

A PHENOMENOLOGICAL INQUIRY OF THE HOLISTIC NONMEDICAL LIVED
TRAINING EXPERIENCES OF END-OF-LIFE DOULAS (EOLDS)

By

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A THESIS

Submitted to
Michigan State University
in partial fulfillment of the requirements
for the degree of

Human Development and Family Studies—Master of Science

2021

ABSTRACT

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A new generation of aging United States (U.S.) citizens seems to be challenging cultural attitudes toward death and dying. The members of the senior baby-boom cohort are demanding more nonmedical end-of-life (EOL) home care, the right to experience a dignified and peaceful death, and the option of environmentally friendly burials. Subsequently, the field of end-of-life doulas (EOLDS) or death doula care is also emerging. These practitioners, who claim to contribute to a better quality of EOL care, are raising awareness as they add a new dimension to the EOL field. The purpose of this qualitative phenomenological study was to understand the lived training experiences of prospective EOLDS to aid the dying and their grieving families. Individual interviews with seven trained EOLDS who completed a training program were analyzed. The results showed that those who attended the EOLD training felt strongly “called” to do EOL work. They also reported that after confronting and accepting their fears and anxieties about their future dying and death experiences, they felt capacitated to assist others on their dying journey. Participants revealed feeling empowered to come alongside EOL individuals and offer genuine comfort and postmortem care to their family.

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ACKNOWLEDGMENTS

This EOLD research project was an incredible journey. One that transcended thoughts and emotions about the present human lifespan divisions, diverse family lives on their own journey, and the afterlife-death dimension. I am eternally grateful to all who made the completion of this research work possible. Chiefly among them is the omnipresent, invisible, yet palpable Divine Being(s) - the wind beneath my wings - carrying me above seasons of doubt and insecurity through to secured confidence. To the love of my life and cheerleader, my husband Jim, whose physical presence and encouraging words nurtured and nourished me throughout this academic endeavor.

I am thankful to have had Dr. Desiree Qin as my advisor, master committee chair, supervisor, and friend. I have been inspired by your dedication to your family, to your professorship, and to your students. Your gentleness and loyal support touched me in countless ways. Thank you for believing in me and standing by me. I also want to thank Dr. Clair Vallotton and Dr. Amanda Woodward for the rewarding experience you both gave me as I completed this research project. Your guidance and support as my master committee members were a great incentive to me to keep moving in the right direction.

To Dr. Sarah Goodwin, you were the reason this end-of-life research project was first launched into being. Meeting you for the first time during your qualitative research class and working side by side to sketch its initial steps set me on this rewarding research path. Thank you so much for your genuine care and generous assistance. To Dr. Scout Calvert – thank you for listening to my original outlines and giving me directions on how to do academic research using available tools at the MSU Library.

To Carin Graves – our HDFS-MSU Librarian I-Continuing – thank you for securing important and relevant peer-reviewed documents and books promptly and cheerfully. You were a reliable right-hand person when I needed validated information.

In conclusion, this study would have been impossible without the seven end-of-life trained doula participants who voluntarily became the unidentified coresearchers for this study. Your sincere interest in this research project and transparency in responding to the seven research questions revealed the main two reasons people like you become trained EOLDs. You were instrumental in helping me complete this research journey and I am eternally grateful for your contribution.

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CHAPTER 1: INTRODUCTION

Background

A current gap of awareness exists among healthcare providers and the general populace about holistic nonmedical end-of-life doulas (EOLDs) (Brennan, 2019; Cochran, 2019; Fersko-Weiss, 2017; Rawlings et al., 2018, 2019, 2020; Rush 2020). EOLDs quietly serve the dying and their families in diverse communities throughout the United States (U.S.) (Brennan, 2019.; Cochran, 2019; Gurevich, 2019). The word *family* refers to “any two or more people who have made a commitment to each other and are bound together by an emotional connection” (Fersko-Weiss, 2020, p. xiv). EOLDs assist individuals and their families with a holistic approach, providing emotional, spiritual, nonmedical support, and guidance to end-of-life (EOL) patients and their families (Fersko-Weiss, 2017; Rawlings et al., 2018, 2019, 2020). Accordingly, this qualitative study aims to investigate the core nature of EOLDs’ lived training experiences. The primary purpose of this study is to elucidate, understand, and promote EOLDs’ salient role in aiding those who seek a peaceful death.

This introductory chapter provides a contextual framework for the topic of EOLDs, the significance of the study, and how I conducted the research. This inquiry’s all-inclusive focus is to investigate the value and effect that EOLDs’ training has in preparing them to provide practical yet compassionate care during an EOL patient’s dying experience. In line with the overarching hermeneutic phenomenological premise guiding this research, this chapter will provide the reader with essential background information, a description of the origins of the study, an overview of the procedural details, and conclusions.

