As a result, we do not understand the experience of the end of life counselor who is not dealing with a personal medical crisis, and we lack insight into the situation when the counselor is also facing an advanced illness. Without this insight, the identification of the practitioners' needs and ways to support this specialty through supervision and ongoing education is a challenge.

The potential issues that may plague my colleagues in this specialty can be identified by looking at other helping professions who attend to clients at end of life. Nursing professionals are frequently studied as they interact with patients at varying stages of the disease trajectory. The feedback from those in the nursing profession and associated research shows there are those who find working with end of life patients meaningful (Dearmond, 2012; Dunn, Otten, & Stephens, 2005; Melvin, 2012; Sinclair, 2011) while acknowledging there are challenges and concerns with compassion fatigue
(Melvin, 2012; Yoder, 2010). Social workers have suggested that building emotional competence is critical (Chow, 2013) while also noting they feel ill-prepared to work with dying patients (Christ & Sormanti, 2000; Csikai & Raymer, 2005). Hospice workers have also reported feelings of fatigue and burnout (Whitebird, Asche, Thompson, Rossom, & Heinrich, 2013).

**Research Questions**

It is a melding of my experiences during my husband’s medical crisis, my personal history as a counselor working with clients facing death, and my observations of colleagues’ personal experiences that inspired me to uncover and analyze the experiences of end of life counselors. Since documenting the experiences of counselors who work with clients who are dealing with an advanced illness was the objective of this research, a qualitative interview study was appropriate. As a means of understanding the experiences of the end of life counselor, and to document their stories, I hoped to uncover, in collaboration with the participants, their thoughts and feelings associated with the following questions:

1. What are the experiences of the counselor who works with clients at end of life?
2. What is it like to enter a relationship with a client knowing that they are going to die?
3. How has this experience impacted the practitioner’s thoughts and feelings about life and death?

**Significance of the Study**

Exploring the experiences of counselors who work with clients who are dying offered insight that is not reflected in the literature. The participants’ narratives highlight
the various constructs (e.g., spirituality, boundary determination, vicarious learning) that may be integrated into the work and life of an end of life counselor. Understanding the stories, including the thoughts and feelings of those who are working with clients at end of life, provides a valuable perspective which can be used to inform neophyte clinicians, supervision practices, and counselor education content. The lack of perspective currently available prompted the question: how do we prepare professionals for a career which we do not fully understand?

Through this research, I hoped to foster an understanding of the counselors' relationships with end of life issues by sharing the specialists' narratives and uncovering the meaning they ascribe to all that they have witnessed. The stories they told detailed the counselors' perspectives as they relate to the impact of the work both on their work and in their personal lives. Without this type of research, one can only speculate as to the existence and significance of constructs such as compassion fatigue, burnout, countertransference, death awareness, and vicarious trauma. Identifying the constructs that exist and understanding how counselors cope with the challenges that they may experience is valuable to the profession and the clients who are served by these practitioners. The counselors’ stories will both enlighten those who are unfamiliar with this specialty and normalize the experiences of other end of life specialists. This visibility into the specialists’ lived experiences will also inform the practices of the counselors who work with this population on a more limited basis. The themes identified can be leveraged by mental health counselors when one of their clients is diagnosed with an advanced illness. A deeper understanding of the benefits and risks of this work on the
counselor has the potential to improve the experience for clients who seek counseling as they face advanced illness and end of life.

This qualitative study was also intended to uncover and highlight the mechanisms used by counselors to cope in times of difficulty. Understanding the end of life specialty and the impact of the work on the counselor can inform counselor educators about the unique needs and requirements for counselors who wish to work with clients at end of life while also reinforcing the value of constructs (e.g., supervision, self-reflection, ethical practice and self-care) already covered during counselor preparation. The themes identified can also contribute to the content of continuing education and alternate forms of career development. Administrators and supervisors will reap the benefits of the findings as they can incorporate the information into supervision and use it to create profiles for recruitment purpose. Once we understand the attributes of a counselor who effectively works in this specialty, a recruiter or hiring manager can identify the same skills in job candidates with the intent of selecting practitioners with the greatest potential for success in this specialty.

The value of this study is not limited to those in the counseling field, as practitioners in other helping professions may find their experiences mirrored in the stories of the counselors. The narratives may normalize the experiences of helping professionals across disciplines, and the themes uncovered in this inquiry may provide additional insight for those working in hospice and palliative care settings, and nursing homes or other facilities that provide care for people who are dying. It is expected that anyone who works with clients coping with an advanced illness can glean information
that may trigger self-reflection and have a favorable impact on the quality of care. This additional insight may inspire all readers to reflect on the ways in which their interactions with those who are dying have influenced their experiences and feelings about their own mortality. Readers of this research will catch a glimpse into the world of this specialty practitioner.

**Conceptual Framework**

It is my belief that individuals determine the meaning and implications of events based on their experiences both past and present, suggesting each will create their reality. This perspective suggests no two people will see an experience in the same way, and there is not a single correct interpretation of an event. The postmodern constructivist paradigm is in alignment with my perspective. Jonassen (1991) offered an explanation of constructivism that mirrors my assessment when he wrote: “How one constructs knowledge is a function of previous experiences, of mental structures, and of beliefs that one uses to interpret objects and events” (p. 59). This explanation suggests that counselors may share experiences as they work with clients who are dying, but these events will have varying meanings for the practitioners. Doka (2014) identified several factors that may influence a person’s interpretation of the events associated with an advanced illness including gender, age, spiritual or religious affiliations, culture, ethnicity, and personal experiences with illness and death.

Mahoney and Marquis (2002) described constructivism as a “family of theories” (p. 799), which includes constructs from an array of orientations including cognitive-behavioral, humanistic, psychoanalytic psychotherapies, Buddhist traditions, and
neuroscience. There are five primary themes of this metatheory: 1) activity, 2) order, 3) self or personal identity, 4) social-symbolic relatedness, and 5) lifespan development (Mahoney, 2003; Mahoney & Marquis, 2002). Each of these concepts categorizes the factors that impact an individual’s perceptions and meaning making, and when intertwined they result in the human experience.

After considering Mahoney and Marquis’ (2002) categorization of the constructivist themes, I have concluded that we are participants in our lives and that we have the ability, through our choices, to make a difference not only in our personal experiences but also in those of others. As a result, determining how end of life counselors’ choices have impacted their experiences and those of their clients was an important component of this study. Since my constructivist philosophy also places significant emphasis on emotions, self-efficacy, and activation while people strive to instill order by creating patterns (e.g., routines around eating, sleeping, and coping), this study endeavored to uncover how these constructs are manifested in the end of life counselor’s practice.

From a constructivist point of view, change or growth occurs when the patterns of an individual’s life are tested or disrupted (Mahoney & Marquis, 2002); a status quo does not inspire change. Humans strive to create organization within themselves by ordering their emotions and their bodies throughout the lifespan. The organization of self is influenced by relationships and language, and storytelling. People organize their thoughts via the stories they share, as Mahoney (2003) noted: “a large part of our meaning-making is experienced and expressed as narrative (story): our stories, ourselves” (p. 8). In
support of this constructivist lens, the interviews were structured to create a space for the participants to share their stories, as a means of understanding their perceptions of their growth and progression.

The themes of this constructive framework guided all phases of this study beginning with the design, and continuing through data gathering and analysis. With the awareness and sensitivity that each counselor will have their unique experiences, no assumptions about the impact of these experiences were made as a result of the existing literature or my history. Themes were mined, but the participants’ stories are honored to ensure the reader appreciates the journey taken by each interviewee. The open-ended questions that served as the foundation for the semi-structured interviews created a platform for the participants to share their stories, and the recursive analysis facilitated my discovery of the meaning behind the story, and how the five constructivist themes may be reflected in participants’ narratives.

Chapter Summary and Dissertation Organization

This dissertation is organized using a five-chapter format. In this chapter, I introduced the reader to the subject of end of life counseling and offered an opportunity to consider the value of understanding the experience at a deeper level. In the second chapter, I provide background about the counseling profession and review the factors that differentiate counseling from other helping professions. Drawing from the literature provided by other helping professions, I also offer for consideration several constructs that may be identified as integral aspects of end of life counseling, and a purview into the tools that counselors may use to cope with the challenges of the work. My third chapter
describes the method I used to collect data and how I applied Gilligan’s Listening Guide
to the data analysis while offering a more detailed explanation as to the rationale for a
qualitative approach. While the fourth chapter cannot completely document the
experiences of the participants, it does provide a summation of the themes gleaned from
the interviews which were mined from hundreds of pages of data. The fifth and final
chapter provides more opportunities to consider the implications of this study and the
possible direction of future research.
Definitions

Some the terms used throughout this document have different meanings in varying contexts. The purpose of the following list is to provide insight as to the author’s intentions when using specific terminology.

Advance Directive - A legal document completed by the client that can help ensure their preferences for various medical treatments are followed if they become unable to make their healthcare decisions. The client's advance directive goes into effect only if their physician has evaluated them and determined that they are unable to understand their diagnosis, treatment options or the possible benefits and harms of the treatment options (State of New Jersey - Department of Health, 2015b).

Advanced Illness - Describes a situation in which one or more illnesses become severe enough that health and functioning are declining, and treatments are becoming less effective (Coalition to Transform Advanced Care, 2014).

Assisted Death - Also known as physician-assisted dying, or aid in dying, and is legal in some states. Assisted death is an option when an adult with a terminal condition is determined to be mentally competent and able to request a prescription for life-ending medication from their physician (Death with Dignity National Center, n.d.).

Burnout – A defense mechanism leveraged by counselors who are working in situations that are emotionally draining with minimal resources available for support (Jenkins & Baird, 2002).

Compassion Fatigue – Secondary traumatic stress or the consequence of assisting individuals who are suffering (Figley, 1995).
Countertransference – Unconscious feelings experienced by a helping professional toward a client that may impact the way in which the professional responds to the client (Wedding & Corsini, 2014).

Counseling – “a professional relationship that empowers diverse individuals, families, and groups to accomplish mental health, wellness, education, and career goals” (American Counseling Association, 2014, p. 20).

DNR/DNI - Acronyms for Do Not Resuscitate/Do Not Intubate, which is a physician's order. Do Not Resuscitate means that, in a situation in which an individual goes into cardiac arrest, no action (including CPR) will be taken to restart the heart. Do Not Intubate means that a breathing tube will not be inserted into the person’s airway if the person has difficulty breathing or respiratory arrest. Each of these orders may be given separately and are usually documented in the patient's medical chart. The patient can change a DNR and DNI order at any time, and experts urge that such orders are regularly reviewed. In a DNR/DNI situation, a patient is kept comfortable. Without such an order, emergency medical technicians are legally obligated to perform CPR (Death with Dignity National Center, n.d.).

End of Life - Period marked by disability or disease in which the client’s condition deteriorates until death.

End of Life Counselors - Practitioners who specialize in working with clients who are facing issues related to an advanced illness and death.

Euthanasia – Literal meaning is "good death" and refers to the deliberate act of ending the life of another person who is suffering from an incurable condition. Many equate this
to a lethal injection, and it has been referred to as "mercy killing." Euthanasia in any form is not legal in any state (Death with Dignity National Center, n.d.).

Hospice - An organization or institution that provides comfort (a.k.a. palliative) care for people coping with an advanced illness when curative treatments are no longer expected to be effective in curing the disease or prolonging life (National Hospice & Palliative Care Organization, n.d.).

Licensed Professional Counselor (LPC) – “Master degreed mental health service providers, trained to work with individuals, families and groups in treating mental, behavioral and emotional problems and disorders” (American Counseling Association, 2011b, p.1).

Life Limiting Illness - A severe medical condition that is known to shorten a person's life. Terminal Condition – An individual who has a medical prognosis with a life expectancy of six months or less if the illness continues its expected progression (State of New Jersey - Department of Health, 2015a).

Vicarious Trauma – the adverse effects experienced by helping professionals who work with people who have experienced trauma.

Vicarious Resilience – The favorable impact on a helping professional after witnessing an individual’s positive adaptation after a significant negative, and often traumatic event (Luthar & Cicchetti, 2000).
Chapter Two
Literature Review

As clients face an advanced illness and approach end of life, they frequently collaborate with a myriad of professionals (e.g., counselor, psychiatrist, social worker, and primary care physician) as a means of maneuvering through a life stage that can be emotional and complex. The complexity of the situation is magnified when the individual facing the illness is young, and the possibility of premature death is likely. Each practitioner is motivated to provide care and support the client, but most will do so in such a way that leverages their professional training and their specialty’s unique point of view. Because the roles are distinct, yet tasks can overlap, it is appropriate to differentiate the function and perspective of the professional counselor from that of other helping professionals (e.g., social workers, psychologists, and nurses). It is also helpful to draw from the literature of the other helping professions to consider the constructs that may have relevance for the counselor working with end of life clients.

This chapter includes a review of advanced illness statistics, which document the frequency with which individuals experience a serious illness that not only impacts their day to day activities but also may decrease their life expectancy. The data support the hypothesis that many people will experience a diagnosis serious enough to cause them to consider their past and present while making significant decisions regarding their future. Although many of these individuals maneuver through the experience without professional support beyond their physician, there are individuals who seek assistance outside the medical realm. One such practitioner who is uniquely qualified to help clients
on their journey is the licensed professional counselor. In this chapter, the nuances of
counseling as a profession will also be addressed. The exploration of the counseling
profession, as well as the end of life specialty, is intended to strengthen the reader’s
understanding of the function the practitioner can play in the lives of patients facing an
advanced illness or end of life. After providing insight into the counseling profession and
the end of life specialty, the chapter transitions to the possible implications of this clinical
work on the counseling practitioner. The literature from other helping professions that
work with dying clients (e.g., nurses and social workers) is reviewed in an effort to
anticipate the lived experiences of the end of life counselor since their stories have not
been documented in the counseling literature. In addition to reviewing the possible after-
effects of the work on professional counselors, information addressing potential coping
mechanisms used by other helping professionals is also offered as a means of
highlighting what was uncovered via this study.

Counseling as a Profession

The titles ascribed to various professions often do not provide a clear indication as
to the nature of the work, leaving consumers and other practitioners curious to how
particular professions meet the needs of their clients. In some instances, generic terms
such as "counseling" and "therapy" are used interchangeably when a title with more
specificity is most appropriate. This lack of clarity is often observable when individuals
are introduced to the vocation of professional counseling. Offering evidence of the
nuances of this distinct occupation is appropriate.
Mellin, Hunt, and Nichols (2011) asked more than 200 counseling professionals to offer their definitions of counseling and, not surprisingly, there was no single definition. Although this research did not produce a consensus definition, the responses did result in three categories that seem to capture the essence of the profession: (a) an array of services delivered to diverse clients to achieve distinct goals; (b) a level of education and credentialing that suggests a commitment to the populations served and the profession; and (c) a focus on growth and wellness (Mellin et al., 2011). The participants' responses suggest that professional counseling should be multifaceted to meet the needs of the client in any life stage, delivered by an individual with a minimum of a master's degree and a license, and guided by a wellness model, as opposed to the disease model utilized in some other professions.

The findings documented in the Mellin et al. (2011) study are in alignment with the consensus definition of counseling presented by Kaplan, Tarvydas, and Gladding (2014) on behalf of more than two dozen counseling organizations: "a professional relationship that empowers diverse individuals, families and groups to accomplish mental health, wellness, education, and career goals" (p. 366). Although each word in this definition was selected with purpose, the themes that highlight the distinctions between professional counseling and other helping professions may be empowerment and wellness. One definition that begins to put the concept of empowerment into a counseling context:

Empowerment is the process by which people, organizations or groups who are (a) powerless become aware of the power dynamics at work in their life context,
(b) develop the skills and capacity for gaining some reasonable control over their lives, (c) exercise this control without infringing upon the rights of others, and (d) support the empowerment of others in their community (McWhirter, 1991, p. 224).

This definition suggests that the empowerment process is multifaceted, complex and requires that the counselor has an understanding of the ways in which this definition can be put into practice.

McWhirter's (1991) explanation of empowerment is germane in the context of end of life counseling, as the clients who are maneuvering through the medical system are often unaware of the opportunities that exist to take control of their situations. Empowerment is a concept that can encompass autonomy and self-advocacy, which can also play a major role when individuals are managing the interactions with doctors and their support systems. Whereas some professionals may be tasked with resolving issues on behalf of the client, counselors will seek to support their clients as the individuals attempt to settle their issues across their lifespan, including those related to end of life. “Decisional autonomy” (Terry, Olson, Wilss, & Boulton-Lewis, 2006, p. 341), or the need to make one’s own choices in relationship to the management of their medical condition, has been identified as an important factor for some individuals at end of life. This concept is directly related to the construct of empowerment, which is a distinguishing feature of the counseling profession.

Utilization of a wellness philosophy, or a "synergistic and multidimensional construct, that is represented on a continuum, not as an end state" (Roscoe, 2009, p. 222)
is a critical component of counseling. Although there are varying definitions of wellness, many reference more than simply an absence of disease, but incorporate a combination of seven dimensions: social, emotional, environmental, intellectual, career, physical, and spiritual wellbeing (Roscoe, 2009). Myers and Sweeney (2008) noted there is evidence that supports the use of the wellness approach when working with diverse clients facing a range of issues not limited to situations involving pathology (e.g., job satisfaction, objectification, transitions, and attachment to animals). This diversity of application suggests a wellness approach will be relevant to those dealing with the issues of death and dying, as these matters can encompass more than disease progression and end of life. When an individual confronts an advanced illness, they may experience the negative effects in their work environment, changes to their self-perception, transitioning away from the role of caregiver and concerns about what will happen to their pets after their passing. In all of these situations, a professional counselor could be a valuable resource for the client. In addition, exploring the ways in which end of life counselors incorporate a wellness, or holistic approach, to their own self-care may be enlightening for peers, supervisors, and counselor educators.

Not all helping professions subscribe to the wellness model; some professions’ training programs are grounded in other theoretical approaches (e.g., doctors leverage a medical model). The models used to conceptualize a client's case can also influence the direction of the helping relationship and the interventions. The wellness approach is infused throughout the curriculum in many counselor education programs as the faculty prepares students for the counseling profession. The wellness model differentiates
counselors from other helping professionals making them uniquely qualified to support clients when they are considering their situation from a multitude of perspectives.

**Counselor Preparation: A Distinction**

One of the key distinctions between professional counseling and other helping professions can be found in the practitioner’s training and education. Although there are several counseling specialties (e.g., addictions, career, clinical mental health, and marriage, couple, and family) all are grounded in standards for a counseling curriculum. When a program is accredited by the Council for Accreditation of Counseling and Related Educations Programs (CACREP), it is anticipated that the curriculum will address eight core areas: professional counseling and ethical practice, social and cultural diversity, human growth and development, career development, counseling and helping relationships, group counseling and group work, assessment and testing, and research and program evaluation (CACREP, 2016). All of the core areas are addressed from a counseling perspective and delivered by educators who are committed to the counseling profession (CACREP, 2016). Despite the comprehensive guidance provide by CACREP, it must be noted that the eight domains have not provided direction regarding curriculum about the specific areas of grief and loss (Doughty Horn, Crews, & Harrawood, 2013).

To fulfill the standards set for professional counselors, trainees must participate in a rigorous preparatory program. Counseling students who aspire to obtain a license to practice independently are required by most state jurisdictions to accrue a minimum of 60 graduate semester hours in a CACREP or regionally accredited program (ACA, 2016a). In addition to the coursework, students aspiring to licensure are mandated by the state to
complete an experiential component during their master's program. This practicum and internship experience generally includes a minimum of 700 hours of clinical work over 3 semesters (ACA, 2016a). Meeting the educational requirements, however, is not sufficient to satisfy licensing requirements as students are required to successfully complete a national licensing exam. It is not until the educational, experiential, and testing components are completed that an individual can obtain their first license. This initial license does not allow individuals to practice independently.

To practice independently (without mandated supervision) an individual must satisfy additional requirements related to clinical experience. The post-graduate experiential aspects must be supervised by a state-approved supervisor and satisfy a minimum number of hours that generally ranges between 3,000 and 4,500 hours, spanning 24 to 36 months (ACA, 2016a). It is not until all of these requirements are satisfied that an individual can begin to practice without supervision, and the process can take several years to complete. Upon licensure, professional counselors are expected to increase their knowledge and skills through continuing education, with most states setting a minimum requirement. How end of life counselors address these requirements and expand their knowledge of this specialty is not documented in the literature, suggesting there is an opportunity for exploration.

When the core areas are incorporated into counselor education, and the individual has satisfied the licensing requirements, the new practitioner is prepared to provide counseling services (including assessment and testing) to diverse populations across the lifespan, while also supporting the profession through research and advocacy.
Assessment and testing are of particular importance since counselors may be called upon to assess a client’s level of functioning when they are considering options available via the Death with Dignity Acts passed in some states. This assessment of the level of functioning may be a requirement in states with Death with Dignity Acts, but this does not suggest that this level of evaluation is limited to only those states. Counselors working with end of life clients may be asked to assess an individual’s level of functioning in a variety of situations (e.g., shift points in care or determining eligibility for independent living).

The graduates of counseling programs who pursue licensure have embraced a counseling identity and perceive the world from the perspective of a professional counselor with an understanding of the distinctions between their chosen field and other helping professions. This unique perspective allows the professional counselor to work with the client during varying phases of his or her life, while also collaborating effectively with other professionals (e.g., doctors, nurses, and case managers) who are also supporting the client on their life's journey. Exploring the commonalities and unique features of the various helping professions interfacing with the client at end of life also provides context for this study.

**Similarities and Differences between Counseling and Other Helping Professions**

Parallel to the American Counseling Association (ACA) consensus definition of counseling, the National Association of Social Workers (NASW) has offered similar clarification regarding the role of a social worker. The NASW (2015) noted that individuals must have a minimum of a bachelor's degree from an accredited university to
obtain entry-level employment as a social worker, whereas a professional counselor must have a master’s degree to practice at any level. Entry-level opportunities in social work generally focus on case management activities, and the ability to provide therapy is reserved for master’s level social workers. Similar to professional counselors in many states, a licensed clinical social worker is required to obtain a master’s degree from an accredited university, and most accredited programs require 60 credit hours. Although the credit hours needed for licensure may be equivalent, a review of the regulations suggests that there are differences in the number of clinical hours required. As an example, the state of New Jersey requires counseling licensure candidates to have a minimum of 4,500 hours over a 3 year period (Marriage & Family Therapy Examiners, 2015), whereas applicants for a license to practice social work must obtain a minimum of 1,920 clinical hours over a 2 year period of full-time employment (State Board of Social Work Examiners, 2015). This variation in experience is significant and clearly suggests that the qualifications for licensure and practice are not equivalent while confirming the title of social worker and counselor are not interchangeable.

Although definitions of both professional counseling and social work acknowledge working with diverse populations, the counseling characterization speaks directly to empowerment, whereas the NASW alludes to a case management approach when referencing the obtainment of resources and facilitation of interactions between entities. Since counselors do not facilitate the attainment of resources (e.g., financial or medical) there is no risk that the client will fear the withdrawal of such services based on their comments, and, as a result, may be more transparent regarding their concerns
(Cheikin, 1979). These distinctions imply differences in how problems will be addressed by each profession while also suggesting both can play a role in an individual's care. Understanding how counselors collaborate with other helping professionals, exploring the challenges presented by counselors attempting to coordinate care, and how they overcome barriers were a component of this study.

Psychologists also support individuals facing end of life. The American Psychological Association (APA) has highlighted the four main roles these professionals may adopt with these clients. The APA (2005) determined that a psychologist may perform in a clinical capacity, an educational role, a researcher function, or from a position of advocacy. Haley, Larson, Kasl-Godley, Neimeyer, and Kwilosz (2003) identified four points at which a psychologist may intervene: (a) before diagnosis, (b) after diagnosis, (c) as the disease progresses and the client is experiencing the dying process, and (d) after the client’s death as a means of supporting the bereaved. This perspective correlates closely with the points on the disease trajectory in which a patient seeks counseling (Gamino & Bevins, 2013). Haley et al. (2003) noted that psychologists may be missing from the interdisciplinary teams that work with end of life clients due to their own perceptions related to their preparedness and others’ beliefs that psychologists only deal with complex issues. Psychologists who may be trained to provide services at end of life may encounter barriers to providing these services as a result of the challenges associated with Medicare and bundling of hospice services (Haley et al., 2003). Professional counselors can experience the same obstacles to offering end of life services.
The Influence of Models on Service Delivery

Counseling, particularly at the end of life, is most often compared to social work and psychology, and although the professions share a desire to assist the client, the differences between the three become most apparent when we consider how this goal is achieved. All three professions may incorporate a therapeutic component within their scope of practice; the models for doing this work will vary. Three of the most common approaches to treatment include: 1) biomedical model, 2) biopsychosocial model, and 3) a wellness or holistic model.

Biomedical model. The biomedical or disease model is purported to be the dominant model in the U.S. healthcare system (Deacon, 2013). This approach suggests that all medical conditions (including mental health disorders) are categorized as a "disease" and are biologically based, with the primary treatment involving a medical or prescription medication intervention (Deacon, 2013). This model adopts a reductionist approach in which the practitioners, usually medical doctors, which includes psychiatrists and may include some social workers working in a medical setting, look for the single cause within the individual and do not scrutinize external factors (Engel, 1981). In this model, the professional is considered the authority and responsible for identification of the cause and the treatment while the patient takes on a more passive role (Papadatou, 2009). From a biomedical approach, health is often considered the absence of disease and not focused on prevention. This model is not in alignment with the philosophy of most counseling professionals, particularly those in an end of life specialty. When working with end of life clients, a curative approach may not be germane since there are
often no viable treatment options. At end of life, treatment begins to focus on comfort and preparation for the final stage of life. Counselors may find themselves in conflict with medical professionals since the doctors may be concentrating on extending life while the client is seeking support in the elimination of treatment with a focus on quality of life. The disparate opinions between helping professionals may trigger anxiety for counselors working as part of multidisciplinary teams.

**Biopsychosocial model.** In response to the disease model, Engel (a medical doctor) proposed an alternative model that extended beyond the biological and encompassed the individual's psychosocial needs (Adler, 2009; Engel, 1981; Papadatou, 2009). In Engel’s (1981) biopsychosocial (BPS) model, the practitioner takes a systems approach in which the individual is considered at multiple levels (e.g., molecular, organ, and nervous system) and in the context of their position within an organizational hierarchy (e.g., two-person system, family, community, and society). This philosophy is a constructivist approach in which the practitioner is aware that individuals have created their meaning and reality as a result of their experiences. Proponents of the BPS model encourage an appreciation of the individual as a complex being, which in many ways is comparable to the perspective embraced by counselors. The BPS model leverages a patient-centered approach (Papadatou, 2009) and shares attributes with a wellness model.

**Wellness model.** Early iterations of the models of wellness were born out of health science and medicine, and as a result of this genesis focused on the physical (Myers & Sweeney, 2005). More recent proponents of a wellness philosophy support a holistic approach that encompasses the mind, body, and spirit, while encouraging self-
advocacy and a strengths based approach across the lifespan (Myers & Sweeney, 2008; Myers, Sweeney, & Witmer, 2000). This approach suggests the individual has the autonomy to make choices and incorporate multiple aspects of their being to fulfill their goals (Zimpfer, 1992). A wellness approach, as opposed to a pathology mindset, is a distinguishing factor of the counseling profession regardless of the specialty. When paired with the transtheoretical model (i.e., stages of change), a wellness approach has the potential to help clients implement change even when they are not facing mental health issues (Granello, 2000). The combination of a wellness model and the stages of change may prove especially useful when working with end of life clients, as the goal of the work may focus on decision-making and communication, and not a mental health diagnosis. One of the objectives of an end of life counselor is to have "sensitivity to the whole person" (Doka, 2014, p. 30), which suggests the practitioner be sensitive to the mind and spirit, as well as the body or physical manifestations of the illness.

The spirituality component of the wellness model is particularly salient for many patients facing end of life, as this facet of their being, although important to them, is not often attended to by their medical providers (Rousseau, 2000). Researchers have documented multiple instances in which religiosity and spirituality have been identified as a coping skill for people dealing with an advanced illness (Balboni et al., 2007; Koenig, 2003; Steer & Lee, 2004). Koenig, the director of the Center of Spirituality, Theology, and Health at Duke University, intimated his support of a wellness approach at end of life when he wrote, "Patients who are dying and their families need to have physical, psychological, social, and spiritual needs comprehensively addressed during
their final days of life. None of these areas should be neglected either in clinical care or in scientific research" (Koenig, 2003, p. 23).

**Advanced Illness and End of Life**

According to the National Cancer Institute (2014), more than 4,500 people in the U.S. are newly diagnosed with cancer every 24 hours. The statistics for 2015 were equally disheartening since researchers suggested a comparable or greater number of people will receive similar news during this calendar year (Siegel, Miller, & Jemal, 2015). In 2010, cancer was the leading cause of death of men and women between the ages of 40 and 79, and the second leading cause of death of women between 20 and 39 (Siegel, Ma, Zou, & Jemal, 2014). The emotional impact of a cancer diagnosis and the life changing implications are significant, making this a situation in which the interventions of a professional counselor are particularly useful.

Regardless of the condition or diagnosis, the emphasis in our country is on battling and conquering disease. This attitude means the objective is to return the body to healthy functioning through medical intervention that often places the patient in a passive role (Zimpfer, 1992), impacting the client’s sense of autonomy. Although many who are diagnosed and treated with medication and/or surgery will recover, there will always be a percentage of the population that is left to cope with the fact that there are few (if any) treatment options and that the illness will ultimately end their lives. More than 650,000 men and women between the ages of 20 and 79 years of age were projected to die from cancer or heart disease in 2015, according to 2011 mortality statistics; almost a third of this group will be younger than 60 (Siegel et al., 2015). We can only speculate as to how
individuals may respond to the possibility of premature death, but we know that some will seek counseling. Gamino and Bevins (2013) report that people will consider end of life counseling after three events: (a) development or receipt of a diagnosis of a life-limiting illness while in counseling, (b) being given a terminal diagnosis, and (c) the progression of an illness while being under hospice care.

Clients coping with an advanced illness or approaching end of life may seek services in various settings (e.g., private practice and agency settings, hospitals, and hospice). Hospice takes an interdisciplinary approach to treatment, and the care team consists of physicians, nurses, social workers, spiritual counselors, bereavement counselors, therapists and home health aides (National Hospice & Palliative Care Organization, 2013). One of the first (if not only) journal articles written to encourage professional counselors to consider a career in hospice was written more than 30 years ago and highlights the value the profession brings to the interdisciplinary team (Cheikin, 1979).

Hospice embraces a holistic approach to care, with an emphasis on "patients as persons" (Corr, 2007, p.112), meaning the individual is not identified by their diagnosis or treatment. This philosophy is in alignment with the wellness approach to counseling, making hospice an ideal setting for the end of life specialist. However, one study involving hospice programs determined that only a small number of participants would refer their patients to a counselor (Nydegger, 2008). Nydegger’s findings suggest there may be a lack of understanding regarding the capabilities of professional counselors.
For the fortunate who have access to services at this difficult time in their lives, there are counselors (and other helping professionals) who have made their careers serving this special population. According to Doka (2014), author of *Counseling Individuals with Life-Threatening Illness*,

Counselors working with families and individuals struggling with life-threatening illness need more than sensitivity - they need skills. These skills not only include an ability to work with individuals and families throughout the life cycle, but also the facility to carefully monitor their own roles and reactions while modeling effective self-care (p. 47).

Although Doka (2014) specifically noted that counselors need a level of competence to effectively work with clients dealing with an advanced illness, many individuals do not have a clear understanding of the factors that differentiate the counseling profession from other helping professions. Since counselors are likely to be a part of the cadre of professionals meeting the needs of end of life clients, exploring the nuances of the profession and the implications of the work is relevant.

**End of Life Counseling as a Specialty**

As previously mentioned, there are several counseling specialties (e.g., mental health, higher education, school, and addictions) that are well-known and the focal point of most counselor education programs. One less familiar and under studied specialty is that of end of life counseling. In this specialty, practitioners work with clients who are coping with the issues of an advanced illness and approaching end of life. Daneker (2006) noted that counselors working with the terminally ill must address the physical,
emotional, social, and spiritual needs of their clients while helping them to meet the challenges of day-to-day living.

A combination of empathy, positive regard and core counseling skills (e.g., open-ended questions, active listening, attentiveness to nonverbal, clarification of meaning, and theme identification), are necessary in end of life counseling (Doka, 2014). Although the strategies used when working with a client facing death share similarities with counseling techniques used to support clients dealing with other issues, there are also distinctions. Therapy with a dying patient requires the counselor be cognizant of: (a) communications regarding death as a possible outcome, (b) the client's feelings about the dying process, (c) the individual's grief related to what has already been lost, (d) the role of anger, (e) transference issues, and (f) the possibility of regression (Cramond, 1970). Although Cramond’s perspective was documented decades ago, similar constructs have been covered by Doka (2014) suggesting the issues related to end of life counseling have not changed considerably over the years. In addition to the areas originally documented by Cramond (1970), end of life counselors also need education related to physical health, decisions required of individuals as their diseases progress, cultural issues associated with dying and death, and a host of financial concerns (Doka, 2014; Werth, 2013). In conjunction with the tactical knowledge just discussed, counselors must explore their position on the life-death continuum, as well as their levels of death anxiety and death awareness (Manis & Bodenhorn, 2006).

Corr and Corr (2013) noted that "dying is a special situation in living; it cannot properly or fully be understood without taking account of the entirety of a person's life,
both individually and within the social systems in which that person is living” (p. 32). Since counselors take a holistic approach, Corr and Corr (2013) suggested that practitioners in the counseling profession are uniquely qualified to provide care to the dying. During the therapeutic relationship, counselors will explore the totality of the client's experience to understand the experience, minimize the individual's pain (be it physical or emotional), and enhance their quality of life (Doka, 2014).

A component of the end of life counseling process involves the completion of an assessment to determine whether mental health concerns are present (e.g., anxiety, mood disorders, and substance abuse; Rainer & Martin, 2013). The decisions being made during this life stage require careful consideration which can be severely impacted by a person's mental state or the progression of the disease (Allen, Eichorst, & Oliver, 2013; Rainer & Martin, 2013; Werth & Crow, 2009). Often, clients do not have the knowledge or confidence to engage with their care team in a way that will increase their level of understanding or preparedness for the future.

Decision making is a critical component of the end of life experience and at varying stages of the disease progression (Doka, 2014). Clients must determine to whom they wish to communicate their diagnosis, and how much detail they want to provide. They will be called upon to decide whether or not they will pursue treatment, and which of the available options are in alignment with their goals and priority of life preferences. Treatment options will not be limited to what will occur as the care team tackles the disease, but will also include a determination regarding care at the very end of life; it is often an emotional time when a client considers discontinuing treatment and the pursuit
of hospice care. The counselor is not exempt from the distress that exists when their clients make decisions that may result in an expedited death.

In addition to making decisions regarding treatment and end of life care, some clients also wish to consider physician-assisted suicide (PAS). Although some consider PAS synonymous with euthanasia, the terms are not interchangeable. The Death with Dignity National Center (n.d.) clarified that the concepts are not equivalent since the patient must self-administer the medication to meet the criteria for PAS. Euthanasia does not involve self-administration of a lethal dose of medication and is not a protected intervention under the Death with Dignity Acts.

Since assisted death or physician-assisted suicide is an option in some states, counselors could be tasked with assessing the mental competence of the client making decisions regarding end of life (Schwiebert, Myers, & Dice, 2000). A comprehensive assessment will eliminate a misinterpretation of behavioral changes that occur at end of life (e.g., conservation of energy) or as a result of medications. This evaluation is a significant component of the counseling process since the individual's mental state can influence their decision making regarding treatment and quality of life. Although diagnosable mental health disorders are uncommon in people facing end of life (Werth & Crow, 2009), it is imperative that counselors be vigilant and make no assumptions about the mental state of a client. Since clients may be experiencing fear, sadness, and grief, they do not require a clinical diagnosis to benefit from counseling interventions.

Manis and Bodenhorn (2006) conducted a useful review of the literature highlighting "the challenges faced by the professional caregivers parallel the process
experienced by the clients" (p. 198). This finding suggests that end of life counselors may find themselves in a position to consider their mortality as a result of situations that remind them of death, otherwise known as mortality cues (Grant & Wade-Benzoni, 2009). Mortality cues are defined as:

Any external stimuli that serve as a reminder of death, including, but not limited to, being in danger, being exposed to the injury/death of others, talking about death, or any other death-related stimuli (e.g., cemeteries, retirement homes, movies; Sliter, Sinclair, Yuan, & Mohr, 2014, p.3).

These cues can be personal (i.e., occurring as a result of dangerous work) or vicarious (i.e., introduced into the individual's life via the work done with others that may be in danger), and both have an impact on the clinician’s experience (Grant & Wade-Benzoni, 2009). Assuming these assessments are accurate, they offer another indication that these counselors may need additional clinical supervision. Clinical supervision may be leveraged to increase the practitioner’s level of support as they personally cope with a range of emotions, including an elevated sense of death anxiety.

Addressing sensitive subject matter. Although this work has the potential to be emotionally charged as a result of (a) the feelings stirred within the counselor, (b) the nature of the counseling session’s content, and (c) the likelihood that the counseling relationship may be truncated (Doka, 2014), focusing solely on these aspects would minimize the complexity of the specialty. In the previous section, I intentionally suggested that a unique body of knowledge pertaining to sensitive and controversial topics is required to meet the needs of a dying client.
Counselor education programs are not directed to address end of life issues in their curricula by CACREP (2016), and the ACA only alludes to the significance of the topic in the *Code of Ethics* (2014). It is, therefore, likely that end of life topics will receive minimal coverage in most graduate programs. It is anticipated that this lack of preparation could result in feelings of insecurity for practitioners as they begin to work with gravely ill clients. This dearth of specialized training is not unique to the counseling profession, as a similar insufficiency was reported in both social work and psychology (Christ & Sormanti, 2000; Haley et al., 2003). Fortunately for counseling practitioners, there is a wealth of information in the literature of other helping professions that addresses a counselor’s informational needs. The following is provided to aid the reader in developing an appreciation for the end of life subject matter and to consider the sensitivity of the issues presented to the counselor via their work.

**Hastened death.** Although euthanasia, physician-assisted suicide, and a hastened death are often used interchangeably, practitioners are responsible for using the most appropriate terms when describing a client’s desire to maintain autonomy and self-control by deciding when death from a terminal illness will occur (Kurt & Piazza, 2012). During this end of life decision-making process, counselors may be called upon to determine the mental competence of the individual and to ascertain if a client is a danger to self or others as they age or their condition deteriorates (Schiewert et al., 2000). Depending on the diagnosis (e.g., dementia) or the disease progression (e.g., cancer metastasis to the brain) the individual may experience memory loss and mood or personality changes,
triggering behaviors that could place the client and others in danger (e.g., leaving the gas stove turned on and unattended).

The Death with Dignity National Center (n.d.) makes it clear that euthanasia and physician-assisted death are two distinct constructs. Counselors supporting terminally ill clients must have knowledge of the nuances of these concepts, and reflect on their personal perspective to identify any barriers that may impede their ability to work with those who are considering a hastened death. How does a counselor resolve any conflicts that exist between their personal beliefs and the preferences of their client? To understand the complexity of this single issue, one need only consider the following question: How does a Catholic end of life counselor respond when their client is considering ending their suffering by terminating their life, and this consideration is in conflict with the counselor’s faith tradition?

Currently, there are five states (California, Colorado, Oregon, Washington, and Vermont) that have enacted "Death with Dignity" legislation, which "allow mentally competent, terminally-ill adult state residents to voluntarily request and receive a prescription medication to hasten their death" (Death with Dignity National Center, 2017). Over the past 12 months legislation was also introduced in 24 states (Death with Dignity National Center, 2017) suggesting the issue of death with dignity, which is often debated, is unlikely to disappear. End of life counselors must be aware of the status of the legislation in the state(s) where they practice. These practitioners must also consider how they will react if and when they receive the news that one of their clients has opted to end their life.
Because hastened death is a complex topic, both the ACA *Code of Ethics* (2014, Standard B.2.b) and the American Mental Health Counselors Association (AMHCA) *Code of Ethics* (2015, Standard 8.0) address some of the issues related to working with the terminally ill. Before the inclusion of the topic in the organization’s ethical code, ACA submitted a perspective on the mental health profession’s involvement in discussions regarding hastened death (Werth & Gordon, 2002). The concept of a hastened death is a knotty issue for counselors, who find they must consider whether they believe a hastened death is legal and/or moral. It is likely practitioners will be positioned on both sides of the discussion since a 2014 Gallup study determined that the general population is divided on the issue (Swift, 2014). The counselor’s religiosity may also be a factor since all religions do not approach the topic from the same perspective. As a result, several writers have documented their religion's perspective on end of life and physician-assisted suicide (e.g., Dorf, 2005; Engelhardt & Smith Itis, 2005; Firth, 2005; Keown, 2005; Sachedina, 2005) while others attempted to summarize the ways in which culture and end of life intersect (Kemp & Bhungalia, 2002). Understanding how a counselor incorporates these divergent perspectives into the work with end of life clients is of importance to the profession. An appreciation of the strategies used by these counselors can inform supervision practices, as well as the curriculum of counselor education programs.

Some clinicians may support a hastened death and maintain it allows for client autonomy or a freedom from external control or influence. Autonomy is of particular importance to clients at this time, as they often are physically dependent on others,
causing them to feel that their lives are no longer within their control (Doka, 2014). This
dependence on others as the disease progresses and the loss of control over bodily
functions (e.g., bladder control and bowel functions) can be challenging, and a factor that
has a significant influence on quality of life (Hilario, 2015). In addition, it can be
difficult for people to transition from the role of caregiver to one who is being cared for,
again causing individuals to reevaluate if this is the life they wish to lead (Mackenzie,
2014). It is during these periods of transition and evaluation that clients and their
families can benefit from the support of professional counseling.

The current medical environment has developed a greater sensitivity to the rights
and wishes of the person dealing with the illness, and the focus is no longer on the
preferences of the provider community, the family, and society. This acknowledgment of
the individual’s right to autonomy at end of life was influenced by the law (Shepherd,
2014) and is reinforced by the American Counseling Association’s (ACA) Code of Ethics
is to respect the dignity and promote the welfare of clients” (p. 4). Although many
helping professionals are in favor of patient autonomy, some counselors may feel
ambivalent as they agree with the need for autonomy but disagree with hastening death
for personal or religious reasons. Understanding how a professional counselor maneuvers
through this internal conflict reinforces the importance of exploring the experience of the
end of life counselor.

**Advanced care planning.** Advanced care planning (ACP) is an umbrella term
utilized to encompass the processes required to document and communicate an
individual's preferences for future care (Allen et al., 2013). Although ACP is accurately associated with the documentation completed by clients as they consider their future, it is a construct that is more comprehensive than mere paperwork. Current strategies for ACP include an exploration of the client's values and goals, accompanied by open communication regarding these issues with the care team and support system (Mynatt & Mowery, 2013). Many might expect that ACP conversations will take place with a doctor, but medical professionals acknowledge that this has historically not been the case, as the emotions of those involved create communication barriers (Larson & Tobin, 2000). This observation reinforces the need for end of life counseling since the counselor can help the client explore their values and build a communication plan if it is culturally appropriate. Counselors must also explore their personal biases about planning for the future as well as understand their feelings about topics included in advanced care planning discussions. How does a counselor respond when their client notifies them that they do not wish to extend their life via mechanical measures (e.g., terminating dialysis or removal or deactivation of a pacemaker defibrillator) when that decision could mean imminent death? How does a counselor bracket their negative experiences with hospice when their client is considering this as the way in which they will spend their final days?

Culture plays a significant role in end of life care and decision making, and impacts the value an individual may place on autonomy (Werth, Blevins, Toussaint, & Durham, 2002). Researchers have found that not all groups view hospice services from the same perspective, or utilize hospice, palliative care services, and other interventions in the same way or at the same rate. These differences are frequently influenced by the
individual’s culture and the culture’s historical experiences with the medical profession (Giger et al., 2006; Noah, 2012; Park, Jang, Ko, & Chiriboga, 2015). It is in these matters in which the skills of an end of life counselor can be invaluable to the client.

The documents associated with ACP direct the individual's care team and family in the event the client's health deteriorates, and the person is unable to advocate for him or herself. Counselors who are working with clients with life-limiting conditions must have a working knowledge of advanced directives, as well as Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders. The DNR is required in the event the client does not wish to be revived if his or her heart stops beating; without this order, the care team will be obligated to attempt to resuscitate the client using chest compressions and medications. Clients who have a DNI in place are providing specific direction to the care team related to their preferences related to mechanical ventilation. Decisions regarding life-sustaining measures are often fraught with emotion and clients look to their support system (including their counselor) to help them process their decisions, which usually incorporate factors pertaining to the client's religion and culture. This emotional minefield is not reserved for the client; the end of life counselor will also be tasked with processing their own emotions and the influence of their religion and culture on their perspective. Exploring the intersection of these factors on the experience of the counselor substantiates the need to learn more about the practitioners.

**Multicultural considerations.** There is no universal approach to facing an advanced illness and death. How an individual proceeds during this phase of life will be impacted by a number of factors, including the diagnosis, their physical condition, as well
as their race, culture, and religion (Doka, 2014; Kwak & Collet, 2013). As a result, counselors may be called upon to support their clients in integrating these aspects into their situation, despite a system that has expectations as to how a patient should maneuver through the health care maze.

Autonomy is a central construct in the U.S. culture, and the idea has permeated the country's healthcare system. Researchers have confirmed this perspective as they have determined that many in the medical profession believe a patient has a right to be told their diagnosis and to make decisions for themselves (Candib, 2002). Some suggest this orientation was precipitated by the passage of the Patient Self Determination Act in 1991 (Newman, Davidhizar, & Fordham, 2006). Although a desire for autonomy and control may be common attitudes, these values are not shared by all cultures (Kwak & Collet, 2013; Newman et al., 2006). As a result, end of life counselors must be sensitive to the cultural variations as they relate to these constructs so they do not inadvertently promote an agenda that is not in alignment with their client’s value.

Some cultural and religious groups believe a less direct approach to communication in medical situations is required while others question whether sharing information regarding a diagnosis is even necessary. There are cultures in which a decision to withhold information is made to ensure the celebration of life and the continuation of hope, and not an outcome of denial (Kwak & Collet, 2013). Counselors working with clients who are facing advanced illness must be sensitive to the cultural considerations that influence all of the individuals (e.g., patients, family, and the care team) involved in the client experience.
Similarly, our health care system has determined that advanced care planning is necessary, but not all cultural groups agree, resulting in cultural conflicts (Allen et al., 2013; Candib, 2002). End of life counselors must be aware of the utilization statistics that indicate Caucasians leverage these interventions more frequently than any other group (Allen et al., 2013; Kwak & Collett, 2013). Counselors must be sensitive to the distinct perspectives of the various cultures and religions if they hope to support the client in making the choices that are best for them, even though the medical system may object. Cultural differences are not limited to communication and decision-making strategies, as variations in how individuals process feelings of grief and loss also exist. Kemp and Bunghalia (2002) addressed the different approaches of several world religions; through this review it becomes apparent that end of life counselors require both awareness of and sensitivity to the customs and beliefs of various faith traditions.

**Bereavement theory.** Understandably, a client with an advanced illness who is contemplating their demise experiences a broad range of emotions. Counselors will be called upon to help these individuals process their feelings of guilt, shame, anger, jealousy, fear, and grief (Doka, 2014). Clients are likely to experience forms of grief throughout their end of life journey. End of life counselors are prepared to help their clients process grief, which some have further delineated as anticipatory grief. Anticipatory grief refers to the emotions associated with a loss before it occurs (Feifel, 1977), and has been debated in the literature (Sweeting & Gilhooly, 1990). More recently this construct has been reframed as *anticipatory mourning*, creating room for individuals who experience feelings of loss after changes in their level of functioning as
their condition progresses; however, this labeling is also not universally accepted (Fulton, 2003). Despite the discussion regarding the labeling of grief, mastering the concepts allows counselors to conceptualize their client’s emotional state, allowing for the possibility of more comprehensive treatment. In addition, they must consider how grief and mourning apply to their personal experiences as an end of life counselor. How do they experience grief as they witness the deaths of their clients?

Although end of life counselors may utilize bereavement theory in their counseling practice, the role is not synonymous with grief counseling. Grief and bereavement counselors focus their energies on aiding clients as they process a loss. Counselors working with end of life clients may assist their clients in this manner, but it is not the focal point of the role. Despite the fact that grief may not be the entirety of the work, end of life clinicians must consider the theoretical constructs of death, dying, and bereavement, which in addition to Kubler-Ross’s seminal theory include the living-dying interval, task-based approach, and readiness to die theory (Copp, 1998).

There are multiple models to consider when doing grief work with clients facing an advanced illness and death. Minimally, practitioners must understand the five stages of death and dying as introduced by Kubler-Ross (1969) and the more recent comprehensive task models (Samson & Siam, 2008). Despite the criticisms levied against Kubler-Ross’s model by Corr (1993) there is value in understanding her perspective of the five stages (i.e., denial, anger, bargaining, depression, and acceptance) as it is a perspective often adopted by clients. Although some practitioners may disagree with the use of stages as they suggest a linear approach, some clients may determine the model does represent
what they are experiencing. As a result, it must be understood by the clinician, even if the counselor does not agree. Kubler-Ross may not have provided empirical substantiation for her approach, but it continues to be utilized in the lay literature (Doka, 2014) making it a required component of the end of life counselor’s repertoire. Interestingly, Ober, Granello, and Wheaton (2012) determined that counselors were still most familiar with the stage model.

Additional ideas that warrant consideration as a clinician works with clients at end of life are the concepts of coping and adaptation. These concepts were debated by Corr (a proponent of coping as the guiding principle) and Doka (an advocate for adaptive strategies) and identified by them as "master concepts in the field of death, dying and bereavement" (Corr & Doka, 2001, p.1). To some readers, the debate may appear to be an argument over semantics, but a deeper exploration of the constructs would suggest that the counselor's preferred concept will ultimately influence the clinician's practice. Personal preferences not only influence practice but may also play a role in ethical dilemmas. Although ethical issues were alluded to earlier, the following section will expand on some of the ideas.

**Ethical considerations.** Helping professionals, including counselors, may be faced with a host of distinct ethical challenges when working with a client coping with an advanced illness. These considerations are unique and influenced by context. For example, a counselor working in private practice may not routinely consider the boundaries of confidentiality because they typically work with clients in the privacy of an office. In comparison, an end of life professional may find the issues related to
confidentiality to be problematic as they could be meeting with clients in less private settings (e.g., home, hospital, and hospice). In this instance, the context can create a dilemma for the practitioner: how much should be discussed and when do the needs of the client supersede the practitioner’s ethical responsibility to facilitate discussions in private settings?

As previously mentioned some of the presenting dilemmas are influenced by the personal beliefs and values of the counselor. As a result, a counselor must be versed in end of life issues and be self-aware. The ACA Code of Ethics (2014) Standard A.4.b. Personal Values offers specific direction as to how a counselor must manage the integration of their personal values in their practice:

Counselors are aware of—and avoid imposing—their own values, attitudes, beliefs, and behaviors. Counselors respect the diversity of clients, trainees, and research participants and seek training in areas in which they are at risk of imposing their values onto clients, especially when the counselor’s values are inconsistent with the client’s goals or are discriminatory in nature (p. 5).

Professional counselors must consider their perspective on a multitude of issues (e.g., PAS, the client’s right to know, decisions to forego treatment as a patient awaits divine intervention) while also identifying the method to be used when faced with an ethical dilemma. Since researchers have suggested there is a negative correlation between the level of support for PAS and religiosity, in many cases those who consider themselves to be more religious are less in favor of PAS (Bevacque & Robinson Kurpius, 2013). Counselors working with dying patients must be aware of these ideologies, as
well as their own perspectives on these issues. How will a counselor maneuver through a situation when their perspective differs significantly from that of their client? This unanswered question is one of the many unknowns that underscore the value of understanding the experiences of the end of life counselor.

The ACA via the Code of Ethics (2014) noted there is not a single approach to resolving an ethical dilemma, but the organization does state specifically that action must be taken:

When counselors are faced with ethical dilemmas that are difficult to resolve, they are expected to engage in a carefully considered ethical decision-making process, consulting available resources as needed. Counselors acknowledge that resolving ethical issues is a process; ethical reasoning includes consideration of professional values, professional ethical principles, and ethical standards (p. 3). Understanding how, when, or if, a counselor incorporates the various ethical codes or their personal values into their work with end of life clients is currently unknown.

**Learning from Other Helping Professions**

The literature addressing end of life counseling and associated issues is sparse. Without research specific to the counseling field, we are forced to draw conclusions from other occupations, while acknowledging that any assumptions may be inaccurate. The following examination of the literature highlights some of the challenges faced by medical professionals, social workers, and psychologists who work with those who are dying. A review of the trauma literature will also be presented, as the ramifications experienced by trauma professionals may offer additional insight.
Medical Professionals

Medical professionals, particularly nurses, are frequently studied as they interact with patients at varying stages of the disease trajectory. The feedback from the medical profession and associated research shows there are those who find working with end of life patients meaningful (Dearmond, 2012; Dunn et al., 2005; Melvin, 2012; Sinclair, 2011) while acknowledging there are challenges and concerns with stress and compassion fatigue (Kearney, Weininger, Vachon, Harrison, & Mount, 2009; Melvin, 2012; Whitebird et al., 2013; Yoder, 2010). These variations in the research confirm that the experiences will vary by individual and are impacted by multiple factors, including personal history and personality (Dearmond, 2012). In the Dearmond (2012) study, the themes identified were mostly positive and centered on growth, whether it was personal, spiritual, or both.

Yoder's (2010) qualitative study identified compassion fatigue as an area of concern for nurses and determined this response was generally triggered in three situations. Compassion fatigue (considered a precursor to burnout) was most often initiated when: (a) nurses cared for patients weathering serious threats to their emotional, physical, or financial situation or imminent death; (b) system issues (e.g., workload, long hours) presented themselves; and (c) personal issues impacted their work situation. Melvin (2012) added to our understanding by determining that those without adequate coping mechanisms were more likely to develop compassion fatigue. Based on the documented experiences of various medical professionals encountering compassion
fatigue, it would be reasonable to question the frequency with which this construct also impacts counselors who work with those who are dying.

A review of the counseling literature did not uncover works regarding compassion fatigue as a result of end of life counseling, but there is literature on a related construct identified as *empathy fatigue* (Stebnicki, 2007). Stebnicki (2007) noted that although compassion and empathy are often used interchangeably, these identifiers are not synonymous. According to Stebnicki (2007), compassion has been described as a feeling experienced by most people, which does not necessarily require training to draw out, whereas accurate empathy is a therapeutic skill that can be taught. Empathy communicates a level of understanding that can exist whether or not an individual is experiencing compassion, and offers the client the opportunity for growth. Empathy fatigue is reported to impact those who are able to experience the pain of clients as they share their narratives associated with grief, depression, and loss. Stebnicki (2007) also suggested that counselor empathy fatigue creates barriers to personal growth while simultaneously placing the counselor at risk of impairment, and this impairment puts them at risk of violating the ACA *Code of Ethics*.