I became curious about this topic while volunteering as a harpist during the “eleventh hour” (the hours to minutes before death) at Spectrum Hospital Cancer Wing in Grand Rapids, MI. There,

I noticed marked differences in how families held space (or simply being lovingly present) for their loved ones' last moments of life. Some stayed calm, caring, and reassuring. Others did not. Watching these different scenarios play out piqued my curiosity and inspired this EOLD research. The first step in this research project involved researching peer-reviewed literature related to accomplishing a peaceful death. During this process, a unique group called EOLDs stood out to me as a possible resource to help the elderly and people with terminal illnesses achieve a tranquil end.

EOLDs are emerging paraprofessionals who are growing in numbers and popularity in the U.S., and most noticeably so, in the last five years (Rawlings et al., 2018, 2019, 2020). The National Hospice and Palliative Care Organization [NHPCO] (2021, April 22) testifies that EOLDs do not replace hospice care or palliative care medical teams. Instead, EOLDs complement healthcare services provided to dying individuals and their families by adding volunteered or privately paid services. Individuals interested in the work who wish to explore becoming EOLDs typically study the literature about EOLDs available online, volunteer at local hospice facilities, or enroll in an EOLD training program (Fersko-Weiss, 2017; Webster et al., 2018). Online articles about EOLDs are usually written by individuals who have worked in the EOL field as nurses, social workers, chaplains, physicians, administrators, or even other professionals outside the EOL field who felt called to become committed EOLDs (Fersko-Weiss, 2017; Karnes, 2019).

Some of these individuals have become EOLD trainers and have established their own training programs. For example, (1) Henry Fersko-Weiss—a former social worker in hospice care—founded the International End-of-Life Doula Association (INELDA); (2) Alua Arthur—attorney, adjunct professor, ordained minister—founded the Going with Grace training program and EOL planning services; and (3) Marilynne Rush—an RN, former birth doula, president of the

National End-of-life Doula Alliance (NEDA), and NHPCO-EOLD council member—co-founded the Lifespan Doula training program and founded The Dying Year doula training program. Many other EOLD leaders are engaging in the mission of moving the work EOLs provide forward by offering post-COVID-19 online training programs that range from 15 to 72 hours long.

Although Rawlings et al. (2018, 2019, 2020) have written three major academic peer-reviewed papers based on EOLs in Australia, academic research about EOLs is minimal (Rawlings et al., 2018, 2019, 2020). This lack of research means that most people dealing with EOL issues are not aware of EOLs (Cochran, 2019; Fersko-Weiss, 2017; O'Brien, 2015). This is potentially because EOLs have only recently emerged. Such unawareness limits the opportunity to hire and work with EOLs. Therefore, this phenomenological investigation hopes to fill this research gap as it focuses on the lived training experiences of EOLs. This study aims to understand the EOLs' qualifications to serve those at the end of their lifespan by addressing awareness around their lived training experiences. I hope to raise public awareness of EOLs' work and promote their facilitation of more peaceful ways to die.

A clear understanding and description of the EOLs' lived training experiences may provide an enhanced account of their nonmedical holistic role in the EOL field. Those working in the healthcare system, the EOL patients and their families, and others interested in this topic may benefit from this study's results. A better comprehension of who the EOLs are may also give prospective employers in the healthcare system and in families the information needed to hire them with more confidence and to work alongside them with better understanding and cooperation. The National Hospice and Palliative Organization (NHPCO) created the EOLD Advisory Council in April 2018 with the purpose of educating their hospice and palliative care personnel about the EOLs' role in the EOL field (NHPCO, 2021, April 22). Lastly, this phenomenological study

could also help add and disseminate information for future academic research studies on EOLDs' nonmedical holistic work. I will explain the problem and the purpose statements in the next two sections.

Problem Statement

This research project does not aim to describe a problem and its solution. Peoples (2020) maintains that a phenomenon or a lived experience is not a problem, yet it is still called a phenomenological problem. Writing about a problem may be out of line with phenomenological research. However, Van Manen (2014) explains that we may consider a lived training experience phenomenon as a problem since it needs explanation.

Therefore, a phenomenological inquiry may start by asking, “what” is the essence of *X*'s lived experience, and “how” “it” was experienced. The questions are then investigated until the description of its universal meaning or essence—such as, grief—is found (Creswell & Poth, 2018, p. 75). To find this universal meaning, I investigated the EOLDs' lived trained experiences as experienced and narrated by them and used interpretive hermeneutic phenomenological analysis to guide this research.

The words *lived experience* refer to something important that happened to individuals either by choice or without it, expectedly or unexpectedly, negative, or positive, and of which they are consciously aware (Smith et al., 2013). In addition, Smith et al. (2013) describe *lived experience* as “a unit in the flow of time...which is made up of parts of life, linked by a common meaning” (p. 2) also known as a phenomenon. Phenomenology studies a phenomenon, event or process that appears as a structure experienced from the first-person point of view (usually regarded as subjective) and which the person attempts to understand (Colaizzi, 1978; Smith et al., 2013).