Bailey, Murphy, and Porock (2011) determined that not all nurses were able to invest themselves into the relationship with their patients at the level needed because of their feelings about death and dying, and a concern that they would make mistakes in their words or actions. Bailey et al. (2011) also confirmed the value of self-awareness as it relates to emotional intelligence (EQ), while purporting there is not always a correlation between years of experience and the level of emotional maturity.
Additionally, researchers have also documented that beginning counselors with higher levels of death fear have a greater level of distress when working with clients facing life-threatening cancer (Kirchberg, Niemeyer, & James, 1998). These gaps suggest that self-awareness and death anxiety may be factors in the efficacy of the work of nurses and end of life counselors.

Although the support provided by professional counselors and nurses is distinct, the risks associated with the work are shared. Both nurses and counselors working with those who are dying must have the emotional stamina and skills to engage in conversations, while acknowledging the toll that those conversations may be taking on their quality of life. Nurses and counselors must be prepared for the raw emotion that may surface after a person is told that they are dying. Helping professionals who have supported someone in their personal lives as they maneuver through a similar experience may find it less challenging to discuss death. One finding also noted in the nursing literature was that individuals who had experienced loss were at an advantage because death had been "acknowledged, normalized and integrated into the continuum of life" (Sinclair, 2011, p. 182). Researchers speculated that nurses must develop EQ to provide care and to cope (Bailey et al., 2011), and one can conclude that this will also be required of the end of life counselor.

Palliative care is a holistic approach to working with individuals who are dealing with an advanced illness, and it is an alternative to a biomedical model. Three of the primary distinctions between a palliative model and the traditional means of treatment include: (a) an acceptance of death as a part of life, (b) an active engagement of the
person who is ill, and (c) the encouragement of the care provider to foster a relationship with the dying client (Papadatou, 2009). Palliative care professionals working with end of life clients have reported varying levels of burnout as a result of extreme physical and emotional fatigue (Pereira, Fonseca, & Carvalho, 2011). Factors contributing to the burnout of palliative care staff can be related to a low level of confidence in one's ability to communicate painful news to patients, limited treatment options, the tasks associated with the job, as well as concerns about the patient's financial security.

**Other Helping Professionals**

Like medical professionals, social workers who assist people at the end of life experience emotional difficulties due to the number of deaths they witness and the work they do with the bereaved families. Chow (2013) noted that the impact of working with the dying can result in both traumatization and grief while suggesting that hearing the stories of those who are dying may lead to secondary traumatization of social workers. Although there is literature that highlights the implications for social workers, we cannot assume the outcome will be the same for counselors, so specifically exploring the implications for counselors is needed. Because the interventions and methods used to support an end of life client may vary by profession, understanding the experience of the end of life counselor will identify similarities and differences among the professions.

There has been some discussion in the literature as to whether working with human-induced trauma (e.g., sexual abuse) puts practitioners at a greater risk for vicarious trauma as compared to those supporting individuals coping with naturally caused trauma (Cunningham, 2003). Cunningham (2003) determined that social workers
were at greater risk when facing human-induced scenarios and that there was a negative relationship between working with cancer patients and one's safety concerns. Cunningham’s (2003) findings regarding the negative correlation were contrary to earlier studies that suggested that an individual's thoughts regarding their mortality and concerns about the possibility of loss of others were elevated when practitioners (e.g., nurses and social workers) worked with critically ill patients (Ayyad, 2013).

Social workers who practice in hospice (and in other scenarios where their clients are dying) are bombarded with a steady stream of mortality cues that elevate one's death awareness. According to Grant and Wade-Bezoni’s (2009) typology of mortality cues, these instances can be considered chronic (i.e., recurrent and lasting) or acute (i.e., short-lived and/or intermittent). These cues (e.g., dealing with the injured, sick, and dying) in combination with the individual's level of death anxiety have been shown to impact burnout and engagement (Sliter et al., 2014). However, social workers who had personal experiences with death (e.g., loss of a parent or grandparent) felt more prepared to provide services as they had an understanding of the emotional ramifications of death and were more aware of the available resources (Huff, Weisenfluh, Murphy, & Black, 2006). While the literature suggests that some social workers face burnout and compassion fatigue when they work with dying clients, other researchers have found that many experience the specialty as gratifying and an impetus for self-reflection, change, and spiritual growth (Dearmond, 2012).

Social workers are prevalent in hospice, meaning they work with patients at the very end of life. However, it appears their level of training may not adequately prepare
them for this experience. Huff et al. (2006) found that only 5% of their 189 social work student participants had taken a full class in death education, and none of that cross section felt confident in their abilities to work with dying individuals during their field placement. Huff et al.’s (2006) findings are similar to those from an earlier study by Azar (1997) in which 76% of the 50 social work graduate students polled reported they did not feel prepared to work with terminally ill patients and that they were interested in taking a course on death and dying. This raises the question of how prepared do end of life counselors feel to work with this population?

The psychology profession can play an important clinical role. As previously noted, Haley et al. (2003) identified four points during the disease progression where a psychologist could intervene. It is at these same points (e.g., before diagnosis, after diagnosis, during the dying process, and after death) that counselors may also engage. The role of the psychologist is different from that of the nurses and social worker, as those professions may provide more tactical support such as identification of resources, completion of paperwork (e.g., advanced directives), and pain management. Interestingly, these differentiations can also be applied to the end of life counselor.

The role of a psychologist may be most salient immediately after diagnosis as it is often a period filled with uncertainty and rampant emotions. There are also many psychosocial issues presented as the disease progresses both for the family and the client themselves. According to Haley et al. (2003), there are few post-doctoral training options available to prepare psychologists to work in hospice and palliative care. This fact is also true for professional counselors; hospice placements are often reserved for social
workers. As a result, psychologists faced with end of life patients are forced to repurpose their existing skills and may find themselves using outdated models for coping with grief and loss. The lack of ongoing education pertaining to end of life, death, and grief is not unique to psychologists. This educational void is also a barrier that counselors working with this population may face, as few continuing education opportunities exist that are geared toward this specialty.

Psychologists are not exempt from compassion fatigue, but it is often masked by "the conspiracy of silence among the profession" (Figley, 2002, p. 1440). According to Figley (2002), both compassion and empathy draw down the therapist's energy and come at a cost. Ongoing interaction with those who are suffering can take an emotional and physical toll causing many practitioners to leave their practices for positions with less contact. Self-care is imperative if one hopes to mitigate compassion fatigue. Ongoing work with a population that is facing death requires both an awareness of the risks and a plan to address compassion fatigue as a means of preventing burnout and maintaining compassion satisfaction (Ray, Wong, White, & Heaslip, 2013). The identified self-care strategies and heightened awareness will also help the individual mitigate the risks of empathy fatigue. The psychologist, and one can also assume the counselor, must consider how compassion fatigue could negatively impact ego functions leading to an increase in countertransference and a decreased ability to manage countertransference (Hummel, 2013).

Psychologists, and similarly counselors, are not exempt from experiencing professional and personal losses. Kouriatis and Brown (2014) were interested in
understanding how the loss experience and their ability to cope impacted their practice. Their phenomenological study confirmed that, at least for some, a therapist’s losses do impact their practice in both positive and negative ways. Interestingly the therapists felt that they had to monitor their behaviors to ensure that they did not over-identify with or control their clients (Kouriatis & Brown, 2014). The participating psychologists were mindful that “their fragile psychological state at times posed a challenge in their therapeutic work” (Kouriatis & Brown, 2014, p. 100). Interestingly, as a result of their experienced losses, some of those interviewed felt their competence improved. These experiences suggest that counselors dealing with loss through their work may encounter similar feelings and implications to their practices.

Another group of professionals that may shed light on the experiences of end of life counselors is those practitioners who focus on trauma and crisis situations. Professionals who focus on clients coping with trauma (e.g., counselors working with victims of sexual assault or violent crimes) or crisis (e.g., disaster response teams) experience emotionally charged situations during the course of their work. What makes these situations so difficult is the fact that the professional, in an effort to relieve a client’s suffering, may actually internalize the pain of their clients (Figley, 1995). As a result of the repeated exposure to another individual’s hardship and suffering through detailed descriptions, professional caregivers in these situations are susceptible to compassion fatigue and burnout (Figley, 1995; Quitangon & Evces, 2015). This suggests that the end of life counselor may be at risk as they listen to their clients’ narratives related to their illness and impending death.
Secondary or vicarious trauma is an unintended consequence of trauma work, and those who are less experienced or have a personal trauma history may be at greater risk of the negative outcomes due to repeat exposure (Pearlman & Mac Ian, 1995; Quitangon, St. Cyr, & Nelson, 2015). However, the perspective that personal history increases risk is not unanimous. Elwood, Mott, Lohr, and Galovski (2011) found as they reviewed the literature that researchers were divided as to the significance of a personal trauma history as it relates to one’s risk of impairment. When one considers the complications potentially presented by a practitioner’s personal history, this suggests an end of life counselor may experience more difficulties when they have been personally impacted by an advanced illness or the death of a loved one.

**Implications for Helping Professionals Working with Clients Facing Death**

Having considered from a broad perspective the impact of end of life work on other helping professionals, it is now necessary to explore in more depth the hazards and benefits experienced by these practitioners. Exploring the risks and rewards of working with the dying, as well as the implications of supporting clients dealing with trauma, will provide insight into the potential impact of end of life counseling. Earlier these constructs were introduced, and at this point, they will be explored in more depth.

**Countertransference.** Mental health practitioners have been considering the concept of countertransference since Freud labeled the construct in the late 1950s. Originally, countertransference was perceived as a negative process, but over time, it has become accepted as an expected component of a therapeutic relationship (Katz & Johnson, 2006). Wedding and Corsini (2014) noted that countertransference is:
Traditionally defined as the activation of unconscious wishes and fantasies on the part of the therapist toward the patient. It can either be elicited by and indicative of the patient’s projections or come from the therapist’s tendency to respond to patients as though they are significant others in the life, history or fantasy of the therapist (p. 607).

It is not unusual for practitioners to experience this phenomenon, and the possibility is omnipresent in end of life care since it is a common response to suffering (Katz & Johnson, 2006). When professionals assist clients who are addressing issues associated with their own mortality, the caregiver is reminded of the losses they have experienced and the inevitability of their own passing (Doka, 2014). If not dealt with appropriately and leveraged effectively, countertransference may reveal itself in the professional’s practice though feelings of powerlessness, frustration, sadness, anxiety, and exposure of the practitioner’s death anxiety (Arbore, Katz, & Johnson, 2006; Evces, 2015).

**Vicarious trauma.** McCann and Pearlman (1990) introduced the construct of vicarious trauma, which they described as "the profound psychological impact of working with trauma victims" (p. 143). This definition suggests that helpers who repeatedly hear very difficult stories through their work as therapists may begin to experience alterations to their self-perceptions, perceptions of others, and their world view (McCann & Pearlman 1990; Quitangon & Evces, 2015). Counselors working with patients at end of life will hear about client difficulties, and this ongoing exposure may increase the possibility that these specialists may experience vicarious trauma.
The effects of empathic engagement are cumulative, and some who are coping with vicarious trauma will experience intrusive thoughts while also developing fear, trust issues, and a desire to separate themselves from their clients (Quitangon & Evces, 2015). The ACA (2011a) also noted several behavioral changes that may be observed in individuals impacted by vicarious trauma: (a) extreme fatigue, (b) avoidance of intimacy, (c) negative work habits (e.g., absenteeism and tardiness), and (d) emotional changes (e.g., increased irritability and anger). Due to the lack of research pertaining to the experiences of counselors working with dying patients, the prevalence of these behaviors due to vicarious trauma is unknown.

**Vicarious resilience.** Therapists and trauma workers experience vicarious outcomes based on their interactions with clients. Although vicarious trauma has been covered in the literature for decades, vicarious resilience was introduced into the discussion within the last ten years (Hernandez, Gangsei, & Engstrom, 2007). Luthar and Cicchetti (2000) define resilience as “a dynamic process wherein individuals display positive adaptation despite experiences of significant adversity or trauma” (p. 856). Vicarious resilience refers to a positive transformation that occurs within the counselor in response to their client's resiliency (Hernandez et al., 2007). The practitioners experiencing vicarious resilience report a renewed sense of hope, growth, a reevaluation of their own challenges, and an elevated level of frustration tolerance, suggesting a positive change to their inner experience (Hernandez et al., 2007; Hernandez, Engstrom, & Gangsei, 2010). The vicarious learning that occurs when counselors work with clients
who have overcome challenges can then be applied in the counselors' lives during periods of crisis.

**Grief.** Grief is considered an expected response to a loss and in most cases is perceived as normal and healthy. Grief may be triggered by the death of a client, but it can also be triggered by the loss of the relationship with the individual who died, the inability to fulfill the professional goals set for treatment, the uncovering of unresolved personal losses or an increased sensitivity to one’s own mortality (Papadatou, 2009). This suggests the source of grief may not be easily identified by the practitioner and, as a result, processing the grief can become problematic. In addition, there are instances in which individuals are not offered the opportunity to openly express their feelings of loss because the relationship is not known (e.g., therapist), the loss is not acknowledged (e.g., death after a long illness), or the loss is not valued (e.g., very elder). In these situations, when an individual’s loss is not acknowledged by the self or others, it is conceivable they may be facing disenfranchised grief (Doka, n.d.). Since counselors may not be in a situation in which they can openly mourn the loss of their clients, and as a result are in a position where they lack social support, they may experience this form of grief. Romesberg (2004) has determined that disenfranchised grief can lead to compassion fatigue and burnout.

**Compassion fatigue.** Secondary traumatic stress, or compassion fatigue, is the behavioral or emotional consequence of assisting (or hoping to assist) another individual who has been traumatized or is in pain (Figley, 1995; Figley, 1999). This preoccupation with assisting those in need is observable in practitioners in various helping professions
and has been linked to a lack of self-care (Figley, 2002). According to Figley (1995), compassion fatigue is the price helping professionals pay for their empathy and kindness.

Helping others, particularly those who have a history of trauma, takes an emotional toll on many caregivers, but some practitioners are more susceptible to the deleterious effects of the work. The results of Thompson, Amatea, and Thompson's (2014) quantitative study involving more than 200 practitioners suggest that mental health counselors with fewer years of experience, minimal coping strategies, and limited mindfulness techniques were most likely to experience compassion fatigue. Thompson et al. (2014) did not report the participants’ specialties, so it is plausible that the practitioners were serving a variety of populations, and may have included counselors working with clients coping with a life-limiting illness. Other researchers determined that mental health care professionals with a personal history of trauma may need additional support to minimize their risk of compassion fatigue as they may have the propensity to over-identify with their clients (Ray et al., 2013). The possibility of overidentification could be an issue for end of life counselors when they (or someone they love) are also diagnosed with an advanced illness, as the counselor is actively working with patients who are dying. Compassion fatigue and burnout are often considered synonyms when describing an individual’s response to chronic emotional and interpersonal stress; however, there are distinctions between the two constructs.

**Burnout.** Job burnout, which is triggered by an array of events, including compassion fatigue, has been identified as an area of concern across multiple settings, while being examined from multiple perspectives in various arenas, including palliative
care (Pereira & Fonseca, 2011; Pereira et al., 2011), hospice (Whitebird et al., 2013), nursing (Medland, Howard-Ruben, & Whitaker, 2004; Yoder, 2010), and mental health professionals including counseling (Killian, 2008; Lee, Cho, Kissinger, & Ogle, 2010; Osborn, 2004; Ray et al., 2013; Sadler-Gerhardt & Stevenson, 2012). Maslach (2003) specifically noted in her writings pertaining to burnout that “for many individuals contact with someone who is dying (particularly when it is a child) is most difficult of all” (p. 44). Participants in a more recent study confirmed that working with chronically ill patients was a triggering event (Yoder, 2010). These findings suggest that, although all helping professionals are susceptible to burnout, individuals who care for the dying may be at a higher risk.

Helping professionals often perceive that individuals (i.e., clients or ourselves) are the cause of burnout when, in fact, it is the situation that is the catalyst. In the context of end of life counseling, it would not be the clients that are the trigger, but the continuous exposure to the details of their situations, often with little possibility for improvement, that tax the practitioner. Job burnout is a defense mechanism utilized by individuals who are working in fields that are emotionally draining with insufficient support (Jenkins & Baird, 2002). Burnout has also been explained as an outcome of the cumulative effect or a process that develops over time when one begins to feel ineffectual (Figley, 1995; Papadatou, 2009).

Researchers have determined that there are typically three elements that are predominant in individuals coping with burnout: (a) emotional exhaustion, (b) divesting oneself from the work or situation (i.e., depersonalization), and (c) feelings of inadequacy
(Maslach, 2003; Maslach, Schaufeli, & Leiter, 2001). Lee et al. (2010) identified a similar typology in counselors noting that clinicians with favorable opinions of their employment and a positive self-regard were likely to have the lowest risk of burnout. Although emotional fatigue is a primary indicator of burnout, one cannot overlook the physical exhaustion that may accompany burnout that ultimately impacts both psychological and physical wellbeing (Maslach, 2003). The presence of burnout often results in highly skilled helping professionals reporting turnover intentions (Leiter & Maslach, 2009; Tziner, Rabenu, Radomski, & Belkin, 2015). The negativity associated with burnout is not reserved for the work setting, as it also has the potential to carry over into the individual's personal life (Lee et al., 2010; Medland et al., 2004).

**Death distress.** Despite death’s inevitability, many experience negative emotions when they consider the topic, and the degree of an individual’s discomfort can impact their work with those who are dying (Neimeyer, Wittkowski, & Moser, 2004). A level of discomfort was also observed in neophyte counselors when faced with issues related to clients dealing with a serious illness (Kirchberg et al., 1998). This suggests that counselors working with end of life issues have found ways to overcome feelings of distress, or they did experience these negative emotions from the onset of their work. An understanding of how (or if) counselors are experiencing death distress when working with those who are dying will shed light on the death attitudes of these professionals. The concept of death distress encompasses a number of related constructs including death awareness, death obsession, and death anxiety.
As mentioned earlier, individuals who work with the terminally ill are frequently faced with mortality cues (Grant & Wade-Benzoni, 2009). These cues in combination with the individual's level of death anxiety impact the person’s quality of life. Despite the potential risks to their own quality of life, some professionals expose themselves to dying and death in the workplace. According to Sinick (1976), "Counselors must first make peace with themselves regarding the prospect of their own death. When they deeply realize that the prospect is not a probability but a certainty, they can begin to accept death in others" (p.123). Thus, it may be easier to work with those who are dying when you face the inevitability of one’s own death.

The level of death anxiety experienced by an individual has implications on many levels. The practitioner-client interactions are influenced, and the clinician’s degree of comfort in speaking about end of life issues is impacted. Death anxiety levels have also been found to predict the theoretical approach selected by counselors in training (Belviso & Gaubatz, 2013). Belviso and Gaubatz (2013) determined that an individual with a higher death anxiety is more likely to select an objective orientation (e.g., cognitive behavioral theory) over a more subjective approach (e.g., existentialism). This theory selection ultimately influences the way in which care is delivered and could impact treatment outcomes.

**Coping and Adaptive Strategies Used by End of Life Helping Professionals**

Corr and Doka (2001) have debated the distinctions between coping and adaptive strategies. In the literature, there is no consensus as to how one can categorize the ways in which people handle death, dying, and bereavement. Whether the responses are
classified as coping mechanisms or adaptive strategies, the concepts apply to the clients and families of those who are dying, and also to the people responsible for their care. Despite a lack of agreeing on coping and adaption, Corr and Doka (2001) are united in their interpretation of the distinction between the terms reaction and response. In their analysis, a reaction is a behavior that could be considered spontaneous, whereas a response connotes an effort to manage a situation. Although the following techniques used by practitioners could be categorized as either coping mechanism or adaptive strategies, all would be more accurately labeled as a response, while many could also be used proactively to prevent compassion fatigue, burnout, vicarious trauma, and countertransference. The following qualify as a response since each can become a conscious choice for dealing with difficulties after being incorporated into a professional’s toolbox. Utilizing these strategies before an issue becomes chronic minimizes the risks to both the client and the clinician. There is a gap in the literature regarding the integration of these techniques by end of life counselors, so until researchers begin to explore these topics, making any assumptions about the application is conjecture.

**Self-care**

Although self-care is frequently recommended to clients and practitioners as a means of maneuvering difficult times, there is no standard definition used to conceptualize the construct. The elucidation put forth by Richards, Campenni, and Muse-Burke (2010) encompasses attributes in alignment with the wellness approach leveraged in counseling: “Self-care refers to any activity that one does to feel good about
oneself. It can be categorized into four groups that include: physical, psychological, spiritual and support" (p. 252). Self-care has been identified as an important strategy for coping with the challenges faced by those working with trauma clients and those who are dying. Kearney et al. (2009) noted that self-care strategies can be classified as those which require self-awareness, and those that do not. The authors reported that both approaches are effective, but individuals who practice strategies based on self-awareness are more likely to experience a stronger connection to the work and have reduced stress. Techniques useful in developing self-awareness include mindfulness practices and reflective writing (Kearney et al., 2009). Doctors are also being trained in narrative medicine, which allows them to hear and reflect on the meaning of their patients’ stories and how they as the physicians are impacted by these stories. Charon (2001) wrote: “Reflective practitioners can identify and interpret their own emotional responses to patients, can make sense of their own life journeys, and so can grant what is called for—and called forth—in facing sick and dying patients” (p. 1899). Although Charon was referencing medical doctors in his statement, it could also be applied to the counselor working with clients who are dying.

Mindfulness strategies are used across disciplines as a means of centering the self and reducing stress. Kabat-Zinn (2003) defined mindfulness as “the awareness that emerges through paying attention on purpose, in the present moment, and nonjudgmentally to the unfolding experience moment by moment” (p. 145). Mindfulness practices can be guided or self-directed allowing the individual flexibility as to how and when to utilize this intervention. The efficacy of mindfulness practices in therapy has
been addressed in the literature (Brown, Marquis, & Guiffrida, 2013) suggesting the practice also has a role in the practitioner’s self-care repertoire. Kearney et al. (2009) noted that mindfulness practices were instrumental in improving the self-awareness of physicians working with end of life clients. Thompson et al. (2014) also documented that mindfulness attitudes of counselors had a favorable impact on both compassion fatigue and burnout. Since physicians working with clients at end of life and counselors have both reported benefits associated with mindfulness practices, it is reasonable to conclude that end of life counselors would also benefit from these strategies. However, researchers have not explored the use of mindfulness practices as a self-care strategy for end of life counselors.

Pearlman (1999) also suggested self-care is essential to the well-being of practitioners. She reported the results of a study in which 117 psychologists ranked 24 activities used to maintain self-care. Three of the top five strategies (e.g., social events, encouragement from co-workers and other practitioners, and consultation) involved some type of interaction with others. This reinforces the importance of social support in maintaining wellbeing. Another study reviewed by Pearlman (1999) suggested similar strategies used by those doing trauma work. The trauma workers found consultation with co-workers to be most helpful. There is no research suggesting end of life counselors leverage the same methods as preventative strategies or as a means of coping, but the present study provides that missing perspective.

**Managed case load.** One of the factors that increase the risk of compassion fatigue and burnout, with a strong influence on feelings of exhaustion, is an excessive
workload (Maslach et al., 2001; Thomas, Kohli & Choi, 2014). What constitutes "excessive" is unique to the individual but monitoring the number of cases with a high degree of emotional stress has proven helpful for some in mitigating the risk. With this in mind, one coping strategy used by some helping professionals is managing their caseloads to ensure a balance exists and that a long work week is not required (Killian, 2008). Those working in trauma have also experienced reductions in secondary stress by incorporating cases that did not have a trauma component and using a portion of their work week addressing non-clinical activities (e.g., research; Chrestman, 1999). Although these options may be ideal, it can prove problematic for those whose primary practice is with a specialty population (e.g., trauma victims) that presents few options for diversification. Cunningham (2003) determined that practitioners working with clients who were sexually abused or clients with cancer were impacted by the work when 40% of the caseload consisted of one of these populations. To minimize the risk and improve self-care, it has also been suggested that practitioners minimize their on-call availability and maintain boundaries (Maslach, 2003). Although these self-care strategies are utilized by a variety of helping professions, researchers have not explored how, or if, end of life counselors incorporate similar practices.

**Relationships**

The importance of relationships and a strong support system should not be overlooked as one reflects on the coping strategies used by counselors. These relationships can take many forms (e.g., companionship of co-workers, support groups, and supervision) and each serves a distinct purpose. Stebnicki (2007) reinforced the
importance of “connections” (p. 334) and encouraged counselors to not only leverage personal relationships but also to take advantage of professional associations as a means of seeking additional options for self-care.

Social support in the workplace. One of the temptations associated with negative feelings, overload, and burnout is to isolate. Although the urge exists to sequester oneself in solitude as a protective mechanism, it is not always the most beneficial approach. Connection with peers who can acknowledge, empathize, normalize, and provide a reprieve has been proven to have a positive impact on burnout (Maslach, 2003). An extensive study of hospice workers (n=931) highlighted the importance of social support for individuals engaging in the demanding work of hospice (Whitebird et al., 2013). Whitebird and colleagues reported that hospice workers placed a high value on interacting with colleagues and opportunities to engage in support groups related directly to their experiences, as a means of maintaining mental health. This perspective was reinforced by Medland et al. (2004) as they reviewed the benefits created by improving the social support in an oncology unit by fostering an environment in which the staff could acknowledge the feelings (e.g., grief and stress) associated with their work in safe and supportive places with their colleagues. Tempesta (2003) also determined that social support for a group of nurses working in hospice made the work experience less stressful. This suggests end of life counselors may reap the benefits of social support in the workplace.

Individual therapy. It is often recommended that helping professionals maintain a therapeutic relationship with another practitioner, as it promotes self-awareness through
the identification of personal beliefs and biases. Researchers have documented the value of required mental health counseling for students in counseling graduate programs, even when psychopathology was not present, noting an increase in self-awareness, improvement in negative feelings, an appreciation for the client experience and the counseling process (Oden, Miner-Holden, & Balkin, 2009; Prosek, Holm, & Daly, 2013). One could assume if there are benefits to a counseling relationship for students, more seasoned practitioners will benefit as well. Quitango and Evces (2015) specifically recommend personal therapy as an option for mental health professionals working with disaster victims as a method of self-care when coping mechanisms are inadequate. Katz (2006) also recommended individual therapy when end of life practitioners’ self-healing strategies for coping with countertransference prove ineffectual.

Clinical supervision. It has also been noted that practitioners need a venue to express themselves as a means of coping. Clinical supervision, which is distinguished from teaching and administrative supervision, often provides the counselor with this opportunity. Although there is no single definition of clinical supervision, Bernard and Goodyear (2014) suggested the presence of the following attributes: (a) supervisor and supervisee are generally from the same profession, but this is not an absolute; (b) there is a hierarchical relationship that exists because there is an aspect of the relationship that involves evaluation, since the supervisor is responsible for gatekeeping and the wellbeing of the client; and (c) the relationship spans a course of time. In some instances this outlet is also the practitioner’s immediate supervisor which some consider to be problematic (Grosch & Olsen, 1995; Melvin, 2012) as it may be difficult to be transparent with the
person who has the power to terminate your employment. Melvin (2012) indicated "there is an inherent dichotomy between providing emotional support and subsequent evaluation" (p. 610) suggesting it may be more appropriate to secure a third party to serve as a sounding board. This point causes one to ask how this would apply in a counseling arena and what challenges may exist when subordinates address compassion fatigue with their supervisors.

Pappadatou (2009) specifically stated that the key task of a supervisor working with end of life practitioners is to:

Help team members provide quality care by focusing on (1) the service they provide and the relationships they develop with the dying and bereaved, (2) their collaboration with others and other professionals or teams, and (3) the impact of caregiving upon themselves and the team (p. 278)

Without a support system that encourages practitioners to reflect on the impact of their work on their own quality of life, this facet of the experience could easily be overlooked. It must be noted that there is no single method used for supervision, and supervision is most useful when the supervisor does not attempt to impose their beliefs on the supervisee.

Clinical supervision can take a variety of forms, and it need not be limited to one-on-one interactions between the practitioner and a supervisor. Catheral (1999) highlighted the value of peer supervision and the benefits of professional peer groups for individuals dealing with secondary trauma. Peer groups can provide support by (a) intervening to help with some aspects of the work (e.g., being on-call during non-
business hours), (b) creating an environment in which the individual can express themselves and feel heard, and (c) providing perspective (Catheral, 1999).

**Chapter Summary**

The counseling profession consists of several specialties and in most cases counselor education programs have structured the curriculum to meet the needs of practitioners in these fields. To aid the specialists and the profession, researchers have dedicated considerable energy to exploring the experiences and needs of practitioners in the counseling specialties of mental health, substance abuse, school, and higher education. One sub-specialty that has not been thoroughly examined through research is the group of counselors who work with clients coping with an advanced illness and approaching end of life. The risks and benefits experienced by these counselors are unknown, so one must draw from related literature disseminated by other helping professions to appreciate the potential implications of the work. Without an understanding of the counselors’ experiences, supervisors and counselor educators are left to provide support in an area of which little is known. It is the paucity of research pertaining to counselors that work with end of life clients that was the impetus for this study.
Chapter Three

Methodology

Introduction

As a counselor who has worked with end of life clients, I have experienced the personal satisfaction of supporting someone who is attempting to plan for their future and making meaning of their past, while concurrently processing my feelings as multiple clients succumbed to their illnesses. As previously mentioned, I have also witnessed the challenges my peers faced as they did this work while simultaneously coping with an array of difficulties in their private lives. Although I may have personally experienced some of the constructs outlined in the previous chapter (e.g., countertransference and trauma), I did not assume that my colleagues would share these experiences. As a result, I conducted a qualitative study in which I explored the meaning the participants ascribed to their experiences via the stories they told about their work with end of life clients.

The counselors' experiences as they worked with clients facing end of life were the focal point of this inquiry. Through the interviews with the counselors, I hoped to introduce the reader to the range of issues related to this work and the implications on the life of the clinician. An observer might find themselves wondering, what is it like for the counselor who knows that the majority of their clients will die and how does this impact their personal feelings about death? One might also inquire as to how these end of life counseling experiences inform their practice, and how the work is done during times of personal difficulty. In the following chapters, I have documented and explored the experiences of the end of life counselor. I unearthed, in collaboration with the
participants, the counselors’ thoughts and feelings associated with the following research questions:

1. What is the experience of the counselor who works with clients at end of life?
2. What is it like to enter a relationship with a client knowing that they are going to die?
3. How has this experience impacted the practitioner's feelings about life and death?

The literature provides minimal insight as to how counselors maneuver through the complicated situations associated with working with clients at the end of life. We also cannot discern from the literature how or if these clinical experiences affect the counselors, and I have a curiosity about that which is missing from the counseling journals. Since I was motivated to understand the experiences of my colleagues, a qualitative approach was the most appropriate research paradigm. According to Creswell (2013) "we conduct qualitative research when we want to empower individuals to share their stories, hear their voices" (p. 48). Qualitative research traditions are used within the counseling profession (Hays & Wood, 2011). However, researchers do purport that the majority of the studies in the counseling literature are quantitative in nature (Berrios & Lucca, 2006; Hays, Wood, Dahl, & Kirk-Jenkins, 2016).

A wide range of phenomena of interest to the counseling profession including self-injury (e.g., Brown & Kimball, 2013), withdrawal of life support (e.g., Jacobs, 2002), experience of on-line counseling (e.g., Haberstroh, Duffey, Evans, Gee, & Trepal, 2007), providing palliative care to the terminally ill (e.g., Alvarez, 2007), and the therapists’ experiences as they work with clients (e.g., Weisshaar, 2007) have been explored using qualitative research. Qualitative studies have been used to capture the stories of other
helping professions supporting people in particularly difficult situations (e.g., Miller, 2012), including care at end of life (e.g., Gwin, 2009). There are also examples of qualitative research leveraging an interview study exploring topics related to advanced illness (e.g., Bristowe et al., 2015; Sessions, 2011), grief and loss (e.g., Viglione, 2013), and counseling (e.g., Stephens, 2008).

**Rationale for a Qualitative Interview Study**

There is much to learn from the experiences of others, and an important means of getting to these stories is through the use of interviews conducted as qualitative research. In this study, I explored how the counselors who work with those who are dealing with an advanced illness think and feel about their experiences; I also wanted to understand how the work has impacted their lives and relationships. Weiss (1995), in his seminal work *Learning from Strangers*, noted:

> We can learn how events affected their thoughts and feelings. We can learn the meanings to them and their relationships, their families, their work, and their selves. We can learn about all the experiences, from joy through grief, that together constitutes the human condition (1994, p. 10).

Weiss (1995) also noted that a qualitative interview study is ideal when the researcher aspires to accomplish specific goals. In his writings, he identifies seven objectives which make an interview study appropriate, and two of those objectives applied in this instance. Weiss (1995) suggested that an interview study is relevant when one hopes to provide a comprehensive accounting of an event that is not typically experienced. In this study, I intended to compile the experiences of counselors who worked with people at end of life,
which most practitioners would likely agree, is not a common encounter. Also, Weiss (1995) noted that a qualitative interview study is applicable in scenarios where the researcher intends to document an experience from the inside and help the reader to relate to the interviewee. I shared that aspiration and, as a result, explored how end of life counselors processed their experiences and how they reacted in certain situations. Through the results of this inquiry, I hope to educate those who are unfamiliar with end of life counseling and help the reader to witness the experience from an insider’s point of view. Through their stories, the participants provided insight into their thoughts and feelings associated with the work.

Research Design

Since this was a qualitative interview study, there are attributes related to data collection that warrant explanation. It is important to elucidate the format of the interviews, as well as the frequency and structure. All aspects of the design were purposefully selected and are supported in the literature.

Data Collection: Interviews

Interviews conducted as part of a qualitative study require attention to the structure of the questions. An interview is more than a casual conversation even though an observer may not appreciate the distinctions. In general, conversations are a mutual exchange in which either party can ask questions, expressing ideas or opinions, while an interview requires that the researcher set the stage by asking questions related directly to the research question. The interviews were semi-structured, meaning there were specific questions that guided the exchange (Appendix A), but the format was not rigid, nor were
all participants required to respond to all questions. This fluidity allowed me to take the
discussion in the direction that was needed to tell their stories. It also offered me the
freedom to deviate from the interview guide to take the conversation to a deeper level.
Interview questions addressed an array of topics, including but not limited to:

- What do you think about before and after a session with a client?
- What impact has your work had on your thoughts about your own mortality?
- What is it like for you when one of your clients dies?

It is important to note that this study involved two interviews with each
participant. The second interview allowed me the opportunity to seek clarification on
topics raised in the first interview and also address areas that may not have been
explored. Follow-up interviews also enabled me to introduce the participant to some of
the components associated with my analysis. The I poems (a concept explained later in
this chapter) were shared with my research methodologist to confirm the structure of the
poems was in alignment with what might be expected in this type of study. They were
also shared to validate that the subject matter had meaning to others who were not as
connected to the material as I was based on my experience. Two participants were
identified as key informants during the interview process based on their demonstrated
receptivity to participation and their affinity for the subject matter and their curiosity
about the research. Both participants were eager to participate in the study and expressed
their chagrin when the interviews were complete. They were both interested in sharing
their experiences but interested in those articulated by others. During our follow-up
conversations, they were also asked to reflect and comment on the findings. Both of the
key informants met with me to discuss the themes explained in the following chapter. One’s emotional response affirmed that she could relate to the constructs that had been identified.

Before the start of the initial interview with each participant, the purpose of the study was reiterated, and the participants received via email a copy of the informed consent (Appendix B). They were then asked to read and return (via email or fax) a signed copy of the document. I also reminded the individuals that the sessions were to be recorded and transcribed for data analysis purposes. However, they were informed that they could request that the recording be paused or discontinued (none of the participants asked that the recordings be terminated). Participants were also emailed a copy of a demographic questionnaire and asked to return the completed document prior to the interview. The questionnaire was a single page word document on which they could document demographic information such as gender, race, ethnicity, years of clinical experience, years of experience working with end of life clients, the highest level of education completed, practice venue, and information related to their spiritual or religious practices if appropriate (Appendix C). During the analysis of the data, the demographics helped to identify comparison cases. Table 1 summarizes the information provided by the participants.
### Table 1

**Participant Demographics**

<table>
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<tr>
<th>#</th>
<th>Gender</th>
<th>Race</th>
<th>Ethnicity</th>
<th>Degree</th>
<th>Identified Specialty</th>
<th>Place of Practice</th>
<th>Yrs of Ex.</th>
<th>Length w/EOL Clients</th>
<th># of cts</th>
<th>Spiritual or Religious</th>
<th>Religion</th>
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<td></td>
<td>Christian</td>
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Audio recordings ensured that the respondents’ stories were captured without losing content or speech patterns that may have had meaning (Weiss, 1995). The existence of recording equipment and note taking introduced a unique dynamic during the face to face interviews, so it was imperative to create a situation where these instruments became almost invisible to the participant. This was achieved by spending an extended period with the participant, as a means of fostering the relationship and creating a sense of comfort regardless of the venue.

**Approach to Interviews**

When convenient for the participant one-on-one interviews were conducted in person; in circumstances when that was not feasible, one-on-one conversations were facilitated via telephone. A landline was used for phone interviews to ensure I was using Health Insurance Portability and Accountability Act (HIPAA) compliant technology. Although phone interviews have been debated as a viable option for qualitative research, there were sufficient benefits to substantiate the use of this option (Novick, 2008). Face-to-face interviews were conducted in the participant’s workspace. It was proposed that a semi-private public space (e.g., a room at the library) might be utilized if that was more suitable for the participant but it was not necessary to pursue this option. Since we were discussing sensitive topics and emotions were triggered, privacy was a factor when considering the location and times of the interviews. Regardless of the interview format, participants were reminded to maintain the privacy of their clients and asked to refrain from using client names at any point in the interview. The final decision of the interview
type and location was made collaboratively, but I was mindful that the venue must create a climate where the interviewee could be transparent and risk vulnerability.

As was anticipated, the semi-structured format using open-ended questions elicited the practitioners' perspectives on a broad range of topics including burnout, countertransference, death awareness, training and education, supervision, self-care, and disenfranchised grief. I reviewed these themes in detail in Chapter 2. Literature from other disciplines in which practitioners assist clients at the end of life suggested that counselor preparation requires something more comprehensive than grief and loss training if a counselor is to support a dying patient effectively. Understanding how a clinician builds their death competence, which is defined as a "specialized skill in tolerating and managing clients' problems related to dying, death, and bereavement" (Gamino & Ritter, 2009, p. 51) was also an important aspect of this inquiry.

Researchers have suggested that interview length has an impact on both the participant and the interviewer, as interviews lasting over two hours may lead to fatigue (Weiss, 1995). With this perspective in mind, I limited the initial (and subsequent) interviews to fewer than 90 minutes, and an interview guide was available during the interview but was not offered to the participants in advance. One participant requested the questions in advance of the interview, but after explaining my rationale, the interviewee agreed to receive them after the conversation. Weiss (1995) encouraged the use of more than one interview in qualitative research as it helps to foster the relationship and results in additional insight from the participants as a result of their reflection (Weiss, 1995). Therefore, I conducted two interviews, and during the period between the first and
second interview, transcriptions were completed. The transcriptions were available to the participant upon request, but only one interviewee requested copies. I conducted all interviews (face-to-face and virtual of which there were 22 in total) and completed three preliminary transcriptions to ensure I was intimately aware of the content of the interviews. All transcriptions completed by a third party were audited and edited for accuracy. The Montclair State University Institutional Review Board approved the use of a vetted service.

**Participants**

This study was dependent upon the selection of professional counselors who satisfied predetermined criteria. Although other helping professions share experiences with counselors, this study focused on helping professionals who were trained and educated in counseling programs. The following section provides insight into the recruitment strategies and selection criteria.

**Sampling and Selection**

Following Creswell’s (2013) suggestions regarding sample size, I interviewed 11 end of life counselors for this study. Merriam (2009a) noted that the number of participants is determined by the research question, must be sufficient to answer the question, and is considered adequate when it becomes apparent no new information can be obtained. Criterion-based sampling was used to select participants who (a) had experienced the phenomenon of end of life counseling and (b) could verbalize their experiences (Creswell, 2013). To be considered for this study, the counselor was required to have a minimum of a master's degree in counseling, and be actively employed.
in the field working primarily with clients who have a life-limiting illness or have left the field within the 12 months immediately before the inception of the study. One participant had left the specialty of end of life counseling more than 12 months prior but was still employed by hospice as a bereavement counselor, so she was included in the study since her past and current work experiences were directly related to end of life work.

Participants were required to have a master’s degree in counseling to be selected for this study since that is a standard criterion for licensure as a counselor across the country. In addition, participants were expected to have a depth of experience that was obtained by working with multiple end of life clients over an extended period of time.

Candidates for the study were licensed in their state of practice, suggesting they had accrued a certain number of clinical hours. Of the 11 participants, eight people were licensed for independent practice (e.g., Licensed Professional Counselor) and three were working toward licensure under an approved plan of supervision (e.g., Licensed Associate Counselor). New graduates who were unlicensed but working as counselors supporting clients with an advanced illness were not considered for this study. It was determined that the novice practitioner would not have the breadth of experience useful for comparative purposes.

**Participant Recruitment**

Professional counselors who worked with clients coping with a life-limiting illness were pursued through outreach efforts made to the membership of the American Counseling Association (ACA). This particular professional organization has approximately 56,000 members in the U.S. (ACA, 2016b). However, there is not a
division or interest group dedicated to counselors who are working with clients facing and advanced illness or end of life. As a result, an invitation to participate (Appendix D) was submitted via the ACA Open Forum. In addition, participants were recruited through outreach efforts made to the membership of the ACA divisions, specifically targeting the Association for Adult Development and Aging (AADA), the Association for Spiritual, Ethical and Religious Values in Counseling (ASERVIC), and the American Mental Health Counselors Association (AMHCA). The ACA does not make member email addresses available, so an invitation (Appendix D) was submitted via the associations’ forums and list serves: ACA Connect, Association for Adult Development and Aging Community, ASERVIC Connect, ASERVIC-L mailing list, ACA’s Grief and Bereavement list service, and AMHCA’s Open Forum Digest.

Participants were also recruited from the Association for Death Education and Counseling (ADEC), which is the largest interdisciplinary organization in the field of dying, death, and bereavement. I submitted my recruitment letter on ADEC’s on-line, member-only networking group. As a result of these efforts, 11 participants were identified, and the individuals were located in six states and Washington, D.C.

**Data Analysis**

Audio recordings and transcriptions were key components of the analysis. The interviews were recorded using a digital recorder and the files were downloaded to a dedicated computer, which was password protected. The audio recordings allowed me the opportunity to reflect on the tone of the interview, along with the emotional aspects that could not easily be captured in the transcriptions. Verbatim transcriptions were
central to the analysis as they are the most important data source in an interview study such as this. Of course, observations and awareness of the counselor’s work setting also informed this study; however, it was not a primary source of information for this study.

**Transcription Preparation and Data Analysis**

Data analysis began with the first interview and the transcription of data. As noted earlier, I transcribed two of the first interviews to enhance my familiarity with the data. McLellan, MacQueen, and Neidig (2003) provided specific guidance to maintain the integrity of the interview and the transcription process by offering suggestions regarding both the format and the specificity of the transcription. McLellan and colleagues (2003) also encouraged transcriptions that are verbatim, including pauses, mispronunciations, and non-verbal sounds (e.g., laughter, intakes of breath) which increased the naturalness and consistency of all transcripts. I incorporated these suggestions to ensure the standardization of transcriptions. Before the initiation of the first transcription, I documented the requirements in my research journal.

Nineteen of the 22 de-identified interviews were transcribed by a vendor who used Microsoft Word. The quality of transcriptions was validated as I listened to the recording and read the transcriptions concurrently. I corrected any identified errors and worked with the corrected versions during analysis. Word files were password protected, and documents were saved on the dedicated project laptop (also, password protected), with redundant copies saved on an external drive. All materials are maintained, as previously mentioned, in a locked firebox in my home office.
Listening Guide

I was responsible for all analysis, and the primary method involved Gilligan’s *Listening Guide*, which has been used for more than 30 years and was “designed to facilitate psychological discovery” (Gilligan, 2015, p. 69). This approach to qualitative analysis is dependent on the researcher’s intimate involvement with the interviews through a minimum of four readings (labeled as “listenings”) intended to identify three distinct types of information (Gilligan, 2015; Gilligan, Spencer, Wienberg, & Bertsch, 2006). The multiple listenings of the interviews uncovered the 1) plot, 2) first person voice, and 3) contrapuntal voices (Gilligan, 2015).

**Plot.** The first step of the analysis involved not only listening for the plot but capturing my response to the interview (Gilligan et al., 2006). Specifically, this means I, the listener, was attentive to the participants’ stories by understanding what is happening, where the experience is taking place, who is involved, when it happened, and why it occurred. Along with listening for the storyline, I was tasked with monitoring my responses and bringing these into the analysis. This engagement of the researcher suggests neutrality is virtually impossible since I had emotional responses to both the person telling the stories and the narratives.

**I Poem.** The I poem is intended to serve two purposes: encourage the listening of the first person voice and offer a means of hearing how the participant speaks about themselves (Gilligan et al., 2006; Koelsch, 2015). The creation of the I poem is summarized in three steps (a) the identification and underscoring of all instances of the reference to self in the first person (use of “I”), (b) the identification of the verb
immediately following the use of “I”, and (c) the inclusion of only the additional words that add to the clarity of the statement (Gilligan, 2015; Gilligan et al., 2006; Koelsch, 2015). In the creation of an I poem, I maintained the original order of the words, but I did remove words. However, to honor the I poem creation process, I did not add content that was not spoken by the participant (Gilligan et al., 2006). The result of this analysis includes a research poem that is grounded in data and highlights the relationship between the interviewer and the interviewee; artistic form was not the objective of the I poem (Koelsch, 2015).

**Contrapuntal voices.** The third step in the analysis process, which involved at least two listenings, returned the focus of the analysis to the research question (Gilligan, 2015; Gilligan et al., 2006). During this process, I identified the voices I was listening for and then listened keenly for that voice throughout the interview. During this process, I uncovered multiple meanings, conflicting responses, and information that was not in alignment with previous statements.

**Final analysis.** Despite multiple listenings, the analysis was unfinished until I had synthesized the information that was gained via the interpretation of the interviews. Gilligan and colleagues (2006) encourage the researcher to return to the question that was the genesis of the study and consider 1) what has been learned, 2) how is the interpretation known, and 3) is there proof of this understanding. Although each of the listenings may be interesting in its own right, it is not until all of the listenings are considered in conjunction with each other that the analysis is complete.
Researcher Positionality

My decisions to use Gilligan’s Listening Guide as my means of analysis allowed me to take a position different than that of a neutral observer. As one who was leveraging Gilligan’s approach, I was tasked not only with capturing the participants’ perspectives, but I was expected to assess my own reactions to all that I heard and read. Intellectually, it seemed strange to be charged with capturing my reactions to the content and the interviewees throughout the interview and data analysis process, but on a personal and emotional level, it felt authentic and appropriate. This approach to data analysis goes beyond simply keeping a research journal. This point is not to suggest that my journal was not an important part of the process but rather to highlight that the analysis process is designed to capture reactions as one is interacting with the data via the transcriptions. One observation I made as I reviewed the hundreds of pages of transcriptions is that my connection with this counseling specialty and my deep regard for the professionals created a dynamic within the interview process that might allow observers to discern that these were conversations between colleagues and not simply impartial research interviews.

As a counselor who has worked with clients facing an advanced illness and an individual who has supported a loved one during a medical crisis, I could be considered an insider. Since I have worked with clients at this stage of life, I have a unique perspective of the issues that may impact others doing similar work. Although my experiences allowed me to foster a relationship with the interviewees based on our commonalities, they also created the potential for assumptions, bias, and could trigger the
curiosity of the participant. Only one participant specifically asked about my personal motivations for this study. Finlay (1998) noted that the commonality could result in assumptions by the researchers that could go unchecked if not assessed through reflexivity. As Bourke (2014) also pointed out, there was the risk that I could make the inaccurate assumption that my experience would open doors for conversation when in actuality my determination of sameness could hinder the communications with the counselor. Determining the appropriate level of self-disclosure was necessary, and the intent was to limit personal details to those that are related to the study to avoid complicating the interview (Weiss, 1995).

I identify as an insider based on knowledge and experience, but I cannot overlook the other factors that may have influenced my positionality. Although I have worked with people who were dealing with an advanced illness, the way in which services were delivered, as well as the methods, were distinct. With this in mind, no assumptions were made that our experiences were identical. Although I have a history as a practitioner, I entered these interviews as a researcher with the intent of gaining insight to share with others. I have considered the implications of the power differential that was present during the interviews. As the researcher, I ultimately determined the questions asked in the interview, which then impacted the stories told. Even in instances where one might perceive that no differential exists, there was the possibility that I had the potential to influence the participants (Finlay, 2002).
Research Integrity and Trustworthiness

Maintaining the integrity of the process was an important part of the research design. As a result, I used a three prong approach to establish trustworthiness: reflexive journaling, member checking with participants (including the integration of key informants), and the integration of critical friends for the duration of the process. Each of these minimized the risk of bias and maintained the integrity of the study.

Reflexive Journaling

Although open to self-reflection, I was initially resistant to the journaling process. I have learned to appreciate the benefits of capturing the details of the research journey and my self-examination. I began journaling during the preparatory phase and continued as I progressed in the research coursework. The journaling process has proven useful, and I have used my reflections to clarify my sample selection and the locale of interviews while also considering my research question. As a result, I continued the process of reflexive journaling to maintain an "audit trail" (Merriam, 2009b, p. 229) of my thought processes, reactions, and decisions. Like Finlay (1998) I attempted to bracket or “set aside presuppositions and previous assumptions (based on theoretical understanding and personal/professional experience) to attend genuinely and actively to the participants' views” (p. 454). I also acknowledge that my experiences cannot be entirely excluded from the equation.

Reflexivity, or maintaining a conscious awareness of my relationship with the people and processes of my study, was critical to the trustworthiness of this research (Finlay, 1998). My early experiences with reflexivity (e.g., clarity around research
design and positionality) are in alignment with those outlined by Darawsheh (2014) in her analysis of her reflexivity during her research process. Congruent with Darawsheh (2014), my experiences during the analysis phase mirrored hers (e.g., transparency and sensitivity to the fact that my experience could impact my findings). This self-examination was a critical process during the analysis since the Listening Guide suggests that researchers document their responses as they are listening to the transcriptions, and acknowledge the barriers that prevent one from maintaining a neutral posture (Gilligan et al., 2006).

My primary journal was kept as a Microsoft Word document, so the entries could be sorted and coded, allowing me to search for the themes within my thoughts. The electronic version was supplemented with a handwritten journal to allow for spontaneity, which was an important part of my process. These handwritten journal entries were entered into the electronic version with an annotation that details were initially captured manually. Reviewing Ortlipp’s (2008) use of journaling confirmed for me the benefits of the practice.

**Member Checking**

I am cognizant that my experiences with my research topic as a counselor working with clients at the end of life creates the potential for bias. I also acknowledge that it was important to ensure the quality and trustworthiness of this study if I intended to make a meaningful contribution to the counseling profession via this study. As a result, I adopted a pair of Maxwell's (2010) suggestions regarding validity. Maxwell (2010) reviewed eight options of which two are particularly germane to my study: (a)
participant corroboration and (b) seeking out contrary cases and discrepant perspectives. Member checking, or asking interviewees to review the data and interpretation to determine plausibility, was an ongoing part of the process. During the second interview, participants were asked to react to constructs identified through their initial interview or the interviews of others.

Another form of member checking involved the integration of key informants into the process. Key informants are used in qualitative research to validate the claims made as a result of the study. Marshall (1996) noted that key informants are selected from the group of participants and generally meet five criteria: (a) familiarity with the subject matter based on their position, (b) demonstrated a depth of knowledge about the topic, (c) indicated a desire to participate in this capacity, (d) communicated their thoughts and ideas clearly, and (e) demonstrated ability to maintain an unbiased perspective. The identity of key informants could not be ascertained until after the study began, but two participants were identified as candidates to fulfill this role, and both of these participants were engaged in a follow-up conversation.

Member checking has demonstrated the ability to increase the trustworthiness of a study. However, Hallett (2013) raises an important point when suggesting that there can be risks to this approach, particularly when the findings may have a less than flattering connotation or when re-reading of the narratives could be damaging. With this perspective in mind, I approached member checking with caution acknowledging that a tool used to increase the trustworthiness of the study has the potential, if not done with discretion, to create discomfort for the participants. Loh (2013) made a useful suggestion
when proposing that peers of the professional reflect on the experience as well. Since my dissertation committee consists of helping professionals, their review of the data also offered another perspective as to the plausibility of the responses. In addition, members of my committee, along with my critical friends group, served as a form of “audience validation” (Loh, 2013, p. 7).

**Critical Friends**

The process of gaining insight from fellow doctoral students was initiated during my doctoral coursework and continued into the dissertation process. Members of the critical friends group had an understanding of the research subject as a result of exposure through discussions initiated in previous sessions and conversations as the proposal was drafted. Members of the group came from doctoral programs outside of counselor education, and no one had firsthand experience with the topic, inspiring them to ask questions from a unique point of view. Critical friends have demonstrated the ability to ask difficult questions while holding me accountable to a high degree of academic rigor. Periodic discussions with the three doctoral students caused me to reflect on the questions included in the interview guide and consider the techniques I utilized to ensure the interviews did not migrate into counseling sessions as a result of my clinical experience.

**Chapter Summary**

Researchers support the use of qualitative studies when the intent is to explore the experiences of others. This chapter reviewed the details related to recruitment and participant selection of this interview study, and also highlighted the interview format and data preparation. Gilligan’s (2015) *Listening Guide* was also presented as a means of
informing the reader about the iterative process of data analysis. Also included were the strategies used to maintain the trustworthiness of this research. In the next chapter, I will review the results of the analysis.
Chapter Four

Findings

Introduction

As explained in earlier chapters, the intent of this qualitative study was to hear and document the experiences of counselors working with clients who are approaching end of life while uncovering the impact of the work on the counselors’ thoughts and feelings about their own lives. This study was not intended to simply recount events but to understand what those events meant to those who lived them. I suspected that the stories would be complex, and that some of the underlying meanings would not be apparent to the participants even though they themselves were trained to identify unspoken messages. As a counselor I know that the analysis and interpretation skills that appear to come naturally to mental health professionals when working with clients may not be applied so easily to our personal situations. Through this lens, the goals were to honor their stories while exploring the meaning they assigned to various events, and also maintaining my own awareness of what was unspoken, conflictual, and statements that triggered response or reaction within me.