In sum, phenomenological research concerns a phenomenon or an experience of something significant in a person's life that was lived in a period, such as the participants in the EOLD training experienced (Colaizzi, 1978; Creswell & Poth, 2018; Dahlberg & Dahlberg, 2020; Peoples, 2020; Suddick et al., 2020; Van Manen, 2014, 2016, 2017). A phenomenological research question has the following components: (1) it asks about lived experience, (2) it is free from assumption(s), and (3) it is easy to understand without the need for clarification.

Purpose Statement

The purpose of this qualitative interpretive phenomenological study was to examine the value and effect that EOLDs' training has in preparing them to provide practical yet compassionate care during a patient's dying experience. Therefore, the aim of this research is to find the answers to the following questions:

- What qualifies EOLDs to do their work?
- What differences or changes can participants detect within themselves after their EOLD training?
- How does the EOLD training empower participants to serve EOL individuals?
- Would you recommend EOLD training to someone who feels called to do EOL work?
- Would you hire an EOLD?

Research Question

The main research question guiding this study is *What are the nonmedical holistic lived training experiences of EOLDs?* This study's research question complies with MSU-HRPP's requirements for a research question as there are no reasonably foreseeable risks to participants because the seven planned interview questions were related to their EOLD training. All participants received the same disclosure of information regarding participation in the research

including descriptions of research activities, research procedures, explanation of voluntary participation, and withdrawal without penalty, in addition to the name and contact information for the researcher and the educational institution—Michigan State University (MSU).

Conclusion

I have outlined in Chapter 1 the topic to be researched and its significance. It has included the problem and purpose statement, the configuration of the research questions, a brief description of the methodological framework, and a summary. In Chapter 2, the literature review—I expound on relevant peer-reviewed research and theories about death and dying as well as information about those in the EOL medical healthcare system. I then transition into the main focus of this research—the EOLDs—including a focus on who they are and what they do to assist the dying and their families. In Chapter 3, the Methodology section, I describe the study’s design, the researcher’s role, reflexivity, and the research procedures. I close Chapter 3 by explaining four constructs of validity and reliability: credibility, transferability, dependability, and confirmability, and presenting the ethics framework.

CHAPTER 2: LITERATURE REVIEW

To guide the development of this study, the overall goal of this literature review is to gain a solid understanding of existing research on the human death and dying industry in the U.S. The intent is to critically evaluate the different research bodies in this field, starting with a human developmental perspective before focusing specifically on the last stage of the lifespan. Next, I will review and highlight the overall trends to guide the appropriate approach to investigate the research question – What are the holistic nonmedical lived training experiences of EOLDs? – and other related queries. Using a deductive approach, I will analyze EOL caregiving practices from the broader healthcare perspective to the unconventional holistic EOL comfort care. Lastly, I will discuss relevant literature that relates directly to the lived nonmedical training experiences of EOLDs.

Lifespan Development Perspective

Although the human lifespan varies across societies, the basic tenet of human development is that individuals grow and change from conception throughout their lifespan until death (Santrock, 2019; Walsh et al., 2020). The lifespan follows a multi-dimensional development pattern: physical, cognitive, and socioemotional (Kail & Cavanaugh, 2019; Kuther, 2020; Santrock, 2019). These developments interact and overlap; for example, in the brain's growth, the cognitive expansion that may affect understanding concepts such as poverty may also help develop empathy toward people under those circumstances (Kuther, 2020; Santrock, 2019).

Last Stages of Development

Since current 65-year-olds (y/o) are leading healthier, more productive lives than their predecessors in past generations, I will use Santrock's (2019) and Walsh et al.'s (2020) concept of late adulthood or young-old (from 65 y/o to 84 y/o) and older oldest-old (85 and older) throughout

the discourse of this literature review. Those categorized in the young-old group may still retain physical strength and cognitive ability that allow creativity to manage “the gains and losses of aging” (Santrock, 2019, p. 15). However, the oldest-old may start to display physical frailty, cognitive deterioration, chronic illness and reach a point in the lifespan where medical intervention becomes challenging (Walsh et al., 2020). During this developmental phase, a different shift occurs toward maintaining and managing the physical, cognitive, and socioemotional decline as individuals grow and change (Etkind et al., 2017; Santrock, 2019). The regulation and adjustments of loss (e.g., impaired vision and hearing, decreased cardiovascular performance, changing sleep patterns, erectile dysfunction, etc.) become a salient focus in late adulthood (Etkind et al., 2017).

Aging demands accommodation and adjustments of one’s capabilities to challenge cherished freedoms and independence (Etkind et al., 2017). Thus, aging may prompt some individuals to carve new paths by proactively surveying their multi-dimensional decline and circumstantial environment for opportunities to optimize and enjoy life (Santrock, 2019). Therefore, being aware of life expectancy and mortality projections may keep caregivers of the aging population well informed and open to necessary changes and accommodations.