To engage in meaningful conversations around end of life counseling, I searched for individuals who satisfied a specific set of criteria, and excluded individuals who responded to the recruitment activities but did not meet the minimum required education. This decision meant professionals from other disciplines were not interviewed as part of this study. I also excluded individuals who had been retired from the counseling profession for more than 24 months.
About the Participants

The 11 participants in this qualitative research study were distributed across the U.S., with the majority practicing east of the Mississippi River. All of the participants were advanced degree mental health professionals who had a minimum of a master’s degree in counseling, with three participants having doctorates. The participants had an average of 12 years of clinical experience (not specifically end of life counseling), with the range of experience spanning between 24 months and 27 years. The average length of time spent working with end of life clients was 8.5 years, with some spending their entire clinical career in this specialty. The counselors were employed by or working in a variety of settings including private practice, hospice, hospitals, community agencies, and other for-profit entities, with five of the participants experiencing more than one practice venue. For these 11 counselors, the place of employment also impacted the case load size with private practitioners carrying the smallest caseloads (<10) and hospice counselors carrying the largest (30+). It should be noted that factors related to environment and case load size seemed to influence the participants’ feelings about the work and the potential for burnout.

Of the 11 counselors, ten were white females, and the single male participant was African American. All participants described themselves as spiritual, religious, or both, with eight identifying an affiliation with an organized religion (e.g., Pentecostal Christianity, Roman Catholic, Christian, and Christian Methodist). For the participants in this study, these religious affiliations or the alignment with spiritual practices were more
than demographics; they were a primary component of a key construct, which will be discussed in more detail later in this chapter.

All of the counselors participated in two interviews that were scheduled at least three weeks apart, which allowed time for reflection by both the interviewer and interviewee. The initial conversations lasted between 60 and 90 minutes, and the follow-up interview averaged one hour. The second interviews were used to delve more deeply into ideas which were raised by the participant in the initial interview, and also as an opportunity for member checking. Interviews were conducted either face-to-face or by phone, at the convenience of the participant, and the sessions were recorded and transcribed. Interview transcriptions were available to the participants but only one of the counselors requested copies of these documents. As an additional form of member checking, two participants were identified as key informants, providing another opportunity to discuss the meaning of the identified themes to these individuals who were interested in this research and well versed in the end of life specialty.

**Understanding the Counselors’ Experiences Using Gilligan’s Listening Guide**

It is appropriate to revisit the key points of Gilligan’s Listening Guide, which were discussed in an earlier chapter, to ensure a reader’s baseline understanding of the approach. The Listening Guide is different from other qualitative approaches in that data is not coded in the traditional sense, so a brief review of the process seems germane and will manage the readers’ expectations as to what they will experience as they proceed. As noted, Gilligan’s Listening Guide is a multistep process that requires the researcher to analyze the data or transcripts and their personal reactions to what they have heard and
read (Gilligan, 2015). In this instance, this self-reflection component helped me to understand the meanings I was ascribing to the participants’ responses and stories, while also encouraging me to assess where my experience as an end of life counselor may have tainted my reaction.

Using Gilligan’s Listening Guide involved four readings of the transcriptions, otherwise known as listenings, with the intent of uncovering information that would help me and ultimately the reader understand the gestalt of the experience of end of life counselors. To summarize, researchers using Gilligan’s Listening Guide incorporate the identification of plot, develop I poems to hear clearly the first person accounting of experiences, and the identification of multiple points of view as articulated by each participant. The analysis process is not complete until the researcher synthesizes all that was uncovered and drafts an analytical essay. In this chapter there will be instances in which a specific piece of the analysis, I poems, is used as evidence of a construct because a summary of the first person experience did not convey the idea with the same power as the participant’s actual words.

Through my immersion in the transcripts and repeated listenings of the session recordings, it became apparent that these professionals used more than a dozen principles to foster their own wellbeing. These strategies were evident in the lives and practices of the participants but most of the concepts will not be covered in depth as part of this discussion since the constructs are familiar to the counseling profession as a whole, and not unique to end of life work. To clarify this point, the subjects of self-care, self-reflection, and self-awareness were articulated as important to the participating
counselors but these constructs are not unique to end of life counselors and, as a result, will not be central to this analysis but there will be links to these topics as I share some of the participants’ stories.

As the participants shared their experiences it was evident that these practitioners had much in common with other counseling professionals, yet the distinctions of the work were equally apparent. It was during the examination of the differences that the two primary themes of this study, psychological safety and unexpected gifts, were identified, resulting in the development of a model that demonstrates how these practitioners are able to sustain themselves in the work. It is the nuances of the specialty and the demands of the work that make this practice unique and result in a situation where end of life counselors may consciously or unconsciously seek out ways to protect themselves and to feel safe. I have labeled this protective mechanism as psychological safety. The second construct, unexpected gifts, feeds the counselors’ motivation to continue in the work. It is the combination of the protective mechanism of psychological safety and the unexpected gifts which increase the likelihood that an end of life counselor will continue in the specialty despite the existence of an emotional roller coaster.

The term psychological safety is used in business settings to describe an individual’s comfort or sense of safety as they engage in a situation with minimal risk of negative consequence (Lyu, 2016). In the organizational development literature this concept is used to support the creation of an environment that is conducive for engagement, which ultimately encourages team members to take risks and participate in activities without fear. As an example, a manager concerned about psychological safety
would work with the team to create a setting where there is mutual trust and respect, so people will be creative without feeling self-conscious. In most instances, psychological safety is used to describe an environment created by one individual (or an entity) for another. For the purposes of this study, I am diverging from the traditional application of the term psychological safety by using it to encapsulate the actions taken by the end of life counselors to create their own safe haven in which they are strengthened and nurtured. This construct and the related sub-themes will be discussed in more depth later in the chapter, but first I will expand on why this construct is necessary for these practitioners.

The counselors’ statements, along with the descriptions of their experiences, led me to the conclusion that when these counselors do feel depleted and vulnerable, they may recover if they have a space where they feel emotionally safe and secure. For a space to be nourishing, especially when it involves an employer or supervisors, it must have an atmosphere that encourages honesty about feelings and leverages tools that already exist in their tool box. Although many of these specialists provided services in the homes of their clients, with some making house calls in the middle of the night, none mentioned a fear for their physical safety but at some point all alluded to a construct I have labeled psychological safety.

**Participants’ Experiences**

I pursued this research with an understanding of the work as I had experienced it, but as I fostered relationships with the participants, I was impacted in a myriad of ways when I listened to my counseling colleagues tell their stories. In many instances their
experiences were a stark contrast from what I had known. After spending dozens of hours with the participants via our interviews, and many more hours immersed into the transcripts and recordings, I feel compelled to focus attention on the subtleties of the end of life specialty as represented by these dedicated individuals. I am purposely using the word “dedicated” as it reflects the counselors’ commitment to their clients often under emotionally and physically exhausting conditions. The variations of the work highlight the need for psychological safety.

To engage effectively with their clients these counselors need a solid grasp of the fundamentals of counseling, along with a depth of knowledge on a wide range of topics not typically addressed in the counseling relationship (e.g., advanced care planning and disease progression), while supporting caseloads made up of sick or dying patients, and experiencing multiple client deaths each week. The distinction here is in the frequency in which these counselors were exposed to death and the possibility that more than one of their clients could die in a single week. Those counselors with large caseloads (in two instances, the counselors had hundreds of clients requiring them to do much if not all of their work by phone) felt challenged to build the deep relationships they would like to create and they were, at times, ambivalent about their experiences. It was not uncommon for the counselors to feel fortunate they could help some clients, while simultaneously feeling they had failed because people died before they could obtain the assistance needed to create a better end of life experience.

After mentally preparing to conduct this research, I felt primed to hear whatever the participants had to share about the work and its meaning. I thought I had sufficiently
reflected on my related experiences, what the work meant to me and had created a plan for how I would address my own emotions during this study. Despite my attempts at self-reflection and preparation, I discovered early in the process that I was surprised by the intensity of some of the participants’ experiences. My original vision of what our interviews would entail was influenced by my point of view, but after my first interview with Raphael, a counselor who is often with the client and family immediately before and after the client’s death, I felt as if blinders had been removed. As Raphael talked about being physically in the room with clients just before they died, my belief that this specialty had a unique set of needs was affirmed.

The participants shared many stories about their relationships with their clients, what it is like to experience the death of a client, and their feelings when there is no closure. When Cameron, a mother of two young children, talked about shedding tears as she witnessed the final breaths of a child as part of her work, I had a heavy heart. I listened in awe as she shared about the growth she experienced being present in those final moments, and the impact it had on her relationships with her own family. Cameron has implemented change in her own life based on what she has witnessed working with clients at end of life.

Each of the counselors relayed experiences that could be considered “a-ha” moments. I was stunned to hear that Deedra and her colleague had positioned the body of a decedent after his unexpected death, as a means of shielding the man’s wife from a gruesome scene. The suddenness of the client’s death left Deedra hypersensitive to the possibility of death. Deedra was aware that her client would die but when the death
occurred on an accelerated schedule it was hard for her to process. Unlike Cameron, she was not able to reframe the experience in a more positive light, and that event and subsequent experiences caused her to reevaluate her ability to do the work. I had not anticipated that end of life counseling could entail this level of physical intimacy.

As part of Gilligan’s process, I was tasked with journaling my reactions to what I was hearing, and I became grateful for this component of the process. The word “wow” peppers my thoughts and my journal as I consider what these 11 counselors have shared. Many of my interviews were done over the telephone, and in some instances I was grateful for this since I could focus my attention on what I was saying and not the message I might be sending via my facial expressions and body language. I was glad that participants couldn’t see the tears in my eyes as they told their stories. Although some of the participants talked about crying with their clients, and I could hear them holding back tears during the interview, I was attempting to maintain my boundaries as a researcher. The question I asked most often as they shared their stories was what was that like for you? As I reflected on our conversations, I could hear that their experiences have been life changing.

As I expected, there are constructs associated with end of life work as reported by the participants that are shared with counselors across disciplines (e.g., the need for self-care and the role of supervision), but there are also nuances associated with this specialty that would be foreign to many practitioners (e.g., death visits and regularly searching for clients’ names in the obituaries). Based on my interviews, one of the most significant distinctions between a counselor who works with end of life clients and other
practitioners is the precipitating event that was the impetus for the client to enter into a therapeutic relationship. This event, the diagnosis or identification of an advanced illness, has the potential to result in death while the counselor is in relationship with the client, and will impact 1) the subject matter of the sessions (e.g., advanced care planning, anticipatory grief, and decision making), 2) the relationship between the counselor and the client, 3) the location of the work (e.g., client’s home, hospice, and hospital) which also blurs the lines of confidentiality, and 4) the length of the therapeutic relationship (e.g., 24 hours to more than 36 months).

The counselors in this study suggested their work is collaborative and that they are active participants in the process, not merely reflectors of the client’s experience. Many of these relationships transcend the clinical realm, and in some instances the boundaries are sufficiently blurred that the relationships could appear to an outsider to be more like friendships than therapeutic alliances. However, the comments of the participants suggest these are therapeutic connections and this work requires a client-counselor relationship that pushes the limits of what our profession deems appropriate. Fae noted that “your heart and your soul really need to be in this.” Avari and Tahra would describe themselves as being “hands on,” noting they had accompanied clients to medical appointments and hospice interviews, suggesting again that boundaries can be blurred.

Stacia, who works in a hospital setting, described her work as “companioning”:

Yeah, I think – I like the term companioning that Allan Wolfelt uses in his bereavement work. I think that’s a really nice way to label our relationships with our families and because we do, we say we will walk this journey with you. That is case with my team, where we’re really able to do that which is great... through all the twists and turns.
In total, there were 22 interviews, and one constant was the idea that these practitioners were dedicated to their population, and that they found meaning in their unique roles as they journey with their clients. Words like “unique” and “special” were commonly used, and, to put it bluntly, what makes this work different is that it involves the preparation for death. As Avari described it:

…you know, it’s kind of like, how many people get to be in the delivery room when someone has a baby? It’s kind of like that’s what you are – you’re the midwife for somebody that’s dying.

Throughout the interviews several of the participants reinforced the importance of being emotionally ready and grounded to both begin and continue this work. Being ready to do end of life counseling often had different meanings, as some felt it was important for them to have considered their own death, while others suggested a spiritual connection was required. The timing of entry into the specialty was also important. Cameron reinforced this point when she reported that she had declined an opportunity to work on a pediatric hospice team earlier in her career because the timing wasn’t appropriate based on her personal circumstances since she was contemplating having a family. However, when presented with the opportunity a second time, after the births of her daughters, she opted to work in pediatric palliative care, where she has since witnessed both the beginning and end of life. These participants seemed to have entered the specialty at a time in their lives when they felt ready to handle whatever they would experience as an outcome of the work.

Regardless of how they entered the end of life specialty (e.g., happenstance, personal experiences with death, or conscious career choice) the participants were
unanimous in their response to the question *if you knew then what you know now, would you do it (end of life counseling) all over again?* Most responded immediately and without hesitation that the answer was “yes.” Those who did not immediately conclude they would revisit this specialty did respond affirmatively after they spent some time processing the question. At the end of our first conversation I asked Fae what the interview experience had been like for her and she commented on the question that had the most impact on her:

I think that the biggest question that kind of resonates with me is when you asked me, would I be doing this if I knew then what I know now, and would I do it all over again, and the fact that I would say yes was actually odd…I’m kind of realizing that I also feel very blessed to be doing it….I don’t know, maybe it is something about being the ultimate milestone in someone’s life and being able to help someone. I don’t know, it’s sort of interesting to think about.

To understand the significance of this “yes” response, I considered that the work was often described as sad and “heavy.” The heaviness was a result of the subject matter, the occasional feelings of self-doubt and the experience of loss after the death of a client. Although these losses are experienced as part of the work and the counselors enter the relationship knowing the client’s death is likely, there are still feelings of grief. As Etana noted:

There are clients that you just have a different connection with, they get into your heart a little more even though you are keeping that separation. They are the ones you remember the most, they are the ones you think about when you are not with them, and some of those have been hard.

Several others shared Etana’s sentiment that some deaths were felt more deeply than others but the feeling that this work takes a “toll” were not unanimous. Astrid, who has a military background noted, “I must have an odd personality because it really doesn’t
seem to take a toll on me” and she went on to say that she reminds herself “it’s not
happening to me.” Astrid also came to the conclusion that anyone doing end of life work
should be comfortable with their own mortality or the work is likely to take its toll.

Although all of the participants relayed stories of clients who left imprints on their
hearts, it appears to be the cumulative effects of the work and how it is done that has the
potential to wreak havoc if not attended to on a regular, often daily, basis. Tahra
explained the implications of the work on her:

It really is this sort of cumulative boulder that I have been pushing up-hill and I
finally realize, oh my God, that boulder is really heavy, and then, like I said when
I look back at the last month or six weeks or two months or whatever and oh,
that’s why, that makes sense and you know, and that is one of the risks of
investing the way I do in the work that I do.

The counselors in this study often attempted to focus our conversations around
others in their system (e.g., clients and clients’ family members) and struggled at times to
talk about themselves and their feelings. This may support Dik and Duffy’s (2009)
hypothesis that those who perceive their work as a calling have motivations that are
focused less on self and more on others. I regularly reminded the participants that this
study was to understand their experiences, and not the experiences of their clients.

As I asked the counselors to reflect on their experiences some of them indicated
they hadn’t contemplated the experience from their point of view. Avari noted: “Again, I
would have to say that I haven’t spent a lot of time thinking about me in all of this.”
Etana also commented that it was difficult for her to focus on herself during the interview
because she decided to pursue counseling as a career specifically to attend to the needs of
others. These types of comments were befuddling to me, as they conflict with the value
the counselors seemingly placed on self-awareness and self-reflection. On one hand the counselors indicated it was very important to understand their thoughts and feelings about the work and death, and yet those same counselors would comment that they haven’t thought about what this means to them. Etana may have captured the reason why some of the counselors avoided considering what their experiences mean because “it is usually a deep process and it’s exhausting.” This contradiction may also exist because it can be frightening for the counselor to consider how they feel about the end of life constructs as this reflection is another reminder of their mortality.

Some participants entered the specialty comfortable with end of life issues, because they had witnessed death or experienced loss at a young age, while others learned they had the skills only after entering the field. Those who had experienced the passing of a loved one noted how those deaths had increased their comfort with end of life; therefore they felt they were more prepared and more confident talking about related topics. However, having skill, comfort, and confidence does not mean that the work is without its challenges. As the counselors spoke about their experiences, I attempted to discern the deeper meaning behind their comments related to spirituality, supervision, self-care, case load size, boundary setting and burnout. As I analyzed the interviews using the Listening Guide, it became clear to me that there was a need for psychological safety, or a haven in which the counselor felt protected, nurtured and strengthened, as they supported individuals coping with an advanced illness or approaching end of life. Sub-themes influencing psychological safety may vary by individual; however, I
identified three which appear to be most salient: spirituality, boundary setting, and connections.

**Psychological Safety**

The interviews exposed the ups and downs of the specialists’ work, as the participants described situations that could equate a work day to an emotional roller coaster. As the participants shared the details of final conversations with their clients, and discussed what it is like to know a client will never return for another session, they also spoke candidly about their own sadness and grief. Some held back tears during our interviews, even though years had passed since the person they were speaking about had died. Others noted a desire for strength to shoulder “a burden” that could be fatiguing and the potential to cause burnout. All of the participants described experiences that could be construed as psychologically draining, which made me curious about the steps they took to protect themselves and bolster their strength.

The participants were acutely aware of the emotional toll the work had at varying points in their careers. As is the case with many growth opportunities, recognition is the first step. Fae captured the essence of many of her contemporaries’ comments when she categorized her work as “physically and emotionally, mentally exhausting.” Tahra also confirmed that this was not a typical feeling of fatigue when she said: “it is not a physical exhaustion, it is something deeper… yes, sometimes it gets the better of me.” The specialists are acutely aware of the implications of the work and have indirectly suggested the need for something that could nurture and strengthen them so they can continue. Their comments also suggest that the weariness is something beyond that
which can be attended to through rest or sleep. It also implies that without support the weight of the work could sap an end of life counselor’s energy and motivation. Deedra, who works for a hospice with limited resources and more than 2,600 clients, implied that psychological safety was lacking in her environment when she said, “I find that something in this work is wearing on my soul.”

Maslow was one of the first to document the importance of safety, while suggesting adults in some circumstance are more motivated by a desire for safety than the satisfaction of a physiological need (Maslow, 1943). This implies that a person may forego food to alleviate fear or to seek protection. In the past, when reflecting on Maslow’s construct of safety, I often considered the physical well-being of a person (e.g., elimination of physical danger or bodily harm) without giving significant attention to Maslow’s safety need as it related to a person’s state of mind, or the psychological dangers that may impact an individual. During this study, I broadened my perspective and considered the concept of safety beyond a physical paradigm. As I focused on what the participants were saying about the work, their environment and their relationships, it was apparent that although the work was rewarding and in many instances, life changing, it had the potential to cause harm.

In his writings, Maslow does not use the term psychological safety as he explains the second tier on the hierarchy but he alludes to a need for aspects of safety that are more nebulous than tangible (e.g., order, familiarity, and religion) when he discusses what is required for a human to feel safe (Maslow, 1943). The experiences of the counselors in this study suggest that a need for safety goes beyond the physical if they are
to be effective in their work. Maslow expands on the concept of safety in his later 
writeings and intimates that people may be dependent upon other entities when they 
pursue lower level needs, such as safety (Maslow, 1968). I agree with Maslow that a link 
to external sources (e.g., family, God, employer) is often necessary to meet one’s safety 
needs, and these linkages became clear as the end of life counselors described how they 
used spirituality, connections, and boundaries for strength. In my assessment they 
leveraged this triad to create psychological safety, or the equivalent of what Avari 
described as a “bubble.”

Avari, a counselor who works primarily with clients (and their families) who are 
coping with a cancer diagnosis, identified a need to deflect some of the emotions 
associated with the work, and she was one of two counselors to offer a description which 
I relate to a shield. As she shared her analogy she seemed embarrassed and concerned 
that I wouldn’t understand her perspective when she said, “I’m often just trying to protect 
myself, you know, like I’m in the Wizard of Oz, traveling around in a kind of bubble.”

When I considered her comment in the context of what she had disclosed about her 
counseling practice, I felt her need for safety. Avari needed specific attributes present in 
her environment if she was to feel fortified enough to do the work on a day to day basis.

Through their comments, the participants offered visibility into how they created 
environments in which they could effectively do their work. Their insights can be 
summarized using three sub-themes that contributed to psychological safety: spirituality, 
connections, and boundaries. It is important to note that each participant leveraged these 
constructs in unique combinations, meaning psychological safety did not consist of an
equal measure of the three subthemes for all 11 participants. Similar to how I might use the dials on a stereo to create the ideal balance for my musical taste by adjusting the treble, bass, and volume, each participant calibrates their levels of spirituality, connections, and boundary setting to create their own psychological safety. In the instance when an individual was not able to create the right balance to meet their need, the participant felt adrift and struggled to identify the missing component.

**Spirituality**

As noted in the previous section, spirituality is one of three sub-themes that are central to the creation of psychological safety. Since spirituality can be an ambiguous term, this discussion will provide clarification as to the distinction between this concept and religion, as well as how it was experienced by the participants in this study. Through the words of the counselors the reader can appreciate the relationship between this sub-theme and the construction of psychological safety.

Both the demographic feedback and the comments of the participants suggest that spirituality, as opposed to a more narrowly defined theme of religion, is the more appropriate sub-theme of psychological safety. Although spirituality and religiosity are frequently used interchangeably, and some overlap may exist, these words are not synonyms. Spirituality is a broader, more nebulous construct that may or may not encompass religion, and religion is generally related to specific practices associated with an ideology or institution (Miller & Thoresen, 2003). All of the participants in this study described themselves as spiritual and/or religious, and a subset of the group specifically aligned themselves with a particular religion. The counselors often talked about the role
of religion and spirituality in their clients’ lives and confirmed that it was not unusual for sessions to include this content. Stacia, who identifies as Christian, notes that spirituality “plays a huge part in my work” and she was one of the only to offer a definition of spirituality: “anything that connects you to something that’s bigger than me.” She was also the only counselor to admit that she “struggled” when a client had no spiritual connections. This self-identified challenge, which she discusses with a supervisor (an important contributor to her psychological safety), may be attributed to her developmental stage as a counselor since she has just over two years of experience.

Regardless of the participants’ years of experience or their self-categorization as spiritual or religious, all of them leveraged a connection to or belief in something outside of themselves for additional strength and centering. This connection was often reflected through prayer, and some of the participants spoke about praying prior to their sessions. These individuals were reaching out to another entity that was not always referred to as God, and in Cameron’s case it was described as “healing energy.” The role of spirituality and a belief in something beyond life on earth was evident in one of Avari’s I poems. For her there is comfort in knowing that her clients’ spirits live on after the death of their bodies:

I was raised Episcopalian,
I don’t go to church but
I’m incredibly spiritual, and if it weren’t for that,
I don’t think I could do this
I don’t believe that when you’re gone, when your body is no longer working that the person you were is completely disappeared.
I don’t believe that, and if I did,
I don’t think I could do this.
Fae shared a similar perspective in that she believes there is something after death both for herself, “I know where I’m going” and her clients, “I’m blessed to be in a position to talk to people and to be perhaps one of the very last people that these individuals speak to before they pass away and pass on to the other side.” Fae was not the only participant to reference a place or space that was not on this earth. The “other side” was rarely named as heaven even though seven of the counselors align with religions that incorporate this construct into the teachings. Why the participants only referenced this “other” place without naming it is unclear, but it does suggest that these counselors perceive specific subjects as off-limits even when they are speaking about topics they previously identified as important.

Raphael was the first to introduce the constructs of religion and spirituality as important components of his process, but this was not surprising since, as mentioned earlier, he has experience as a chaplain and is currently a minister (It is worth noting that two other participants, Astrid and Martha, also had some connection with chaplaincy.). He described practices which included mindfulness and centering prayer during which he prays for his client, the family, the visit, and himself. Etana’s prayer practice gives her confidence and also suggests she believes she is not doing this work alone: “I ask God to put the right words in my mouth for that client.” Martha also prays for herself, “Lord, let me be an instrument of peace and healing for this person.” Many of these counselors called upon an entity, not always referred to as Lord or God, for guidance and strength at varying points in the day. Astrid starts her day with a prayer: “When I get up in the morning, actually, I am asking God to assist me today.”
The repeated references to an “other” that was unseen but provided strength and guidance demonstrates that these individuals did not feel they were doing this work alone. Having their spiritual practices available as they did their work centered these counselors, and their rituals were comforting. Through prayer, many of these end of life counselors leveraged their connection with an entity to provide the right words at the right time, suggesting feelings of safety. People are generally not inclined to ask for help and admit their frailties unless they believe they will not be harmed by demonstrating their vulnerability. By utilizing their spirituality, in whatever form had the most meaning to them, these counselors were able to create a safe haven for themselves that contributed to their psychological safety.

Connections

The second sub-theme important in the creation of psychological safety is the fostering of relationships with individuals who are empathetic, understand the unique nature of end of life counseling, or have experience with the grief associated with advanced illness and death. This need does not suggest that the individual must be a practitioner in the specialty to appreciate the nuances, but it does imply that the individual should acknowledge that working with this population can be fulfilling and fatiguing, and for some, lonely and isolating. Raphael was very specific about the need for these connections:

I think, and again this is where it's important for counselors to have colleagues that they can share with or debrief with and talk about their work experience, you know, with others who can identify with their role. Because we need a place to express our grief and to express our feelings, a safe place, a place where folks can understand, give us feedback as well as support.
These connections often existed between the participants and other end of life counselors, practitioners from related fields (e.g., hospice nurses or social workers), and immediate supervisors; however, they were not limited to professional relationships. What mattered most was not the person’s position but that their presence created a safe space for processing and helped to alleviate the feelings of isolation that some of the practitioners experienced. Stacia noted that her boyfriend and others in her life hold her accountable when she is “not doing a very good job of mending my emotional needs.” Using Miller and Stiver’s (1997) vernacular these relationships are empathetic and empowering, meaning the individuals in Stacia’s life understand that her work is difficult and they support her in attending to her own needs.

In those situations when participants described feeling isolated it was generally due to being “on the road” or working in private practice where there was less access to others in times of need. Solita, a private practitioner who did not believe supervision was realistic for professionals in her situation, created a solution to her feelings of isolation:“I have a good network of people. I mean, I have a good network of family and friends around that I try to keep active with and if I have something— I have confidants, you know, I have different circles of people that I can talk to about a few different things. I mean honestly it’s almost like, you know, that show where you want to call lifeline. I have different friends who I know are really good at certain things, and you know, others who are not. So, I can pick and choose who I want to talk to about certain items and know that there’s like a good choice for me to kind of talk things through about whatever it is— about whatever issue.

Avari also looked outside of her field for these connections because she has yet to encounter another professional in this specialty who can relate to what it is like to work with people in their 30s, 40s, and 50s who are facing end of life.
Those who worked in settings where they had easy access to others were less likely to talk about having feelings of isolation as it was easier for them to connect with empathetic listeners during difficult periods. However, these connections in the workplace were not automatic and when they were absent the participants struggled. The connections that were the most meaningful to the participants were those that have a sense of mutuality (Miller & Stiver, 1997). For participants in this study, the existence of at least one relationship that was construed as mutual was more likely to lead to growth and minimize the risk of burnout. These mutual relationships were fostered by the counselors with people both in and outside of the profession, and some of these connections were in a supervisory capacity. When a participant did have a supervisor, the relationship had the potential to be a meaningful connection when the supervisor had related experience; however, experience as an end of life counselor was not enough to facilitate a connection. The participants were more likely to have positive feelings about their supervisors when there were mutual feelings of respect and trust. The power differential often existed without having a negative impact on the quality of the connection when the supervisor was emotionally available to the counselor. In these connections, supervisees expected supervisors to create a safe space where the counselors could share candidly without fear of repercussions, which fostered growth through self-disclosure and empowerment. Etana, who has worked with more than one supervisor during her 11-year career, said her need for a growth connection was satisfied when the person would listen and could empathize with her experience.

How I've usually used supervision is about how I'm feeling about the work or how I'm experiencing work or thinking about the work on various different levels and
being able to talk about it. Because I process by talking and if I only process internally, I ruminate. It becomes a sinking ship. But if I'm talking out loud and I'm getting feedback, even if I'm not getting feedback but just the empathetic support that I've been fortunate to have in my career of good supervision, is by talking it out loud, I'm working through it and then it doesn't eat me up… This is not like any other work and no experience prior to this prepares you for it.

It is apparent that having access to other professionals in the field can contribute to psychological safety, but other relationships also serve this purpose. The relationships with loved ones, a higher power or God, or empathetic others also fortified these counselors. When they could not turn to colleagues for support they shared their feelings with others in their life that accepted them unconditionally and listened empathetically. As I reflected on the participants’ remarks as they shared what it was like to talk about themselves, it was clear that the interviews had personal meaning to these participants, as we created another empathetic connection. These short-term connections offered the participants a safe opportunity to process verbally, offering them another relationship that contributed to their psychological safety. Cameron’s comments about the interview process were echoed by others who spoke about the validation and rejuvenation gained by talking to someone about the work:

I really appreciate it. I don’t think I stop and reflect nearly as much as I have today. I would say that overall I feel reaffirmed in the work that I do, where I wrote down some notes, some summaries that you gave me or some reflections of, you know, how I reflect the work that I do and so I appreciate that.

Boundaries

Spirituality and connections were not enough to create psychological safety, as the participants repeatedly spoke about the need to set clear boundaries to separate themselves from the work, while also acknowledging that the boundaries traditionally
adhered to by the counseling profession were often too rigid and could create barriers. For example, Martha worked for three years with a client who had no family, and she noted “my family became her family, and she just was one of those ladies that we had a lot in common, and I cooked for her, my husband cooked for…my son played saxophone for her.” This suggests that boundaries were addressed in two ways by these specialists: some were fortified and others were softened. It was in the softening of the boundaries that some of these counselors may have incorporated behaviors in their practices that might make other counseling practitioners feel uncomfortable.

Cameron said that she “compartmentalized” by 1) leaving her work at the hospital, which implies she does not work after hours, and 2) creating rituals when she arrives at home to clearly delineate the end of her work to herself and her family. Stacia noted: “burnout can happen so, so, so quickly because it is so emotional and so heavy that you have to be able to separate yourself from it.” Stacia also felt that in those instances in which she felt overwhelmed it generally occurred when she hadn’t “enforced” her boundaries. Boundaries and compartmentalization were viewed as “protection” but there was also an awareness that an overuse of these behaviors could result in negative outcomes such as complacency or inauthentic empathy. In this study the counselors needed to find the right level of boundary setting to avoid burnout or disengagement.

There were also instances in which the participants demonstrated that the traditional boundaries (e.g., length of session, confidentiality, self-disclosure, receiving gifts) became more fluid as the counselors worked with this end of life population. The boundaries and ethical guidelines were most likely to be blurred in those situations where
it was beneficial for the client (e.g., sending unsolicited emails to clients as a way of checking in; accepting gifts which have a nominal value) and not harmful to the counselor. For those who flexed their boundaries in certain areas to meet the needs of the clients, they considered how their decisions aligned with the American Counseling Association’s (ACA) *Code of Ethics* (2014). Through their reflections they determined flexing from the norm was in the best interest of the client and they had the professional confidence to make these decisions. For example, attending a hospice facility visit with a client could be considered an extreme extension of the counseling boundaries, but both Avari and Tahra attended these assessments as a means of supporting the client during an experience that could punctuate the client’s awareness of their own mortality. This self-confidence also reinforced the participants’ connection with self so a secondary benefit was an increase in psychological safety.

Although the need for boundaries was a common subtheme, how this was actualized varied considerably. Some of the participants limited their caseload size, while others were adamant that their phones were turned off at the end of the workday. Some described their ability to compartmentalize their feelings about their clients and the work, and created a strong separation between their practice and personal lives. The goal of most was to leave the client issues at the office, and some created rituals to have a sense of closure at the end of each workday. For the two specialists who had their offices in their homes, there were more barriers but this separation was possible and was facilitated by the size of their caseloads. The counselors who had a private practice in their homes had the fewest clients. Avari created a “transition time between things” and
in a very tangible way she developed a space where she could do the work. Avari was aware that if she did not set boundaries around her time or the types of cases that she accepted she would not have the strength to be with her clients in the way that she determined was most effective.

**Integrating Subthemes to Create Psychological Safety**

Although each of the subthemes has been explained as a standalone construct, the creation of psychological safety was facilitated when these themes were integrated. The specialists who responded with an emphatic “Yes!” to the question *If you knew then what you know now, would you do it (end of life counseling) all over again?* provided examples through their narratives of how each subtheme impacted their ability to proceed. The brief excerpts offered throughout the previous pages support the sub-themes identified through the use of Gilligan’s Listening Guide. A more comprehensive discussion of two participants’ experiences will demonstrate how spirituality, connections and boundary setting meld to create psychological safety. The profiles of Martha and Deedra demonstrate how psychological safety is created and highlight the difficulties experienced when a gap exists.

**Martha - integrating the triad to create psychological safety.** Martha, who describes herself as an existential humanistic counselor, entered the profession after the birth of her only child when she concluded that contributing something to the greater good was more important than a lucrative career. She was originally told that she could not have children, so the birth of her son had significant meaning and was viewed as a “gift” by both her and her husband. Although not specifically stated, the use of the word
gift to describe the pregnancy suggests the event was attributed to a higher power, giving us a glimpse into Martha’s spirituality. Prior to her interviews Martha identified herself as non-denominational, a term generally used to describe an entity that is not affiliated with a specific branch of a Christian religion.

There is something about experiencing birth (and witnessing death) that often triggers a period of self-reflection and this was evident in Martha’s story. Her decision to obtain a master’s in counseling came with financial consequences but she expressed no regrets about her choice despite her partner’s periodic comments about their financial situation. Martha’s personal fulfillment superseded her family’s financial security; it wasn’t a result of selfishness but altruism. Her focus became about having a positive impact on society, and when acquaintances suggest her position must be depressing she describes it as “the best job ever.”

In the midst of our conversations I wondered what she was doing to maintain this attitude as she was managing a caseload large enough for five counselors in an area with few resources while also working for a demanding employer. The analysis of the transcripts demonstrated a direct link between her ability to perform in her “ministry” and spirituality, the ability to set boundaries while maintaining some key connections. Through the integration of these constructs, Martha had created psychological safety.

Although she stated she did not enter the counseling profession with the intent of working in this specialty, Martha believes that her end of life work is her calling. Initially I wondered if her career choice was simply coincidental but at the end of our first interview she shared that her mother died of cancer when Martha was 11 and that no one
was allowed to talk about it, suggesting this specialty was not happenstance. As she related her childhood experiences to her current position, she used the term “gift” for a second time, this time specifically naming God as the benefactor:

I really believed that God’s given me that gift. And it was a gift I didn’t really want because it came through the death of my mom and the horrible experience of grieving her loss alone. But, it’s a gift I’m so glad to have.

Martha’s lived experience explained her desire to create a safe space where those who were dying or grieving could speak openly about their feelings. There also is a parallel between the safe space she attempts to facilitate for others and the psychological safety she needs and has created for herself.

Martha described her current position (hospice counselor) as a ministry and noted “as soon as I started doing it, it felt like I had come home.” She also reported she was raised as a Catholic and that she also worked as a chaplain, which solidified her spiritual connections and helps to explain how deeply rooted she is in spirituality. Religion and spirituality were a key component of Martha’s world before she entered the end of life specialty, and she incorporates this into both her practice and her self-care. Our interviews were peppered with her comments about mindfulness, meditation, God, and spirituality. It was apparent that spirituality was a central theme in her life and her work when she noted:

Well I believe we are all spiritual beings but I believe that we’re all sacred, every life is sacred, every human being is sacred and this journey that we’re on, I don’t know how any of us get through it without considering the sacredness of each breath we take and so when we’re faced with the inevitability of the end of our journey in life. So I think that we all start to question meaning and purpose and legacy, what has been my legacy? Have I fulfilled what I was meant to do? Have I been in connection with my creator? What is my relationship to the eternal? And these are things that we need to talk about.
Martha volunteers for her church and although she was previously liberal with her time and energy she now sets boundaries “because they overwhelm me with their need.” She knew that she had to start responding with “no” after she heard herself saying to her spiritual advisor, “I am just like toast, I am done” because she was feeling depleted in her work since much of her energy was focused on caregiving and end of life. Her “spiritual advisor” gifted her Allen Wolfelt’s 2012 book, *Companioning You! A Soulful Guide to Caring for Yourself While You Care for the Dying and the Bereaved* along with the advice, “say ‘no’ more often.” Martha determined that she was taking on the role of caregiver in too many arenas, which was impacting her ability to be with her clients and the quality of her personal life. To maintain psychological safety, Martha limits her volunteering, turns off her work phone at 6PM and directs her clients to use other resources after hours. She also has informed her clients that she would not be seeing them before 8:30 because it doesn’t fit into her life. This boundary setting was difficult at first as it conflicted with her upbringing (child of immigrants who instilled in her the importance of work ethic) and the expectations of her employer (if you care about your clients, you give all) but she persevered after an experience that made it apparent that her strong attachment to the work was damaging her psychologically and physically. Martha may not be able to control her caseload, or the distance she must travel to see a client but she has learned to separate herself from her work which minimizes the damage that could occur as she is impacted by more than 100 deaths per month. Martha highlighted her crossroad when she witnessed the emotional toll the work was taking on colleagues, too.
But I know for me that was a turning point for me. That was probably four or five years ago when I just said enough. I’m not going to allow people to put me in this place anymore because people don’t do it without your consent. So, I have to own my part of it and just start saying ‘no’ to people or not trying to please every manager that approaches me with work.

Martha alluded to the importance of connections in her life when she spoke about her relationship with her spiritual advisor. In this relationship she is transparent about her feelings and knows that she will get support. According to Miller and Stiver (1997) this would be growth connection based on empathy and empowerment.

She also noted that she puts effort into maintaining relationships with bereavement counselors and members of the Association for Death Education and Counseling (ADEC) to avoid feeling isolated because her local network of people in this specialty is small. Martha’s fostering of these relationships, which takes time and effort because the individuals may be in other parts of the state or country, reinforces the importance she places on having people who understand her experience. However, this is another area where she has determined boundary setting is important because “the last thing I want to talk about when I am not working is work.” Interestingly, Martha did not identify her manager as an important connection because “she’s not a trained counselor, she’s not a bereavement specialist, there’s just some blind spots with her.” She seeks mentorship from someone outside of the organization who she respects and feels “she went through a lot of struggles and she’s kind of gone the same road I did.” This speaks to the need for connections to understand the point of view of the end of life specialist.

Martha also conveyed her feelings of connection with people who she has never met but noted they speak to her “heart.” One of these individuals, author Allen Wolfelt,
gave her permission to set boundaries through his book, *Companioning You!* It was important for her to have someone she respects give her permission to set boundaries while contradicting her internal dialogue and years of conditioning that she must give more than 100% to have value. His writing helped her to see that she is not letting a dying person down if she attends to her needs, too. She feels a similar connection to psychologist Carl Rogers, and Zen master Thich Nhat Hahn. These types of connections imply that one does not need to personally interact with an individual to feel supported by that person. These types of affinities can contribute to one’s feelings of psychological safety as they create a sense of belong and acceptance within the end of life counselor.

In her current situation, Martha has created psychological safety so she is enjoying her work despite the presence of obstacles. Her ability to cope cannot be linked directly to one specific subtheme; it is the combination of the triad that has manifested in a safe and growth oriented environment. This is in contrast to a period in her past when she was not feeling safe and as a result was unable to cope with events in her work place. During that period she lost weight, felt perpetually exhausted and took months to recover from a medical procedure that should have taken weeks. It wasn’t until she started to process her thoughts and feelings with some of her connections that she was able to work through her “distress.” It was also through the experience that she was able to see the value of creating a more positive situation for herself.

**Deedra – lack of integration and gaps in psychological safety.** Deedra, like Martha, opted for a career adjustment after a life changing event. Unlike Martha’s joyous experience, Deedra’s career change was triggered by the tragic death of her significant
other in a car accident: “the fact that I came out alive was by the grace of God.” This reference to God was a foreshadowing of her spiritual position that was clarified as she elaborated on her history. Deedra, who was raised in Roman Catholic tradition, noted “I don’t adhere to a lot of the rules and regulations or the administrative pieces” but does describe herself as spiritual. She noted that her spirituality has deepened over the years as she worked in hospice and as she maintained a relationship with her spiritual director for 20 years. This is one connection that has contributed to Deedra’s psychological safety but this relationship is not sufficient to sustain her in her work.

It was after the death of her loved one that she opted to pursue a master’s degree in counseling since she had a new appreciation for the value of relationships. End of life counseling was not Deedra’s first work experience after graduate school but when an opportunity presented itself she said “it just made sense to me.” She felt an affinity for the work since she had experienced the pain of loss at a young age, and she communicated the depth of her knowing when she said, “I know in my gut that everything can change in an instant.” Although she started in the specialty feeling as if it was the right fit, after working with end of life issues for eight years she was beginning to doubt her decision. Deedra was one of two participants in this study who shared during their second interview that they were questioning whether this was still the right specialty for them at this time in their lives. Deedra was emotional from the onset of the second interview, so it was apparent that her situation was taking a toll on her wellbeing.

Deedra experienced her lowest level of psychological safety when there were significant gaps in her connections, and her boundaries were blurred. Deedra would
extend herself to her clients which would deplete her, and she did not have the mechanisms in place to sufficiently rebuild herself. She noted more than one period when supervision was lacking and she did not have a resource to turn to for support or questions. At those times she would seek input from outside of the agency but her self-report suggested these avenues were limited. During her first interview she said she could speak with her colleagues but at the time of her second interview she was reporting a changed scenario.

As she struggles to determine where and how to set boundaries, she has attempted unsuccessfully to speak with her colleagues who have seniority and more experience with end of life care. She had hoped these individuals could share their ways of coping, and offer ideas that would help her to protect herself without completely walling off a portion of her being. Her experiences were in alignment with what Miller and Stiver (1997) referred to as disconnections and described as “what we experience when we feel cut off from those with whom we share a relationship” (p. 11). Unanswered questions would have been easier for Deedra to tolerate had she felt heard and understood; usually she left the encounters feeling flawed or “different.” She verbalized the disconnect succinctly when she said: “so what’s confusing to me is how can you do this work for 10, 12 years, and how can I be in this place with you, when the work is about connections and it doesn’t feel safe?” On more than one occasion, Deedra used the words safety and connection to articulate what she needs in order to perform effectively by highlighting that which is missing in her environment. To her the current situation seems insurmountable: “it leaves you in the middle of the ocean in a little boat and a tiny
paddle, and it becomes hard.” Although she is still seeking answers, she no longer expects her colleagues or supervisors to provide them but she is hoping that her inquiries will be honored and that she will feel validated. Using Miller and Stiver’s (1997) vernacular she needs mutual empathy, which is “a joining together based on authentic thoughts and feelings of all the participants in the relationship” (p. 29). The disconnections between Deedra and her colleagues are in stark contrast to the value she places on the relationships in her life:

After my car accident, I came away from that car accident with a divining rod that said that the only thing that matters in life are the people in your life. And that’s been my divining rod. I can’t change the world but I can make a difference with the one person in front of me.

As she struggles with connections, she is also experiencing the psychological damage that can come when one does not have clear boundaries. There are few boundaries for her position since counselors have on-call responsibilities, and case load sizes are fluid, and she is attempting to discern where to draw the line emotionally. Deedra equates boundaries with compartmentalization, and in her mind compartmentalizing is a form of denial and a negative construct. Her self-report suggests she is unable to see a middle ground between carrying the burdens of others and denial. If she had stronger connections and an increased sense of psychological safety she may be able to work through these issues, but after the rejection she experienced it is unlikely she will seek support internally. Until she clarifies the boundaries and builds additional connections, her psychological safety will be dependent on her spiritual practices and external relationships.
Centering prayer is a cornerstone of Deedra’s spiritual process and this has become a daily part of her routine. Since her spiritual life is “very important” to her she looks for ways to keep that at the forefront. To help her maintain a strong spiritual life, she participates in a centering prayer group and has gone on retreats. These practices along with journaling, using a mantra, and breathing techniques help her stay grounded. Spirituality may be the sub-theme making the most significant contribution to Deedra’s psychological safety, but that single thread is not strong enough to hold her during times of difficulty.

As was the case with other participants in this study, Deedra shared that the interview process had been helpful for her as it offered her an opportunity to talk and it was “therapeutic.” It appeared that she was feeling the factors of a growth connection (empathy and empowerment; Miller & Stiver, 1997) during our interviews, which could have resulted from my ability to relate to her as an experienced end of life counselor. As we concluded the second interview and determined that the work was both meaningful and difficult, Deedra confirmed her need for connections and psychological safety, “so that’s the opposite poles. You know you love the work but its painful work, and you know, it needs to be supported, and you can’t do it indefinitely without support.”

Unexpected Gifts

Despite the heaviness and the potential for emotional pain, all of the counselors were quick to list the benefits of the work, which inspired them to continue to support the dying and the bereaved. They recounted the ways in which being exposed to death created greater meaning and resulted in change within their lives. These counselors did
not enter this specialty pursuing changes for themselves, but during our conversations it was apparent that they had reaped benefits that they did not foresee. The phrase, *unexpected gifts*, captures the essence of the counselors’ experiences as it speaks to the idea that the participants benefited from the relationships with their clients in ways they had not anticipated. The subthemes of unexpected gifts include personal growth and psychological safety. Interestingly, the areas that contribute to the participants’ psychological safety are the same areas in which the counselors demonstrated personal growth.

**Personal Growth and Wellness**

The participants spoke candidly about how they had grown since they started working with clients at end of life; their transparency is admirable. Avari was frank when she described herself as “superficial” before the work, while Raphael also acknowledged that the work has helped him to “cut through the crap.” There were many types of changes that took place in the lives of the participants, but two areas where the modifications were most salient were in their connections and boundary setting.

Who they were before they started this work is not as relevant to this study as are the people they have become as a result of their interactions with the dying. Fae entered the specialty with limited experience or exposure to advanced illness and death. She noted: “And I think that it’s working with this type of population has actually made me more comfortable with death.” More than one counselor discussed the ways in which this work not only impacted the way they perceive death and their own mortality, but also how it has altered their thoughts about life. The experiences relayed in this study are
similar to those documented in Sinclair’s (2011) study of palliative care and hospice professionals in which the participants noted that working with the dying changed how they are living and their feelings about their deaths. It appears that end of life work is more about living than it is about dying, and exposure to the work makes counselors more sensitive to how they are spending their precious time. As they walk alongside clients who are journeying to end of life, the counselors begin to reflect on their own path. End of life counselors were reminded through observation and discussions that boundary setting is important to quality of life. The message for some was clear: don’t waste time. The work has taught Fae several things including the value of time: “It has also allowed me to realize how precious time is, and how precious relationships are, and that it is not to be wasted by any means.”

The employment experience across professions is often filled with growth opportunities, so it was expected that the participants would relay the things they had learned during their tenure as end of life counselors. The idea that individuals in helping professions are impacted by the lives and experiences of those they serve is not unique to end of life counselors; the recounting of their experiences affirms that these participants were changed based on what they witnessed. What is intriguing about the experiences of the participants is how the work inspired growth on multiple levels. Over the course of her tenure, Fae noted that change has permeated her experience:

I feel like over the past five years I’ve really grown a lot in a lot of ways, you know, personally, spiritually, emotionally, intellectually, understanding how all of this… how certain illnesses progress, treatments, I mean, it’s just amazing what I’ve learned and I have been able to provide insight to people about how they may be able to go about things and understanding what the next steps are.
It is this personal growth experience, another unexpected gift, which was often cited by the counselors as one of the primary reasons they would select this specialty again if presented with an opportunity to go back in time. In hindsight, Solita, who discovered the specialty by chance, would have liked to engage in the work earlier because her growth was significant: “I think just the stories and the journeys that I’ve shared with people and they’ve shared with me, were so enlightening to even my own personal growth, I wish I had done it sooner.” Like Solita, the other counselors who had not purposely sought out this specialty have been impacted enough that they would, despite the emotional roller coaster, re-enter the field even with their comprehensive understanding of what is involved. For those who had created psychological safety, the positive impact of the work was worth the risks.

Solita likened her experiences to “a master’s class in life” suggesting she gained knowledge beyond that which would help her to be a better counselor:

And the more you learn from people, you know, hopefully you don’t have to go through the same thing yourself. You know, you pick and choose, like, from some master learning class. It’s like a master class in life because you’re looking at people and you’re gleaning from them their experiences. And you know, it really is powerful, it’s just very powerful.

Solita and her counterparts learned from their clients’ life experiences and attempted to discontinue behaviors that were unhealthy and increase behaviors that were enriching. Avari noted that she has learned to “appreciate all that is wonderful in life and to really, just be sort of nurtured by it.” The participants’ responses suggest that their own quality of life became a central theme after they started working with the dying and the bereaved. Through their comments it is clear that there is a direct relationship between the work,
and their decisions to make changes that had previously gone unidentified or had proven difficult to implement.

It is not uncommon for the phrase “good death” to be used when talking about an end of life experience or how someone died. A “good death” has no standard meaning and the attributes assigned to this experience are based on the point of view of the person offering the definition (Granda-Cameron & Houldin, 2012). This means a doctor will often include attributes that vary from those of the patient. Although these counselors did not define a “good death,” they did suggest that a better death experience can be precipitated by creating a “good” life. What constitutes a good life varied by respondent but for some it was directly linked to their chosen specialty and the changes made as a result of the work. The participants often felt more prepared for death now that they were adjusting the way in which they lived.

**The Triad of Psychological Safety**

The participants implied and directly stated that the work influenced their connections with themselves and others, including the strengthening of their spiritual connections. Interestingly, the participants shared examples of personal growth in all three areas that facilitate psychological safety: connections, boundaries, and spirituality. Deedra specifically addressed her spiritual growth: “Well, in these years that I worked with hospice, my own spirituality has deepened.”

**Connections – others and self.** The 11 counselors were inspired to 1) change how they live, 2) enhance their relationships with others, and 3) foster nourishing relationships. Accompanying clients on their end of life journeys motivated the
participants to not only improve relationships but also clarified that some relationships needed to be severed if they were to enjoy an enhanced quality of life. Working with this population reinforced for the participants that all connections should not last a lifetime, and that maintaining relationships that provide positive energy (as opposed to deplete it) is important to personal quality of life. Consensus confirms that life is too short to spend time on activities that are not enriching. The end of life counselors in this study needed strong connections to perform the work, and through the work they saw the quality of life benefits of fostering strong connections. As a result, the need and value of strong connections was reinforced on multiple levels, and a cycle related to connections became apparent. Deedra noted: “I’m very aware how precious each day is and while I get upset about stuff of life, in the grand scheme, it makes me just see how important the people in our lives are.” The participants in this study received the unexpected gift of awareness.

Raphael is not new to personal growth and change; however he is enthusiastic about where he is headed based on what he has gleaned from his experiences with clients who are dying:

I have a lot of excitement in terms of my own personal growth; where I am, how I’m changing and growing, and becoming wise and better and stronger, and moving beyond past insecurities, past imperfections, and learning to live with imperfections, and so more self-acceptance and just being more at peace with myself.

Raphael is referring to a very valuable connection, which is the one he has with himself. He along with the others have noted that one of the most important relationships is that which they have with themselves. As mentioned previously, I poems were created for each of the participants as part of the analysis process, and it is in these poems that one
begins to see the link between life and death. The distilling of Raphael’s response to the question: *If you wouldn’t mind giving me some perspective on the before, the you before you had this experience and the you now?* helps the reader to feel his transformation:

> I’ll try.
> I mean, the me before and the me after,
> I think part of the answer is my own journey
> I think the change in me, was being in touch with my own feelings about death, about the meaning of life, and,
> looking at my own life to say what is meaningful and what am I doing in a meaningful way
> so that when I reach that stage in life,
> when I am dying,
> I can look back with integrity.
> I can look back, look back without any regrets.
> I can be at peace,
> so the change was,
> how do I live my life NOW, so that when it comes time for me to die,
> I, I will be ready and prepared.

Raphael captured the essence of the point made by others, that this experience teaches people to live their lives in such a way that they will have no regrets when they approach the end of life.

**Boundaries – movement toward fluidity.** Counselors in this study also made changes related to their boundaries as they relate to both their personal life and professional practice. The unexpected gifts in this arena could be categorized in two ways; the specialists developed 1) the clarity around how boundaries could be changed to enhance the quality of life for both the counselor and client, and 2) the courage to implement the changes that may not be in alignment with the standard practices of the profession. As mentioned previously, some of the participants became clearer about the importance of setting boundaries related to their work schedule and personal time.
However, some were more liberal with their schedule when it came to their clients, often communicating with them more than once in a week. These counselors also noted that a session could be longer or shorter than 50 minutes, and the length was driven by the client. The rules that may govern other counselors’ practices were not as apparent in this specialty because the needs of this population warrant flexibility. Avari noted,

most people who are counselors, there are these rules about, you know, you can’t do this, you can’t do that, and in this kind of work, yes, you certainly do not do the all the stuff you’re not supposed to do but, at the same time, I will, unsolicited send people emails … our relationship is not quite the same as somebody who just, you know, is coming to talk to their therapist because they don’t like their job or something…I’m just a person, and we’re all on this journey together.

Avari’s comments suggest the professional distance that exists between some counselors and their clients may be minimized or eliminated by practitioners in this specialty. More than one of the participants in this study shared stories that highlight the fluidity of the boundaries that exist between the client and the counselor. These relationships and the needs of the clients did result in more frequent meetings, and the interactions could be perceived by outsiders as more personal than professional. Tahra was transparent about the blurred boundaries between her and her clients when she relayed the following experience with a client who was admitted to the hospital for what would be the final time:

I went to the hospital, and I remember as I left at the end of the appointment, she grabbed my hand, and she said, ‘Tahra, I love you’, and I looked at her and I said her name, and I said I love you, too, and she squeezed my hand, and the following morning her husband called me and told me that she had died…Yeah, she will always be with; she will always be with me.
Tahra also shared that the deaths of her clients can be difficult because she has worked with people for years, and described their deaths “like losing a loved one because in many ways they are.”