Projected Life Expectancy and Mortality in the U.S.

The projected life expectancy and mortality in the U.S. is an essential matter to the EOL industry. Medina et al. (2020) explain that it is vital to consider projected life expectancy or a person’s longevity and mortality in the U.S. because population life expectancy is increasing. In 1960 the average U.S. life expectancy was 69.7 years, while by 2017, it had grown a full ten years to 79.7 years (Medina et al. (2020). By 2060, the total population is projected to gain six more years of life up to 85.6 in 2060 (Medina et al., 2020). Xu et al. (2020) report that life expectancy

is 5.0 years higher for women than for men. These data matter for the planning of medical procedures and care in addition to EOL needs.

How People are Dying

Death can occur at any time in a person's lifespan. The deaths of most children are caused by accidents such as falls, house fires, motor vehicle crashes, drowning, poisoning, or by incurable congenital disabilities, cancer, heart disease, or other types of ailments (Kochanek et al., 2019; Santrock, 2019). Most adolescents and young adult deaths occur due to alcohol abuse, motor vehicle crashes, suicide, or homicide (Kochanek et al., 2019; Santrock, 2019). Most older adults are afflicted and incapacitate slowly and progressively with chronic heart diseases and cancer until they die (Etkind et al., 2017; Santrock, 2019).

Moreover, two factors have a significant effect in decreasing life expectancy: first, the slow progress in finding a cure for major leading causes of death such as heart disease, with 690,882 deaths in 2020, and cancer, with 598,932 deaths in 2020 (Admad et al., 2021). Admad et al. (2021) also added COVID-19 with 377,883 deaths as the third leading cause of death in 2020. The total U.S. mortality data reported for 2020 amounts to 3,358,814 – the death-adjusted rate was 828.7 death per 100,000 population, an increase of 15.9% from 715.2 in 2019 – COVID-19 being a contributing, highest among persons aged ≥ 85 years (15,007.4) with age-adjusted rates higher among males (990.5) than among females (689.2) (Admad et al., 2021).

The second factor is failure to eradicate persistent health-risk behaviors such as obesity, smoking, and others (Medina et al., 2020). Smoking is considered “the leading cause of preventable disease and death in the United States” (Medina et al., 2020, p. 4). The Office of the Surgeon General reported in 2014 that over 16 million U.S. citizens experienced medical issues related to smoking, such as lung cancer. Each year, around 500,000 individuals die from smoking-

related illnesses (Medina et al., 2020). Another preventable contributor to mortality is obesity. Obesity significantly contributes to a decrease in life expectancy. CDC (2021) estimated that 42.4% of U.S. adults were obese in 2017–2018. Cardiovascular diseases, type 2 diabetes, and some types of cancer are caused by obesity-related conditions (Medina et al., 2020).

These statistics are relevant because the life expectancy and mortality reports and projections are crucial for planning future U.S. mandates and awareness of social welfare (Kochanek et al., 2019). Current statistics are also vital for guiding inevitable repercussions in the healthcare systems and the EOL field as the recent surge of the aging baby-boomer cohort increases (Medina et al., 2020). Additionally, the unexpected mortality increases due to the ravages of the COVID-19 pandemic.

Aging Baby Boomers

The baby boomers (those born after WWII until the mid-1960s) are reaching retirement age (Henchoz et al., 2019). Henchoz et al. (2019) also observed that it is too early to capture health discrepancies among this cohort. Researchers will need more observational studies in the next decade to generalize health outcomes between the late and early baby-boom cohorts. However, present data show technological medical advances, prevention programs for risk-behavior, and control of common health morbidities as interventions are failing to protect baby boomers from health decline (Cochran, 2019; Henchoz et al., 2019). For instance, approximately 40% of baby boomers are obese today, compared to just 15% of adults in the 1970s; additionally, baby boomers have a higher prevalence of cancer and diabetes than the general population (Song & Ferris, 2018). Hence, despite more extended life expectancy, baby boomers are susceptible to higher rates of obesity, diabetes, and other comorbidities, therefore driving higher health care costs and increasing the need for more health care professionals (Cochran, 2019).

Nonetheless, Brennan (2019) describes the surge of baby boomers as a positive modality for change in the healthcare industry. Kortes-Miller (2018) reports evidence of discontentment about the present modes of medical care at the EOL. Brennan (2019) proposes to stay abreast of baby boomers' inclination for lifestyle changes that embrace environmental concerns and holistic approaches to health care. Brennan (2019) adds that critical life transitions usually require new care prototypes to meet people's needs as they approach the EOL within their cultural context, which should concern EOLDs.