**Spirituality – discovering a calling.** With the exception of two participants (Etana and Stacia), the practitioners in this study did not enter the counseling profession with the intent of working with those who were dealing with advanced illness or dying. Most described situations that led them to end of life counseling as serendipitous or happenstance. As Cameron put it, “I think it came about truly by happenstance, and then I kind of found a comfort there.” This was a shared perception; once the individuals started doing the work they determined it was the right work for them to be doing. When individuals described the specialty as their “right” work, they often clarified their statements by offering examples where they are comfortable in what others might define as uncomfortable situations (e.g., being with people who are grieving, sitting with people during extended periods of silence, and the ability to maintain a calming presence during tumultuous times). Raphael, a counselor and a minister, was asked if he would do another kind of counseling if given the choice, and he was adamant this was the right work for him: “it’s a very spiritual time. No, I’m in the right place; at the right time, doing the right thing. It feels right, and it is right.” He was the first of many to incorporate spirituality into the conversation which caused me to consider the significance of religion and spirituality in the lives of these 11 people.

Despite the potential risks associated with the work, the participants described their chosen profession in terms that suggest it was more than a job or a way to earn a living. It
became apparent to me that none of these counselors did the work for financial gain, and some of them supplemented the income earned as an end of life counselor with other forms of income to meet the needs of their families. If compensation were the primary motivator for these individuals, it seems they could have chosen another line of work.

Fae, a counselor who works in a for-profit organization, was the only participant who indicated “where I work pays quite well” but she was also one who specifically stated, “Especially this type of counseling is certainly more than just a job.” I asked Cameron during her second interview to react to the idea that her work was a “calling,” and she confirmed that the label fit. She noted:

I would say that it does, I would say that does ring true… So I think there is some meaning surrounding why I can, and that’s where I would really relate it to… is that this is kind of a calling, it’s a niche that I found a spiritual connection.

Apparent in the interviews was the internal work motivation, or the idea that the work was done for the personal benefits gleaned from the work (e.g., gratification, fulfillment) and not for external gain (e.g., paycheck, promotion). Although all of the factors that would qualify this work as a job are present, meaning they are getting paid, some have the other accoutrements of employment (e.g., paid time off, health insurance), freedom to quit or risk of being terminated, they do not equate their specialty practice to a job.

These participants were not inclined to use the word “job” in relationship to their practice, with many using words that suggest greater meaning: an “honor,” a “privilege,” “gratifying,” and a “gift.” Earlier I noted that the word companioning was used, and more than one participant indicated they were on a journey with their clients. Etana, an end of life counselor with almost 10 years of experience, determined that being a part of
the end of life experience was a rare opportunity for not only counselors but people in general. “I think it’s a rare journey that most people don’t get to see, so to me it is very much an honor.”

The participants felt it was a privilege to do this work and that this was the right work for them to be doing at this point in time. When speaking about their employment, they frequently used words that carried a spiritual connotation, and described their career choice as sacred work or a calling. I asked several of the participants to clarify what they meant by these terms, and they linked them back to the spiritual, which some also related to religion. Often when we consider synonyms for the word calling, we interchange it with words such as vocation, mission, and purpose. For most readers there is a distinction between the work we would perceive as a job and that which would be a calling. Dik and Duffy (2009) provided a definition of a calling:

A transcendent summons, experienced as originating beyond the self, to approach a particular life role in a manner oriented toward demonstrating or deriving a sense of purpose or meaningfulness and that holds other-oriented values and goals as primary sources of motivation (p. 427).

This definition suggests that an external force may have influenced the chosen path, and that the force could be a higher power or serendipitous events. Fae aligned with this perspective when she said:

…and obviously with a higher spiritual being, that you’re really being called upon to do this work. We’re almost like clergy people, you know what I mean? It’s like--I really feel like you’re, you know, the light is kind of shined on you to do this.
Dik and Duffy’s (2009) definition also suggests that the counselors who believe their work is a calling will find meaning in their work and are motivated to focus on others (i.e., clients) and not primarily on personal gain. The counselors in this study often attempted to focus our conversations around others in their system (e.g., clients and clients’ family members) and struggled at times to talk about themselves and their feelings. This may support Dik and Duffy’s (2009) hypothesis that those who perceive their work as a calling have motivations that are focused less on self and more on others.

Etana, who determined early in her counseling career and long before she had experienced personal loss that this was the work she wanted and was uniquely qualified to do, stated, “There are many things that I have done well in my life, but this one I actually feel is what I was designed to do.” She went on to explain that she has been able to speak comfortably about death and dying as a counselor, daughter, and friend in a culture where these subjects are “taboo.” These descriptors and the idea that one was created for this work suggest something more meaningful than a job. This deeper meaning and connection was reiterated with one participant noting she was meant to do this work even though it was not the work she had originally envisioned for herself, and she came to this conclusion when she discovered how easily she could talk about the subject of death and dying when others in our culture actively avoid it. There were many instances in which a spiritual or religious connotation was either alluded to or specifically articulated. Fae relayed a conversation in which one of her colleagues described end of life counseling as God’s work:

I would say it is sacred because one of my colleagues he put it very eloquently is that you know we are doing God’s work and that’s always in the back of my
mind. I’m always thinking about those words that were said to me that I’m doing God’s work just in a very unique position and sacred position.

As Fae described her work she spoke about creating spaces where her clients are free to talk about topics that are frightening and unwelcomed in many circles. It is in the creation of these safe spaces that Fae is doing sacred work.

The word, *sacred*, appeared in twelve of the interviews, and it was used to describe both the work and the end of life experience. Raphael, a member of the clergy, provided an explanation of what he meant when describes something as sacred:

> When I say sacred, I mean I think of the spiritual realm, I think of the experience being out of the ordinary human experience in a realm that is beyond just ordinary awareness. It's something you can't kind of touch physically. So, it involves a deeper awareness of emotions, of senses, it's something spiritual and you have to feel it, you have to feel it and sense it, and it's hard to describe and you just have to be there in the room to feel it and to sense it in the interaction with the client.

Tahra also views her work as sacred and described it as such when she is asked by others what she does for a living. Like the other participants, Tahra is proud of her career choice and is not afraid to tell people how she sees her work:

> Let's be clear here, I usually tell them what I tell you, that it is sacred work and then it is a privilege to do what I do because it is, and it is tough for me to language it in any other way.

Fae clearly views her work as more than a job when she described it as a “sacred privilege.” Deedra also used the phrase, *sacred work*, along with the word *privilege* to describe her position as a counselor in a hospice setting. There were multiple instances in which the language used to refer to the work inferred a spiritual connection, and aligned the experiences of those in the study with attributes of a calling which were documented by Dik and Duffy (2009). The connection between the work and spirituality, and the comfort provided through spirituality as expressed by the participants was apparent and it
was through ongoing immersion into the transcriptions that the significance of this construct became apparent.

Growth was an unexpected gift of the end of life specialty. Participants shared stories about clients that have left their imprints, and how they were living with more intentionality than they had in the past. The work may not be easy but it does present a life changing, and the retelling of one counselor’s experience helps the reader to appreciate the impact of the work on a life.

**Etana**

Etana, a mid-life career changer, had limited personal experience with death and dying before becoming a counselor after a corporate career. Her first counseling position had her working with clients who were coping with HIV/AIDS but even in that capacity end of life exposure was limited. Shortly after she started working for her current employer she received her first unexpected gift, a deep awareness that this was the work she was “meant to do.” In this type of counseling she felt completely engaged in the work she was “designed to do.” Several years into her career, Etana still finds the work fulfilling, and she also describes it as “satisfying work, it’s rewarding work, it’s important work; it’s also hard work; it’s challenging in a lot of different ways.” The work itself is challenging for Etana and it is not made easier by the fact that it seems to highlight growth opportunities in her own world. As she speaks with her clients she develops an awareness of the areas in her own life that would benefit from change. Change is not always easy, even in those instances where the person who is considering the change is a change-agent like Etana. Etana and her colleagues spend their work hours helping people
to find their intrinsic motivation to address issues, but it can be difficult to find that motivation within ourselves.

Through her narrative Etana identified three areas in her life where she made changes as a result of being on the journey with her clients, and how she looked at illness and life. The identification of these areas and the accompanying motivation to address the issues, were unexpected gifts of the work. Etana did not enter the specialty with the goal of receiving anything from her clients, but she was clear that the personal benefits of the work outweighed the challenges. The resulting changes were significant and had an impact on her and people in her life.

Etana had smoked for more than 30 years (her entire adult life) and after working with many clients who were coping with chronic obstructive pulmonary disease (COPD), she started to appreciate at a different level the need to stop smoking. The suffering that can occur when patients are dealing with advanced COPD would capture anyone’s attention, but particularly that of a smoker since researchers have demonstrated that the most common cause of COPD is smoking (American Lung Association, 2017). Etana is a well-educated person, so she knew the reasons smoking was detrimental to her health but it was not until she witnessed the challenges of COPD first hand and heard what death was like as a result of this condition that she became motivated to change. After more than three decades she finally found the motivation to stop smoking as a result of what she witnessed. More broadly, she now is more motivated to take better care of herself through regular doctor visits because “you know that early detection makes a difference on different kinds of things… Knowing what you know, you think of things
differently.” She also makes time to walk on a regular basis and has altered her eating habits. Her current motivation to take care of her physical self is directly related to her work as an end of life counselor.

Etana, a divorced mother of a 21-year old son, also came to the realization that she would need to have difficult conversations with her child about her future. Although she is healthy, she now knows how quickly situations have changed so she needs to be prepared for an uncertain future. Since she does not have a partner who can speak on her behalf, she has determined that preparing her son for this role is an imperative since he is the individual who will speak for her in the event of a medical emergency. She has witnessed many situations in which families were unprepared to make medical decisions because the unit is not communicating and she has determined this will not be the case in her family. These observations have triggered Etana to take action, and these actions have strengthened the connection with her son while also helping them to learn to maneuver through a parent-child relationship where the boundaries are now more fluid. Etana has had conversations about her preferences at end of life with her son that most mothers in their 40s have not had with their young adult children. The first conversation around the subject was difficult because she had to ask him if he wanted to take on this responsibility and if he would be able to handle the tasks. She recounts the experience:

The same kind of pushback our families give our clients when they try to talk about these things, so it kind of played out. It was a parallel process that was playing out, it was also hard to…. Intellectually he knew we had to have the conversation, emotionally he had a hard time with the idea of thinking about having to make decisions for me at the end life.
Although she has made some changes in this arena her work is not complete because she has yet to document her preferences in writing “even though he has asked me to.” This suggests that the work can highlight the need for change but that knowledge doesn’t always make the change easy to implement. According to Etana, the motivation that inspires an individual to have a planning conversation may not inspire the same person to put preferences in writing because even though an end of life counselor helps others to see the value of completing an advanced directive “it is different when it’s you.”

Etana noted that her appreciation for life has increased because she is now more aware of her own mortality. This heightened awareness and the associated appreciation for each day, was an unexpected gift. She shared that she also thinks about medical test results, both her own and those of family members, differently than she has in the past because her knowledge was expanded once she started the work. She now has an awareness of illness, disease progression and symptomology that may be more common for a medical professional but not typical of a professional counselor practicing in a more generalized area. She referred to this experience as “middle knowledge” which she further explained as “this concept of being able to hold your own mortality or face your own death in full awareness and cognition.”

Despite the increased sensitivity to death, Etana has concluded that the work is not about dying but about living: “To me death is a part of life and that part --that perspective is solid for me.” Death is a part of the journey, not something to be feared, but her clients have shown her the importance of having a good journey which involves sensitivity to her own quality of life. To ensure a good quality of life, she is attentive to
her self-care needs that include daily walks along the beach, time with people she loves and the active pursuit of other activities that are nurturing. Enrichment comes to her through the development of her mind, body, and spirit, and this means she is focusing on both the connection with herself and her spirituality. Etana takes time to center herself and to process her feelings – self-reflection is part of her self-care. Although it can be a challenge for her to set boundaries to maintain her well-being, “sometimes that was harder than others,” she knows that she must if she is to do her best work and live her life concurrently.

Etana is fully aware that she must continue to maintain her boundaries if she hopes to continue to flourish in this work. She admits that this area is a work in progress since her position has the potential to consume all of her time because she, like other participants in this study, is dedicated and compassionate. One participant described this as being “all in.” She cares deeply for her clients so it is imperative that she is diligent about protecting her boundaries or she risks sacrificing the activities that help her to feel connected to herself and fully engaged in her life. As is the case for all of the participants in this study, connections matter and a heightened appreciation for their importance is an unexpected gift of this work.

**Chapter Summary**

The goal of this study was to understand the experiences of counselors who work with clients at end of life. Using Gilligan’s Listening Guide to analyze the interviews highlighted the nuances of a specialty that requires the practitioners to create psychological safety if they hope to sustain themselves in the work. Figure 1
encapsulates how psychological safety is fostered via three constructs (connections, boundaries, and spirituality), which then creates a situation in which these counselors can pursue the work, and uncover the unexpected gifts of counseling end of life clients. In those instances in which psychological safety does not exist, there is the potential for burnout and the possibility that the counselor will leave the specialty.

Figure 1: Integrating Psychological Safety and Unexpected Gifts

Counseling clients at end of life can be emotionally taxing precipitating the need for the integration of available strategies to ensure the counselors are strengthened as they journey alongside those who are dying. The combination of three constructs - connections, spirituality and boundaries, facilitates the development of psychological safety, or a situation in which the counselor feels protected. One participant described her experience as a “bubble” which suggests she feels safe inside and things that may cause injury are maintained on the outside, allowing her to help her clients with a reduced risk of emotional harm. As these specialists develop psychological safety they continued in the work and reaped the benefits of their expected gifts.
As these specialists do the work, they also spoke about the benefits that they have gained even though the work can be fatiguing on many levels. The practitioners entered the specialty in a number of ways, with none entering the specialty with the goal of facilitating their personal growth. However, as a result of their interactions with their clients who are approaching end of life, they did reap benefits that I have labeled as unexpected gifts. The unexpected gifts influenced their lives in a myriad of ways, and in many instances actually contributed to the very factors that influence psychological safety. It appears that the combination of psychological safety and unexpected gifts are a cycle that can sustain these counselors in their work. In Deedra’s case, psychological safety was lacking, she did not have the triad balance she required, and, as a result was considering exiting the profession. Martha, on the other hand, had created a combination of connections, boundaries and spirituality, which allowed her to do the work and discover the unexpected gifts of working with clients at end of life.
Chapter Five

Discussion

Introduction

This study was designed to explore the experiences of counselors who work with clients coping with an advanced illness and facing end of life. I have examined the participants’ experiences through a constructivist lens, and their narratives support the notion that these professionals are people of action. As they took action to enhance their personal experiences that resulted from their work, they also demonstrated other tenets of constructivism including a human’s need for order and structure, the desire to attend to oneself by caring for the body and setting boundaries, a person’s need for connections with others, along with an awareness of the developmental stages within their careers and in their lives (Mahoney, 2003). After interviewing these 11 counselors, many who reported entering the field by chance, it is apparent they have made conscious decisions to continue and develop in this specialty, demonstrating the basic constructivist theme of active agency (Mahoney, 2003). These end of life counselors are not taking on passive roles but attempting to create meaning and purpose for themselves as a way of coping with circumstances that can be emotionally difficult.

It is also evident that these professionals perceive their positions as something other than a job, indicating they have attached personal meaning to the work. This meaning making reinforces the constructivist perspective that individuals interpret experiences to create a sense of order. The purpose of order can vary by individual but for some order creates predictability and safety, and safety is a basic human need.
Although it is rewarding work, there are challenges that exist as a result of doing end of life counseling, and examples within the narratives (and as noted in Chapter 4) demonstrate the participants took action based on what they witnessed which also helped them to identify ways to continue the work. The continuation of the work, while protected by psychological safety, offered the opportunity to experience the unexpected gifts. In the midst of tumultuous experiences these counselors sought out order and structure, through the creation of boundaries, the development of connections, and reliance upon their spiritual foundations. The events experienced through the work with clients coping with advanced illness and facing death may have been the impetus for change, but these participants moved from a place of knowing something needed to change to actually doing something about it.

In alignment with a constructivist perspective these individuals implemented changes in their personal lives as a result of what they observed in the lived experiences of their clients and their clients’ families. Observing the loving moments between a husband and his dying spouse inspired a counselor to appreciate at a deeper level the meaning and value of his relationships. Watching as people attempted to purge their possessions in preparation for death triggered another counselor to reflect on the importance of her “stuff.” These counselors changed their ways of thinking about possession, time, and relationships. As a result of the work there is an increased awareness of self. Raphael expressed a sentiment similar to that of the others in this study:

It has caused me to reflect on what’s important in my life now, and, are my priorities really significant? Do they make sense? Are they moving me forward to
a natural progression in life so that when… whenever my time is to die, I can say all is well, I am at peace, I am ready to let go, I have done my best and I’m happy with my life as I reflect back on it.

A sense of self was obvious as the participants discussed the impact of the work on themselves, indirectly answering the question: what is in this for you? These participants support the belief that we can learn, change and grow vicariously, as we walk alongside our clients. Observing the journey is often all that is needed to motivate change. The changes made by these counselors permeated all facets of their lives including their minds (e.g., what they think about and what they study), their spirits (e.g., how they feel and connect with others), and their bodies.

Through my analysis, using Gilligan’s Listening Guide, it was evident that the combination of psychological safety and the unexpected gifts created a process that sustains these counselors in the work. Although this process was not specifically identified by the participants, all of the elements (e.g., connections, boundaries, and spirituality) were present. To validate my interpretation of what I had heard, I had a follow-up conversation with Etana, a key informant. As we discussed my analysis her response was immediate and visceral, and her words confirmed that she could see the correlation to her experiences.

The participants highlighted through their narratives the tools they used to create order which allowed them to perform in a profession that can be fatiguing on a variety of levels. As these counselors engaged in their work, their lives were positively impacted as a result of their interactions with their clients, and they described these gains in detail. I have categorized these experiences as unexpected gifts, since they were unanticipated
benefits of the work. These professionals did not enter the field motivated by personal gain, but the unanticipated benefits were apparent. Fae shared that watching her clients cope with their difficulties had given her the courage and strength to deal with personal issues in her life, and she was not alone in noting that her resilience was fortified as she witnessed courage and bravery.

In the remainder of this chapter I will interpret the themes that emerged in this study while making connections to the literature related to the practice of working with clients at end of life. These resources are often taken from other helping professions as there is a dearth of information in our field related to end of life work. This section will also explore the implications for practitioners who are currently working in the specialty, their supervisors, as well as offer perspective for counselor educators and employers. Finally, I will review the implications of this study, as well as directions for future research.

**Discussion**

On any given day, a counselor working in any specialty can use a variety of words to describe their work and the profession; it can be invigorating in one moment, and exhausting in another, while also leaving one inspired or discouraged. This emotional rollercoaster can be magnified for counselors who are working with clients at end of life, as they are put in situations where they witness physical and cognitive deterioration, and death. Tahra was clear about the myriad of emotions that she experienced, which included feelings of helplessness, sadness and grief, and her thoughts were echoed by others in the study.
A client’s death is never easy but the loss can be more palpable when the
counselor has been physically present as the client declined or died, or the specialist has
known the client for years and the relationships have shifted over time from purely
professional to something akin to friendship. Papadatou (2009) indicated that a
practitioner may not be able to avoid the grief process if they have developed a personal
attachment to the dying person. When people we care about die, we grieve. When these
end of life counselors experienced the loss of a client with whom they had a special
connection they became the bereaved. These feelings need to be acknowledged by both
the counselors and their support system, to reduce the impact of that which Etana referred
to as “cumulative losses.” The number of deaths experienced by the counselors within a
specific period can also take a toll, so those practitioners with larger caseloads require
more support in order to minimize the emotional impact. The participants in this study
noted that their grief was generally acknowledged but there were instances of
disenfranchised or unrecognized grief. How these counselors will experience their grief
is based on a number of variables including personal history with death, cultural factors,
developmental stage, education, and environment (Papadatou, 2009). Regardless of the
variables that are impacting the counselors’ grief experience, the situation can be less
difficult when there are connections in place and an environment of psychological safety
exists.

Psychological Safety

Death experiences remind practitioners of their own mortality, and the counselors
spoke of the importance of self-awareness and confirmed Doka’s (2009) assertion that
caregivers must attend to the stressors in their lives including their feelings about death. There are implications of witnessing the declining health or death of a client whether or not we are consciously aware of impact (Papadatou, 2009). Just as the work has impacted the study participants’ death awareness it has also reminded them about the brevity of life and changed their perception of time – it is “precious.” Papadatou (2009) noted that those who work with the dying and bereaved have a different appreciation for time as a result of their work.

Although the participants viewed the work in a positive light, we can appreciate the counselor’s need to create a place of psychological safety when we consider their repeated exposure to death and stress, in combination with the subtle messages sent by others who don’t understand the career choice. Friends, acquaintances, and strangers often ask these specialists how they can possibly do a type of work that is “so depressing,” and they respond in surprise when the counselors say it’s rewarding and fulfilling, and not at all depressing but it is unsettling and challenging. In a society where conversations about death are still considered taboo, people marvel at the motivations of one who chooses to work with people who are dying. How many times would one have to hear “I could never do that” before they begin to question their career choice? This negative response to the work reinforces the need for psychological safety. Since so many people do not understand the work, it is particularly important for these counselors to make connections with other counselors who do appreciate the challenges of end of life work.
Any emotional toll that takes place is likely a result of the cumulative losses associated with the work and the reactions of others when they learn about the specialty. One participant found herself creating a fictitious career to avoid the inquisition, while others learned not to elaborate unless probed. Finding ways to create psychological safety was an important factor for those counselors in this study who were able to combat burnout and compassion fatigue.

Traditionally, the term psychological safety is used in business settings where teams have been implemented to describe an environment in which an individual feels comfortable taking risks (e.g., brainstorming, making suggestions, or speaking up) without fear of negative outcomes (e.g., being criticized or ridiculed; Bradley, Postlethwaite, Klotz, Hamdani, & Brown, 2012). Psychological safety encourages interpersonal risk taking and the environment can be created by oneself or others. In the context of end of life counseling, I am repurposing the term psychological safety to describe the environment constructed by the specialist, which sustains them as they experience stress as a part of their work. The participants in this study identified three attributes that contribute to psychological safety, and these constructs, although embraced by all participants, were applied in varying degrees based on the preference of the counselor. The three sub-themes contributing to psychological safety include spirituality, connections, and boundaries. Although these themes are distinct the interplay between the three is noteworthy, reinforcing another constructivist theme of relatedness. In some instances during this study, the constructs were so interconnected it was difficult to
determine where one ended and another had begun. As is the case with a tapestry, the beginning of one thread and the ending of another was imperceptible.

**Spirituality.** No single definition of spirituality exists; for the sake of this research I will refer to spirituality as the connection with something that may (or may not) be outside of oneself. Spirituality and religiosity are not the same construct, and in some circles religion is considered a subset of spirituality. For this discussion, spirituality will be the all-encompassing term and used to categorize an important attribute in the creation of psychological safety.

Spirituality was identified as one of the factors that helped the counselors in this study cope with the deaths of their clients and the emotional toll of the work. The belief that there is something “more” and that death is not the end, were two ideas articulated by participants. The perception that life on earth is not all that exists and the possibility of an afterlife seemed to generate a feeling of hopefulness. Puchalski (2002) noted that spirituality fostered hope in those who are ill: “spirituality and religion offer people hope. It helps people find hope in the midst of despair that often occurs in the course of serious illness and dying” (p. 290). Since spirituality provides clients at end of life hope, it is reasonable to assume it offers a similar benefit for counselors, too, while also contributing to their psychological safety. The relationship between spirituality and the participants’ connections was also apparent, since some of the participants often talked about their connection to a higher power or God. This reiterates the point made earlier that the constructs were so closely integrated that it is difficult at times to see where one ends and another begins.
Connections. Miller and Stiver (1997) explained the distinctions between disconnections and connections, and the importance of mutuality in these exchanges. When empathy and empowerment exist, the connections will nourish and sustain, but when relationships are fraught with disconnections the relationship is not supportive. In this study, the counselors were likely to thrive when they had connections (e.g., significant other, supervisor, colleague, or friend) that understood them and appreciated the difficulty of the work. For connections to be meaningful it is not required that the individual be from the profession but it is helpful since the counselors felt the individual would appreciate the difficulty of the work. There was a desire by the participants in this study to be heard and understood, and the more connections that exist who “get it” the more the counselor benefits. The absence of these connections, and ultimately a gap in psychological safety, creates a void which is difficult to overcome with boundary setting and spirituality alone.

Boundaries. Boundaries are a necessary means for the counselor to protect their time, space, and energy. Parameters that were meaningful were developed by the specialists over time, and in some instances it was by trial and error. It was not until the specialists realized their personal limitations that they were able to set boundaries, and depending on the events in the individual’s personal life, these boundaries could ebb and flow. For instance, a counselor who had experienced several deaths in her caseload in a single week knew that she would need to create space to grieve so she made the decision to cancel appointments. The rationale is that it was better to reschedule an appointment with a client, than risk harm by grieving in the presence of a client. Setting boundaries
that allowed for adequate self-care was important in creating and maintaining psychological safety. These boundaries often centered on the construct of time: counselors limited caseload size, set parameters around the number of days in the office, reduced or eliminated on-call hours, and guarded their personal time. Creating a separation between work time and personal time was imperative and all of the participants attempted to create strategies that helped them to leave their clients “at work.”

**Unexpected Gifts**

The impact of working with clients at end of life can be transformative. The participants in this study recounted many stories highlighting the ways in which their lives were enhanced as a result of the work and their relationships with the clients and their families. The unexpected gifts were often related to the counselors’ connections, spiritual practices, and boundaries, or the triad that fosters psychological safety. The individuals did not enter the specialty seeking personal benefits, however all acknowledged that they had benefited, generally through growth and change, from the experience. One of the unexpected gifts of the work was the discovery that the specialty was their “sacred work” or “calling.”

**Connections.** By observing the relationships of their clients, the counselors were able to identify the growth connections and disconnections (Miller & Stiver, 1997) that existed in their own relationships. In the event a relationship did not foster growth or could not be transformed into a mutually beneficial situation, counselors were inclined to separate. Participants in this study saw the value of nurturing existing connections and
inviting new ones into their lives, and sought out people who were nurturing. An unexpected gift of working with clients at this stage of their journey was often the connection that was developed with the client who was dying. There were instances in which the counselors described their feelings for a client as “love.” This suggests that the counselors fostered connections with their clients that reinforced their psychological safety and also developed a professional confidence that allowed them to flex their professional boundaries.

In addition to changing the ways in which they related to others, these counselors also altered the ways in which they connected with themselves. These changes included modification to routines (e.g., how a person cared for their body or the amount of exercise they did), including the incorporation of personal boundaries to create more space for self-care. Self-care was an important outgrowth of the work, particularly after the counselors witnessed the suffering that could result when a person fails to take care of their bodies, and participants ensured they had adequate time for both exercise and rest. Attention to one’s physical self-care also enhanced the person’s relationship with self, which is the most important connection related to psychological safety.

**Spirituality.** For this group, self-care was not limited to the body; it extended to the spirit. Participants spoke of ensuring opportunities (through boundary setting) for prayer, mindfulness activities, meditation, and yoga. Those who considered themselves religious also discussed the importance of prayer, as well as bible study, music, and attending church. The importance of sustaining their spiritual practices was reinforced because they view their work as “sacred,” “holy,” and “God’s work.” Those who
embraced the idea of an afterlife reported a sense of peace when talking about death and considering their own mortality.

**Boundaries.** Another area of growth for these practitioners involved understanding the fluidity of boundaries. Although counselors are bound by a code of ethics, there is a need for flexibility in this specialty. The determination of what is considered professional conduct when a client is working with a dying client becomes more nebulous. These specialists allowed themselves the flexibility to use their judgment in combination with their wisdom to make decisions that practitioners in other venues will likely never need to make.