The Death System Within the Cultural Context

Death is inevitable, and every individual is eventually involved with someone else's or their own death at some point in their lives (Walsh et al., 2020). Diverse cultural mandates and societal expectations from different geographic locations in the world may guide caregivers whose patients' cultural beliefs honor the dying with various rituals during the pre-and post-death events (Butters, 2017; Santrock, 2019; Walsh et al., 2020). In Santrock's (2019) view, every cultural setting has a death system that seems to share five universal components (p. 606):

(1) *People*—The dying person, family, friends, acquaintances, and their community. Some community members have a designated role with death, such as healthcare system personnel, clergy, caregivers, firefighters, police officers, and the funeral industry.

(2) *Context/Places*—This includes where the person has died and where they will be taken and buried or laid to rest. Dying may occur at home, in hospitals or hospices, on battlefields, at an accident scene, or in many other places. Places where the dead are honored include funeral homes, cemeteries, green-burial backyards, memorial walls, and open nature.

(3) *Times*—Occasions are set aside to remember and honor the dead with visitations, rituals, ceremonies such as anniversaries, D-Day in WWII, Memorial Day, 9/11/2001, and others.

(4) *Objects*—The items associated with death include urns, shrouds, caskets, hearses, unique clothes, and other items specific to a culture.

(5) *Symbols*—Symbols may represent religious rites, ceremonies for the dead, and images used across cultures. For example: skull(s), angel(s), crossbones, and others.

Death in the United States

Advances in medicine and technology, as well as the other public health measures, have caused an increase in life expectancy, which is considered one of the 20th century's outstanding achievements. Adults' health and well-being have improved, and human life expectancy has increased to 79.7 years in the U.S. (Leming & Dickinson, 2020; Medina et al., 2020). "In less than a century, more years were added to a human life expectancy than in all of the prior millennia" (Santrock, 2019, p. 6).

However, when considering longevity, most observers do not evaluate the afflictions experienced among the oldest-old who eventually find themselves overtaken by ventilators and drug cocktails, broken hips and diapers, chemotherapy and radiation, surgery after surgery, and hospital bills (Sinclair, 2019). A cure is almost impossible for many conditions among the oldest-old, as with aggressive terminal cancer, and many terminally ill patients endure unnecessary surgical interventions designed to prolong life (Leming & Dickinson, 2020). Rawlings et al. (2018) claim that dying is increasingly being medicalized due to costly trivial treatments that continue until death; therefore, the cost increase in such medical interventions contributes to a healthcare system that cannot provide dignified EOL care.

Hospitals offer professional clinicians and medical technology to prolong life at any stage of life. As beneficial as these treatments may be, this might not be the best situation for an individual diagnosed with a terminal illness and much less a place for them to die (Santrock, 2019).

Santrock (2019) adds that the rates of those dying at hospitals and nursing homes are still 50% and 20%, respectively. Virdun et al.'s (2017) study showed that optimal EOL care is not part of routine hospital care despite most deaths in hospitals. Hence, more people choose to die at home or in hospice inpatient facilities (Santrock, 2019; Leming & Dickinson, 2020).

Santrock (2019) and Cochran (2019) have observed that individuals near the EOL do not desire to lengthen life as much as they wish to have comfort, respect, and gentle care, which prepare them to die with dignity. A study led by Hamamoto et al. (2016) concluded that terminally ill patients who stayed at home or entered a hospice survived longer than those admitted to a hospital. According to Santrock (2019) and Bannon et al. (2019), older adults prefer to die at home or in a hospice care facility (Santrock, 2019; Bannon et al., 2018). However, those facing the EOL are still encountering various challenges.

Santrock (2019) and Inbadas (2017) note that most people in the U.S. view death from a Christian perspective, in which death is a transition from the physical life to a nonmaterial existence. Other civilizations may accept death and welcome it as culmination of a fulfilled life, e.g., the Tanala culture in Madagascar. Others may detest death and fear it, specifically, India's Gond culture (Santrock, 2019). Santrock (2019) emphasizes that the U.S. is known globally as a "death-denying and death-avoiding" society that seeks the "fountain of youth through diets, surgery, and other means," even in post-death. Families in the U.S. allow the funeral industry to inject toxic formaldehyde to embalm and present their dead during viewing with a "lifelike" appearance (p. 607).

It seems that due to people's fears and their avoidance of death and dying, they have surrendered their power of control over their health and dying to the health care system (S. O'Brien, personal communication, October 29, 2020). Kortes-Miller (2018) adds that people have

allowed drug companies, insurance companies, healthcare providers, policymakers, and the death and dying institutions to regulate their lifespan until post-death. The “dying and death [industry] has [an immense] financial impact we tend not to talk about” (Kortes-Miller, 2018, p. 25).

However, according to Cochran (2019), Kortes-Miller (2018), and Rawlings et al. (2019), baby boomers are asking for better choices and more control over their dying and death. Therefore, baby boomers are promoting the rise of new advocacy groups, such as the Death Cafés, the Association for Home Funerals, assisted physician suicide protected by law in several states, and other death-positive movements. Cochran (2019) also points out that emerging death-positive initiatives raise awareness about new post-death care in the U.S. For example, green burials are believed to be healthier for the environment than embalming and cremation, home funerals, backyard burials, composting burials, ocean burials, and other innovative methods. However, attitudes about death and dying vary among adults of all ages.

Death Awareness and Readiness to Die

Attitudes toward death and dying may vary among the young-old and oldest-old adults; according to Santrock (2019), they still think about death more often, tend to show less death anxiety than young and middle-aged adults, and converse more about death. Etkind et al. (2017) and Santrock (2019) state that those in the middle-aged developmental stage experience a subtle awareness and progressively increasing consciousness that they are aging, that their time left to live is ticking away. On the other hand, older adults tend to embrace inner-contemplation activities and do a more positive life review with less emotional pain than young and middle-aged adults (Santrock, 2019). Furthermore, illnesses and the death of family members and friends become more frequent at this stage. Thus, they become acutely aware of death’s nearness and prepare for

death with fewer unfinished projects or anticipations; for example, their children are grown and are fulfilling their own goals and earthly tasks (Etkind et al., 2017; Santrock, 2019).

Lowey (2015) reports that researchers Glaser and Strauss (1965) studied patients' realization of their impending death. Through observations of patient's interactions with health caregivers, Glaser and Strauss were able to gather and arrange their findings into four contexts of awareness: *closed*, *suspicion mode*, *mutual pretense*, and *open*.

Closed Awareness—This group represents patients with a severe prognosis and clinicians who did not reveal that death was near. However, these patients were able to sense that clinicians were not telling them their actual prognosis. Patients then engaged in suspicion mode awareness.

Suspicion Mode Awareness—Patients search for the truth by using direct and indirect queries to verify their suspicions. In efforts to prove or disprove their skepticism, they may resort to deceitful tactics. For instance, they may instigate a response by saying to the attending nurse that the doctor believes their disease has become severe.

Mutual Pretense Awareness—Rather than acknowledging that death is near and that both the patient and caregivers know the other knows of the impending death, patients experiencing this mode of awareness choose to pretend that all is well. Glaser and Strauss (1965) consider this type of awareness a coping mechanism because the patient is not ready to talk about or face death.

Open Awareness—In this context, both the patient and the clinician acknowledge that death is near and openly talk about it. Glaser and Strauss (1965) believe open awareness is beneficial for both the patient and the caregivers. The patient benefits from accepting their situation and coping with the reality of pending death. The clinicians benefit from being truthful, open, and direct. The freedom to ask outright about the patient's condition is liberating.

Lowey (2015) also describes Copp's (1998) readiness to die theory, which alludes to the physical body's readiness and the conscious self, two distinctly separate entities, willing to split or separate during the last breaths. The following are Copp's (1998) four modes within which death may happen (Lowey, 2015, p. 32):

- The self-ready—The physical body not ready
- The self-ready—The physical body ready
- The self not ready—The physical body ready
- The self-ready—The physical body not ready

The self-ready and the physical body ready seems to be the ideal combination for dying. According to health care providers who work in EOL palliative and hospice care, the coordinated readiness of the dying self and body is their preferred mode (Lowey, 2015; Diamond, 2019). It seems that the interplay of honest transparency and readiness benefits all those involved in anyone's dying process.

Another well-known researcher who studies those at the EOL is Elisabeth Kübler-Ross. In her book, *On Death and Dying*, published in 1969, she describes emotional and spiritual last life manifestations, including fear, worry, a feeling of being overwhelmed, denial, blame or guilt, and acceptance. Kübler-Ross's information about the emotional stages of dying is valuable for EOL clinicians and nonmedical holistic EOLD practitioners because it will help them provide the comfort EOL individuals need.

The Stages of Dying According to Kübler-Ross

The statement "we are born to die" evokes questions about death and dying: does our life experience prepare us for dying and death? (Santrock, 2019, p. 614). Do we become aware of death only when the end is near? Are there gradual emotional transitions into accepting death? (Kortes-

Miller, 2018). Research by Kübler-Ross (1969) and Kübler-Ross and Kessler (2014) explores five emotional states most terminally ill individuals experience when facing their mortality (*denial and isolation, anger, bargaining, depression, and acceptance*):

Denial is a period of disbelief. At first, there is a refusal to believe that the terminal diagnosis is correct and a conviction that a mistake has been made (Kübler-Ross, 1969). Depending on the person's circumstances, they may or may not adjust to their condition and may search for additional medical advice to verify diagnoses (Leming & Dickinson, 2020). Fersko-Weiss (2017) notes that the shared fear of death in U.S. culture is ingrained that the first response is denial when a person is diagnosed with a terminal illness. Furthermore, the constant 'keep them alive at all costs' subliminal marketing messages from the for-profit medical system, alongside the exorbitant for-profit pharmaceuticals, tend to perpetuate death denial (Bregman, 2019). Eventually, the individual in denial reacts to the reality of unfinished projects, unfinished financial issues, and the well-being of those who will be left behind (Leming & Dickinson, 2020).