These end of life counselors also learned to appreciate the importance of boundaries in regard to their time and energy; creating boundaries around their time offered opportunities for self-care. Since time is a precious resource, the participants learned to spend their time wisely and the importance of using their time to appreciate the small and big things in their lives. This appreciation often came after observing clients who were dying with a longing for more. The clients did not express a desire for more things at end of life, but there was a hunger for more time. The participants found ways to carve out personal time to rejuvenate. An unexpected gift for some of the participants was the clarity around the importance of time for self-care, and reflection. Astrid and others learned to set boundaries around their time within the workday, often creating small periods of solace for reflection and quiet.

Just as these counselors have learned to carve out time for themselves, they have also set boundaries around the amount of work they take outside of their work setting.
The participants had empathy for their clients and their situations but when the work day ended, they appreciated the importance of leaving work at work and the significance of creating rituals to signify the end of the work day. Tahra noted her routine or “a ritual before I leave to make sure I don’t take any of their stuff home with me.”

**Integration Creates a Cycle of Sustainability**

When psychological safety was accessible to the end of life counselors in this study they were able to perform the work and withstand the stress that accompanies repeated exposure to illness and death. As these practitioners identified their unexpected gifts they were motivated to continue the work because they were enriched by the experience. Then after experiencing personal benefit from the work, the counselors’ desire to serve in combination with their personal growth prompted the counselor to continue in the process and reinforced the existence of the triad. In this study, as long as there was a meaningful combination of spirituality, connections, and boundaries, the counselors were sustained in the work. In those instances in which the triad was not present in the appropriate combination for the individual, they found themselves reevaluating their career choice. Deedra’s experience, as noted in Chapter 4, demonstrates the ways in which disconnections are detrimental to a counselor’s emotional state. She attempted to seek support in clarifying boundaries from those she believed to be workplace connections only to be disappointed. At the end of her experience, spirituality was her strongest attribute but it appeared insufficient to sustain her; it was evident that she needed more to continue. Martha, on the other hand, had discovered the combination of connections, boundaries, and spirituality that strengthened
and sustained her so she was able to continue in the specialty, and be open to receiving the unexpected gifts available to her through the work.

**Implications for Practice**

The findings in this study can inform the work of individuals fulfilling various roles within the counseling profession. There are opportunities for practitioners, supervisors, educators, and employers to leverage what was learned from the narratives of these 11 counselors. Although the practice settings may have varied, the themes (e.g., psychological safety and unexpected gifts) transcend the venue. There are also implications for related professions that may see their experiences reflected in the comments of these participants.

**Counselors**

Although I used the creation of psychological safety to encapsulate the participants’ need to create an environment in which they could withstand the weight of the work, their narratives highlighted the three sub-themes of connections, boundaries, and spirituality were instrumental for their success. From a constructivist perspective, active agency is apparent when counselors create a safe space for themselves by leveraging the three sub-themes. To sustain themselves in the practice of end of life counseling, practitioners can proactively seek ways to foster connections, explore their spirituality, and examine their boundaries. Strengthening these areas can be completed independently or during individual, group, or peer supervision. Leveraging connections is an important factor if the counselor intends to avoid or combat the isolation that plays a role in burnout. Some of the practitioners in this study referenced periodic feelings of
isolation as a result of their work setting (e.g., having sessions in the client’s home or a work environment that was not conducive to fostering connections) or as they spent time traveling between client sessions. For some of the hospice counselors, they spent a considerable amount of time alone in their cars since their clients were dispersed over several counties within their state of residence. This time alone when not used for rejuvenation (e.g., listening to music or audiobooks, self-reflection) left the counselors thirsting for connections.

**Connections.** The participants consistently commented that having relationships with individuals who understand the work is important and it was evident that engaging with others in the field contributed to psychological safety. Having an outlet where the counselor could be with someone who appreciated the work, even if they were not discussing the work, was beneficial. However, those who work in private practice or were the sole counselor at their facility found the identification of others in this specialty difficult. To address the feelings of isolation which may exist for private practitioners or individuals who are the sole provider of these services at their location, membership in the Association for Death Education and Counseling (ADEC) may be useful; ADEC has more than 900 members in their online community. ADEC sponsors an annual conference, which would present another means of meeting professionals who practice in this specialty. Another option for those individuals who continue to work with the families after the client dies is membership in the American Counseling Association’s Grief and Bereavement Interest Network. Membership in professional organizations such as these may be a way to foster connections.
Fostering nurturing connections with others with whom counselors can express their feelings freely is important, and some of the practitioners in this study used their personal counseling relationships to process their reactions to the work. Researchers have suggested that those working with clients who may experience very challenging situations may benefit from participating in their own therapeutic relationship (Katz, 2006; Quitangon & Evces, 2015).

**Boundaries.** As these counselors relayed their stories, they often referenced the ways in which the American Counseling Association’s (ACA) *Code of Ethics* (2014) informed their work, while some described situations that individuals unfamiliar with the work might perceive as unethical (e.g., buying gifts for the children of a dying client; inviting clients into their home outside of the therapeutic relationship). For participants in this specialty, there are some areas of ethical ambiguity. The *Code of Ethics* (ACA, 2014) sets parameters related to a variety of topics including confidentiality, dual relationships, and gift giving. Participants spoke about incidents in which they made decisions that did not fit neatly into any of the scenarios governed by the ACA *Code of Ethics* (2014). For example, one of the counselors took possession of her client’s ashes after her death because they had fostered a special relationship over the years they worked together. When the client died she had no one in her life except for the counselor and the counselor’s family. The counselor felt that someone needed to take possession of the client’s ashes, and she was the only person able to do so. The results of this study suggest that the practitioners use their clinical judgment when making decisions related to their clients and are not inclined to act as if the *Code of Ethics* (ACA, 2014) is etched in
stone. The ability to maneuver successfully in gray areas builds counselor confidence and is an unexpected gift.

Setting boundaries around caseload size and on-call times is also important in creating psychological safety. When counselors are required to be on-call they need to ensure they are not extending the workweek to a point where there is no down time. Counselors need to have a clear beginning and end to their day, with time to renew. End of life counselors, like other counseling professionals, need to self-advocate for themselves in their workplace (e.g., requesting flexible work schedules, speaking candidly when caseloads become overwhelming, requesting their cases be covered when they take time off) to ensure these boundaries are honored. Creating space for emotional and physical recovery, even when the work may be left unfinished, is critical. As was articulated by the participants in this study, counselors need to be mindful of the cumulative effect of the work.

Spirituality. The participants in this study identified practices that strengthened their spirituality, which in some instances involved participation in religious practices and interaction with a spiritual guide. Based on the results of this study, it is recommended that counselors consider their own spiritual perspective and explore the significance of this theme in their lives. Oakes and Raphel (2008) made recommendations pertaining to client spiritual assessment strategies that may prompt a counselor’s self-reflection in this arena. Prayer was a common practice with some participants specifically referencing centering prayer, and this may be a practice that some practitioners may want to consider as a component of their spiritual practice. Centering prayer, which is often learned and
practiced in a group setting (also reinforcing connections), is a purposeful way to connect with God (Wilhoit, 2014). Other spiritual practices specifically identified by these participants included daily meditation and creating a space for stillness, so the counselors could be emotionally present for their clients. Based on the responses of the 11 participants, finding ways to connect with one’s spirituality and maintain a spiritual practice is imperative to maintaining psychological safety.

**Supervisors**

Although not all participants in this study availed themselves of supervision, those who did articulated that there were many benefits which included increased self-reflection and awareness, and time to process their experiences. Like the practitioners in Crocket et al.’s (2009) research, the counselors in this study suggested that supervision reinforced that they were not alone in the work. Participants in this study were also asked to share their experiences with clinical and administrative supervision; they identified attributes necessary for a supervisor to effectively support them. Based on the responses of the participants, supervisors have the potential to play an important role in the creation of psychological safety if they foster connections that facilitate growth. Miller and Stiver (1997) noted that a growth connection must consist of empathy and empowerment that is mutual. Relationships can be a combination of connections and disconnections, and supervisors should be aware of the ways in which they are contributing to “mutual psychological development” (Miller & Stiver, 1997, p. 17).

Mutuality is a key concept, and supervisors will need to be mindful of the implications of the power differential that exists between them and the supervisee. Power
differentials can cause disconnections, which is not synonymous with the end of a relationship. According to Miller and Stiver (1997), a disconnection is a situation in which an individual feels separated from others. To increase the feeling of mutuality supervisors should leverage models that allow the duo to work in collaboration, such as the constructive clinical supervision model which is based on equality, encourages the supervisee to build on strengths, and to embrace change (Guiffrida, 2015). The attributes of this model, which also advocates for supervisors to adopt a consultative approach, have the potential to build connections based on mutual empathy and empowerment as described by Miller and Stiver (1997). Supervisors who find ways to foster connections with their supervisees will contribute to the supervisee’s psychological safety, and indirectly improve the counseling experience for the supervisees’ clients.

The relationship that exists between the supervisor-supervisee is critical, but the participants also noted that the supervisor needs an understanding of the end of life experience. Ideally the supervisor would have experience doing the work of an end of life counselor, but if that is not possible they could also leverage their personal experiences with loss, illness, and end of life. When asked how important it is for a supervisor to have experience in the specialty, Fae was adamant:

I think it’s imperative. I mean, I feel that a person who has never done this type of work and who wants to direct and supervise but can’t get on the phone and be interactive if you are doing this face to face… If they can’t do your job and the job they expect you to do, and they can’t do it themselves, I mean that’s just counterproductive in the work…It’s extremely important for that person to understand what it means to be in your shoes, either to be in your shoes or to be in your client’s shoes, and to understand the role.
The counselors in this study wanted to be understood, and when their supervisors had a related background they felt a stronger connection. In those circumstances in which supervisors had no experience with this specialty, the counselors felt disconnected and turned elsewhere to develop connections that would foster their psychological safety. If a supervisor is inexperienced in the field, finding ways to build their understanding and knowledge will be imperative if they intend to play a role in the creation of the counselor’s psychological safety. Although the supervisees noted the importance of the supervisor entering the relationship with knowledge related to the specialty, the participants in this study would likely have been receptive to providing some education to their supervisors, as long as they were not the sole source of information pertaining to the practice of end of life counseling.

Supervisors can contribute to the connections component of psychological safety by encouraging these specialists to engage in group supervision or peer support groups, and facilitate the development of this type of group if it does not exist. Peer support groups help individuals cope with difficult situations (Catheral, 1999) particularly when they are made up of individuals who have a shared experience (Maslach, 2003). A structured group supervision process is outlined by Lambie (2006) which encourages participants to develop a personal statement, identify stressors, and discuss balance. This activity, when completed with peers who understand the nuances of the end of life specialty, has the potential to help the participants to identify their unexpected gifts and explore their boundaries while fostering connections. Although Lambie (2006)
recommended this group structure to address potential burnout, the format has the attributes to facilitate the growth of psychological safety.

**Employers**

Nine of the 11 participants in this study were employed by either a non-profit or for profit organization, so considering the role of work climate as it contributes to psychological safety is important. A workplace climate that fosters social support has been demonstrated to impact employee efficacy (Sutton & Fall, 1995; Whitebird et al., 2013). Some of these participants addressed factors in their workplace that either contributed to their psychological safety or detracted from it. As such there are implications of this research for employers. Fae and others who do not work in a private practice articulated the importance of a positive work environment, with a focus on support, trust and respect for the skills of the individual practitioner.

Other participants articulated that a corporate culture which encourages them to 1) maintain manageable caseloads, 2) turn off phones after hours and require minimal time “on call,” and 3) maintain their autonomy, offered the specialists an opportunity to set boundaries at a level needed for psychological safety. Those entities that created opportunities for co-workers to interact with each other throughout the workday and organized situations in which counselors could process their experiences were facilitating connections, and supported psychological safety. Employers are encouraged to solicit feedback from their employees to identify areas of strength and opportunity, which can be done through climate surveys. If gaps are identified via these surveys, employers should consider contracting with consultants to ensure they are attending to the
discrepancies in ways that are meaningful to the counselors working with clients at end of life. Employers should also ensure that members of the leadership team who have not done the work as an end of life counselor are exposed to the experience, which can be done through the sharing of narratives. Leadership is cautioned not to assume that all forms of counseling are created equal and that they require the same support systems and infrastructure.

**Counselor Educators**

The feedback from the participants suggested that the knowledge required to support this population was not covered in their graduate programs. Most of the individuals noted that their programs had prepared them to support clients at difficult times but the programs had not prepared them to be on the journey with people who are approaching end of life, “at [a large university on the east coast] I don’t think they teach you how to be there with people who are dying.” Although the clinical skills may be transferable, the knowledge about the dying process was missing from the counselors’ educational experience. This gap in preparation is not limited to the counseling profession, and has been noted in the comments in other helping professions as well (Huff et al., 2006). Working with an end of life population requires a counseling skill-set similar to that used in other forms of counseling, but also necessitates a body of technical knowledge that is distinct to the specialty. The attainment of this information requires active agency, as the information is not likely to be delivered but must be pursued. The consensus of the participants was that graduate programs do not currently address the technical knowledge needed to engage in end of life counseling. This gap suggests the
need for a discreet course focused on end of life counseling, while also infusing pertinent content throughout the program. For example, issues related to disease progression and identity issues at end of life could be covered in lifespan courses.

The participants also suggested that the relationships and the boundaries between themselves and their clients are fluid, and that the rules and the professional code of ethics that govern the position are not taken literally. This perspective tests the traditional beliefs about what is appropriate (or not appropriate) for a counselor to do in the course of their practice, which has implications for counselor education programs. When counselor educators are teaching discrete ethics courses or incorporating ethics across the curriculum, are they considering the nuances of end of life counseling? It is unlikely since most practitioners have no experience with the population that are approaching end of life.

Ethical ambiguity is prevalent in this specialty. Some readers will feel uncomfortable knowing that participants in this study have expressed feelings of love for their clients. These counselors determine for themselves what would be appropriate in their practices based on their lived experiences with their client, so it will be important for counselor educators to apply ethical decision making models to end of life case studies (e.g., determine if it is appropriate for a counselor to speak at a client’s memorial service; explore when it is appropriate for the client’s family to interact with the counselor’s family; consider how to respond if a counselor is asked to take possession of a client’s ashes). This study suggests that the curriculum that currently prepares counselors may need to flex to meet the needs of this little known specialty that has the
potential to grow as the U.S. population ages. This could be accomplished by incorporating end of life issues in courses beyond those that address counseling across the lifespan. Technical content related to end of life issues (e.g., advanced care planning, understanding hospice and palliative care, Death with Dignity) should be incorporated in courses addressing ethical issues and multicultural issues. Counselors working with clients at end of life must have an awareness of the factors (e.g., culture, religion, gender) that influence the end of life experience, and their perspective on these issues. Although graduate students may not intend to practice within this specialty, there is a high probability that they will be faced with these issues at some point in their career.

In counselor education programs, there is also an opportunity to expand the students’ thinking around theory and the attributes of Maslow’s hierarchy of needs. This study suggests that the construct of safety can extend beyond the physical, and enters the psychological realm. Discussing the broadening of the hierarchy of needs with graduate students will expose them to the construct of psychological safety and how it may apply in their practice.

**Strengths and Limitations of the Study**

Since there is little written about the experiences of counselors who work with clients who are coping with an advanced illness and approaching end of life, it was appropriate to utilize a qualitative design for this study. This research explored the narratives of 11 counselors, which begins to offer insight into the work but the small sample size means the results cannot be generalized. Although we may now have an in-depth appreciation for the experiences of these participants, the sample was limited in its
diversity as I interviewed ten white female counselors and one African American male counselor. I do not presume that a more diverse sample would share the perspective of the eleven participants, and it is understood that a more varied sample could result in different perspectives, and this perspective can be explored in future research. A more diverse sample will allow one to consider variations in experiences that may be influenced by age, gender, race and cultural background. All of the participants in this study identified as either spiritual and/or religious; the construct of psychological safety would likely be comprised of a different set of sub-themes if a counselor did not share this point of view.

Two interview guides were developed and I used them both to ensure the participants had an opportunity to respond to a core group of questions during both the first and second discussion. I conducted the twenty-two interviews and, as an insider with familiarity with the work, there is the risk that the participants did not elaborate in a way they may have with an individual who was less familiar with the work. There is also the possibility that my probes were limited by my Christian beliefs when the participants talked about spirituality or referred to God. Both I and the participants may have assumed knowledge. Assumed knowledge also could have impacted the depth of discussion related to the work itself since we may not have elaborated on points because we had a shared language which may have implied a shared understanding.

Interviews were conducted by phone and in person, with the majority occurring over the phone. This was done for the convenience of the participants and it offered a sense of anonymity so the counselors could speak freely about their clients, their work,
and their employers. The use of the telephone for this purpose may have created some limitations as it did not allow me to respond to the participants’ body language. It is conceivable that the conversations may have veered into different directions had I been able to observe the non-verbal cues. Despite the identified limitations, the attention paid to the procedural requirements of a qualitative study will allow the findings to set the stage for future research. In addition, although the themes in this study may not be generalizable, the knowledge gained can be used by other practitioners who work within this or a related specialty, and those who may work with clients coping with an advanced illness in another setting. The themes uncovered in this study may also apply to helping professionals from related fields who work with clients coping with an advanced illness or facing end of life.

**Suggestions for Future Research**

As a result of this research, I deduced that these individuals working with clients facing end of life created their own psychological safety as a means of sustaining themselves in a profession that can be emotionally and physically fatiguing. This construct, in combination with the unexpected gifts received as a result of the work, fortify the counselors to continue in the work, whereas the absence of these constructs may put the professional at risk for burnout. Future research can confirm the hypothesis that psychological safety is created, and explore whether the model may be appropriate to other helping professions.

This study examined the experiences of counselors who were working with clients at end of life, or had transitioned to a similar role within the past 24 months. A
future qualitative study could explore the experiences of counselors who have left the specialty to determine the relevance of psychological safety and the role of unexpected gifts in their practice. This type of study would provide the insight needed to determine if the absence of these constructs played a role in the counselor’s departure from the specialty. In addition, a quantitative study in which a larger sample was surveyed to determine the prevalence of psychological safety would begin to uncover the generalizability of the sustainability model.

Since all participants in this study identified as spiritual or religious, future research should include participants who do not identify as either, as a means of exploring the make-up of psychological safety when one of the three sub-themes is absent. It would also be intriguing to interview individuals from other faith traditions to determine if spirituality is an important factor contributing to psychological safety across religions. A quantitative analysis would allow an inquiry into the role of spirituality across groups, to determine if spirituality is a component of psychological safety for all faith traditions, and how it is combined with connections and boundary setting for different groups.

Participants in this study referenced a specific skill-set and a body of knowledge that was unique to this specialty, with some indication that this content had not been covered in their graduate programs. To understand how graduate programs are preparing students to serve this population, recent graduates could be surveyed to explore their level of knowledge pertaining to end of life issues. In addition, graduate program faculty could
be surveyed to examine the ways in which their curricular experiences are preparing students for this work.

**Conclusion**

The objective of this study was to uncover the experiences of counselors working with clients coping with an advanced illness or facing end of life. The literature did not offer insight into what was involved in this specialty and we could only draw conclusions from other helping professions if we wanted to understand how practitioners sustained themselves in the work. This study offers a glimmer of insight into the end of life specialty and allows us an opportunity to appreciate the mechanisms used to create psychological safety (e.g., connections, boundaries, and spirituality) and the unexpected gifts associated with the work. The implications of this study are meaningful to counselors, supervisors, educators, and employers, and more research is required to consider the implications of the work on a larger scale.
References


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Appendix A

Interview Protocol - Session #1

The first interview will dedicate some portion of the session to gathering participant demographics via the demographic worksheet. This will not be repeated in interview 2.

DEMOGRAPHICS
Q: Tell me about yourself....

CONFIDENTIALITY
Before we begin discussing some of your experiences, I would ask that you not incorporate any of your clients’ names in our conversation. I know we both wish to protect the privacy of your clients and this allows us to increase our level of protection.

TRANSITION
Q: There are several counseling specialties (e.g., addictions, career, and mental health) and I would like to hear about your decision to work with clients facing end-of-life....

TOPIC
Q: Tell me about your experiences working with clients that are dealing with an advanced illness...

Q: How do you feel about your work... your clients.... your experiences.....yourself?

Q: What do you think about before and after a session with a client?

Q: What is it like for you when one of your clients dies?

Q: What is it like for you when a client recovers and then has a recurrence?

Q: What do you do for yourself?

Q: Tell me about your supervision...

Q: What impact has your work had on your thoughts about your own mortality?

Q: How do you explain your work to people you meet for the first time?

Q: What are your thoughts about sharing your feelings about your client's situation?

Q: Tell me about your preparation for this work...
Appendix B

Consent Form

CONSENT FORM FOR ADULTS

Please read below with care. You can ask questions at any time, now or later. You can talk to other people before you sign this form.

Study’s Title: Understanding the Counselor Experience When Working with End-of-Life Clients

Why is this study being done? The primary focus of this study is to understand the experience of the counselors working with clients who are dying. Exploring how the counselor feels and what their thoughts are about working with a dying client is the focal point of this study. Understanding how these clinicians cope with the impact of a client’s death is an important aspect of this research.

What will happen while you are in the study? In the event you agree to participate in this study you will have up to two (2) face-to-face or phone interviews with the researcher. Each interview will last approximately 90 minutes. Prior to beginning the initial interview, you will be asked to complete an optional demographic worksheet. The demographic worksheet will include questions related to gender, race, ethnicity, education, place of practice, length of practice, size of case load, and spiritual or religious preferences. Participants can abstain from any or all questions included on the demographic worksheet.

During the second interview, you may be asked for clarification on discussion points from a previous interview. You will be asked a series of questions and your interaction with the researcher will be recorded. The recording will be used to prepare a transcription of your conversation with the researcher, which will later be reviewed by the researcher. When the researcher is confident that the transcript is accurate, the recording will be destroyed. The transcript will not contain your name or any other details that would link it to you. A copy of the transcript will be available, if you would like to review your comments. As the participant you determine if the site of the interview is convenient for you and meets your needs for privacy.

Time: This study will take about 90 minutes per interview, and up to two (2) interviews will be conducted over the course of several months.

Risks: During the interviews you will be talking about experiences involving your clients. To protect the privacy of your clients, we will not use their names. Because the clients are dealing with an advanced illness and approaching death, you may experience feelings of sadness or anger. Because you are a counselor working with end-of-life clients, the anticipated risks are not expected to be greater than those which you experience during the course of your professional practice or during a supervision session.

Interviews will be conducted in person or by phone, but informed consent documentation will be shared via email. Because we will be using the Internet for this purpose and appointment scheduling, we believe that your completion of the consent and responding to email presents no greater risk than everyday use of the Internet. Please note that email communication is neither private nor secure. Though we are taking precautions to protect your privacy, you should be aware that information sent through email could be read by a third party.

Although we will keep your identity confidential as it relates to this research project, if we learn of any suspected child abuse we are required by NJ state law to report that to the proper authorities immediately.
Benefits: The benefits of this study for you may include a heightened personal awareness and an understanding as to the impact of this work on your own quality of life and the associated feelings and thoughts that accompany end-of-life counseling.

Others may benefit from this study as the research will provide an increased understanding of the implications of this type of work on the end-of-life counselor and there will be the potential for the development of training to prepare counselors for this specialty. An increased awareness for members of the profession that has the potential to enhance services to the client.

Compensation (not applicable)

Who will know that you are in this study? Although the results of this study may be used in publications or presentations, you will not be linked to any presentations. We will keep who you are confidential.

Do you have to be in the study? You do not have to be in this study. You are a volunteer. It is okay if you want to stop at any time and not be in the study. You do not have to answer any questions you do not want to answer. Nothing will happen to you if you opt not to participate or opt out at any time during the process.

Do you have any questions about this study? If you have questions, please contact me via phone, (973) 615-6597 or email: ducainec1@montclair.edu. Written inquiries can be mailed to: Connie S. Ducaine, Montclair State University, University Hall, Room 3169, Montclair, NJ, 07043. This study is being conducted under the guidance of my faculty advisor, Dana Heller Levitt, Ph.D. at Montclair State University. If you wish to reach her, please contact her at (973) 655-2097 or levittd@montclair.edu. Written communications should be sent to Dr. Levitt’s attention at: Montclair State University, University Hall, Room 3169, Montclair, NJ, 07043.

Do you have any questions about your rights as a research participant? Phone or email the IRB Chair, Dr. Katrina Bulkley, at 973-655-5189 or reviewboard@mail.montclair.edu.

Future Studies It is okay to use my data in other studies:
Please initial: _____ Yes _____ No

Study Summary
I would like to get a summary of this study:
Please initial: _____ Yes _____ No

As part of this study, it is okay to audiotape me:
Please initial: _____ Yes _____ No

A copy of this consent form will be provided to you for your records.

Statement of Consent
I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction.
understand that I can withdraw at any time. My signature also indicates that I am 18 years of age or older and have received a copy of this consent form.

Print your name here  Sign your name here  Date

Connie S. Ducaine  Signature  Date
Principal Investigator

Dana Haller Levitt, PhD  Signature  Date
Faculty Advisor
Appendix C

Demographic Worksheet

Please complete this worksheet before we begin. The information will be kept confidential but do not include your name on this form. If you do not wish to respond to a question, please leave it blank. Thank you.

Date: _________________

- Gender: __________________
- Race: __________________
- Ethnicity: __________________
- Highest Level of Education Completed (X in the appropriate space):
  Masters _______
  PhD _______
- Identified Specialty: ____________________________
- Place of Practice (X in the space that aligns with the location(s) where you work with end of life clients):
  Private Practice _______
  Community Agency _______
  Hospice _______
  Hospital _______
  Other (Please explain) _______
- Years of Clinical Practice: _______
- Length of Time Working with Clients at End of Life: _______
- Current # of Clients Dealing with an Advanced Illness or Facing EOL: _______
- Do you consider yourself spiritual or religious?
  Yes _______
  What religion do you practice? ____________________________
  No _______
- Please note any other information you feel is important to share:
  __________
Appendix D

Recruitment Letter

Dear Colleagues:

I am writing to seek your assistance in recruiting participants for a qualitative study I am conducting regarding the experiences of counselors who work with clients with an advanced illness and are approaching end-of-life. I am looking for professional counselors throughout the U.S. who specialize in end-of-life, to participate in up to two (2) face-to-face or phone interviews which will be conducted over a three month time period. (Each interview is expected to take 60 – 90 minutes.) I would welcome an opportunity to discuss the professional counselor’s feelings and thoughts as he or she works with clients who are coping with an advanced illness.

The information gained via these interviews will help me to understand the experiences of counselors who work with patients who have a life-limiting illness and are projected to die within 12 – 24 months. Significant research has been done regarding the client experience at end-of-life, but there is currently little research that reports on the experiences of the counselors. I am hoping that the analysis of these interviews will offer us insight into the counselor’s experience and help to identify themes that can be used to inform counselor education and supervision.

If you meet the criteria for this study and would like to participate, please contact me. I would greatly appreciate it if you would also forward this request to any of your colleagues who may be appropriate for this study. Anyone interested in participating can reach me by phone (973-615-6597) or email (ducainecl@montclair.edu). This research has been approved by the Institutional Review Board at Montclair State University (IRB Number: IRB-FY15-16-57).

Thank you for your assistance. Please let me know if I can answer any questions or provide additional information.

Sincerely,

Connie S. Ducaine, LPC, LCADC, ACS, BCPC, NCC
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