According to Kübler-Ross (1969), *Anger* is the following common reaction for most patients. Emotions of rage, anger, resentment and even jealousy of other people's good health arise within the patient who asks, "why me?" The patient may direct their intense emotions of anger toward family members, family caregivers, clinicians, and even God.

Bargaining is the next emotional stage where hope for postponing or delaying death is possible (Kübler-Ross & Kessler, 2014). Fersko-Weiss (2017) has observed that most physicians do not talk about death and dying with their patients, thus preserving a false hope of a healing miracle. The patient may engage in negotiations with their supreme being and bargain for an extension of life void of pain in exchange for an "implicit promise" that is "rarely kept" (Leming & Dickinson, 2020, p. 149).

Depression usually replaces anger and rage with an intense sense of loss, acceptance, and submission to dying. Other characteristics of this stage are stillness, introversion, isolation, and times of crying and grieving. Kübler-Ross advises allowing the patient to experience this stage without disruption (Kübler-Ross, 1969).

Acceptance—Kübler-Ross describes this last stage as the end of struggling with death and dying and the beginning of readiness and acceptance for the EOL span journey (Leming & Dickinson, 2020; Santrock, 2019).

Nonetheless, some critics question the validity of Kübler-Ross's theory, which was based on her interviews with 200 terminally ill patients for three years. Her critics argue that she failed to assess and account for the specific effects of the interviewees' illness and medications, caregiving support, and the institutional environment they interviewed (Leming & Dickinson, 2020; Santrock, 2019). Recent evaluations of Kübler-Ross's theory also argue that it lacks universality, meaning that not all patients experience all five stages in successive order of manifestation, as she claimed. For instance, some patients may become angry, bargain, and be depressed simultaneously (Leming & Dickinson, 2020; Santrock, 2019).

Other factors missed by Kübler-Ross' analysis, according to her critics, is that (1) no two individuals experience life's crises nor dying in precisely the same way, (2) men and women grapple with their emotions differently, and (3) in other cultural settings beside the U.S., emotional manifestations before dying may differ (Leming & Dickinson, 2020). Nonetheless, some psychologists have adopted the five stages of dying with the new name of "potential reactions to dying" and recount the stages of dying as taking place in any order and at any time (Santrock, 2019, p. 615).

Despite criticism, it is to the credit of Kübler-Ross's investigations that awareness about the struggles terminally ill patients encounter and manage before dying has become public. The way people die in hospital settings began to be examined more thoughtfully and critically soon after her book's publication (Santrock, 2019). Kübler-Ross is also credited with inspiring the conception of the hospice movement and the birth of palliative medicine, which is currently an essential component of health care in the U.S. (Leming & Dickinson, 2020).

Due to Kübler-Ross' research work, assessing patients' physical pain and emotional distress have become part of the routine measurements of vital signs during regular medical check-ups; for example, blood pressure, pulse, temperature, respiration, pain, and emotional distress (Leming & Dickinson, 2020). Parkes and Parkes (1984) documented that in 1979 (ten years after Kübler-Ross's publication), the staff at hospitals, hospices, and palliative care settings routinely checked for physical pain and emotional distress as vital signs.

Bergman (2019) sees *On Death and Dying* as an attempt to rescue the natural human experience of dying from "medical domination" (p. 8). Corr (2018) also believes that Kübler-Ross's five stages of grieving and the hospice movement came into existence due to an underlying collective desire to reclaim control over the dying process. Arizona State University REACH Institute (2020, September 2) adds that control over the dying process could address unexpressed emotions and unfulfilled wishes that could motivate dying patients and their families to break through denial and the fear of death and dying.

Table 1: Significant Responses Clinicians and Nonmedical Providers May Impart to End-of-Life Patients and Families Transitioning Through Kübler-Ross’s Five Stages of Dying

Kübler-Ross Stages of Dying	Clinicians and Nonmedical Providers Interventions
Denial	<ul style="list-style-type: none"> • Active listening. Provide support as needed. - Be sensitive to patients’ thoughts and ideas even if medically unrealistic - Patients need to feel they are being understood and accepted
Anger	<ul style="list-style-type: none"> • Educate family members who may be on the receiving end of the patient’s anger. - Tell them that anger is a normal part of the dying process. It is anger at impending death, and the patient feels safe taking it out on those closest to them. - Respond to patient’s anger in an accepting and non-provoking manner because their anger is at their situation and not at caregivers.
Bargaining	<ul style="list-style-type: none"> • Pleasant approach—not overly cheerful. - Since patient bargaining often occurs internally, clinicians may not take any particular action. Observe the patient’s expression to gauge your facial expressions during interactions. - If the patient brings up the topic of God or spirituality, provide active listening and emotional support. - Pray with the patient if comfortable with doing so and if requested.

Table 1 (cont'd)

Kübler-Ross Stages of Dying	Clinicians and Nonmedical Providers Interventions
Depression	<ul style="list-style-type: none">• Do not urge patients to “cheer up” or “look on the bright side.” Avoid clichés.- Realize that nothing you do will cancel their impending death. Your actions may be more meaningful to patients than your words- Educate the family about this stage. Encourage them to support the patient in other ways than trying to cheer them up. <p style="text-align: center;">S</p>
Acceptance	<ul style="list-style-type: none">• Patients benefit from non-verbal forms of communication—holding their hands, lightly stroking their back, quietly sitting with them.- Continue to anticipate the patient’s needs. Address their concerns.- Continue to provide emotional support to the patient and family.

Note: Adapted from Lowey (2015). Nursing care at the EOL: What every clinician should know. p.29-30)

Family members report feeling less anxious at hospices than at hospitals because, according to Parkes and Parkes (1984), hospices provide more comfort care to the dying patient and closer contact with the family before and after the loss. However, regardless of the positive progress hospice care has accomplished thus far, mainstream health care in the U.S. still prioritizes curing the disease rather than caring for the dying individual and striving to support the family (Fresko-Weiss, 2017; O’Brien, 2015; Webster et al., 2018).

The Hospice and Palliative Care Movement

The history of hospice within the U.S. healthcare system began in 1978 under the name of the National Hospice Organization. It changed its name to the National Hospice and Palliative Care Organization (NHPCO) in 2000 (NHPCO, 2020). Since then, it has expanded its services from 158,000 patients in 1985 to 1.55 million in 2018 (Leming & Dickinson, 2020; NHPCO, 2020). The goal of hospice and palliative care has been to improve the life quality of patients by treating symptoms and side effects. Also, both institutions offer patients, and their families support in emotional, social, spiritual, and practical issues that illness may bring up, such as connecting families to financial resources or providing additional help for family caregivers (Kortes-Miller, 2018; NHPCO, 2020).

Hospice and palliative care are the standard care for the EOL services in the U.S. Aside from hospices and palliative care services, no other government-approved agencies mediate for the dying and their families in U.S. communities (Cochran, 2019). The NHPCO, 2020) reports the existence of 4,639 Medicare-certified hospices in operation that were paid a total of 19.2 billion dollars for their services in 2018 (p. 17). Most of those who received hospice care in 2018 were: (a) females, (b) 85 y/o and older, (c) Caucasians (d) cancer patients, (e) those who died at places patients called “home” (NHPCO, 2020). Every hospice that became certified by Medicare is also insured by the Medicare Hospice Benefit, enacted in 1982 (Leming & Dickinson, 2020).

Nonetheless, many hospice programs still depend on donations, memorials, and grants to assist dying patients who lack Medicaid, Medicare, and insurance coverage (Leming & Dickinson, 2020; NHPCO, 2020). Additionally, most hospices operate for-profit rather than nonprofit, “less than 10 percent being nonprofit and 6 percent government-run, e.g., the U.S. Department of Veterans Affairs medical centers” (Leming & Dickinson, 2020, p.186).

While palliative and hospice care have a close relationship, palliative care is available at any stage of illness. In contrast, hospice is available when life expectancy is around six months or less (NHPCO, 2020). Palliative care focuses on the patient from the moment of diagnosis to relieve pain and discomfort (nausea, insomnia, shortness of breath, and other troublesome symptoms) due to side effects from the illness and medications (NHPCO, 2020; Vandergriendt & Weatherspoon, 2020). Therefore, if patients live with a chronic disease, they are eligible for palliative care at any time, even before there is a need for hospice or during hospice care (NHPCO, 2020). Depending on the patient's diagnosis, palliative care may or may not continue in tandem with hospice care (see Table 2 for other differences in care between palliative care and hospice).

Hospice is designed for terminally ill individuals who have six or fewer months to live and are no longer candidates for curative treatments (NHPCO, 2020; Rawlings et al., 2020). Therefore, hospice care focuses on enhancing the quality of life of the EOL individuals by reducing physical pain and suffering while upholding the right that every dying person must live fully up to their last breath (Kamal et al., 2017; Kortes-Miller, 2018). For admittance into hospice care, the patient needs certified approval from their primary physician or a hospice doctor to receive comfort care instead of curative care (Cochran, 2019; Medicare.gov, n.d.).

Table 2: Critical Differences Between Palliative Care and Hospice Care

	Palliative care	Hospice care
Who is eligible?	Anyone with a severe long-term illness, regardless of the stage	Anyone with a terminal illness whose doctor determines they have less than six months to live
What does it involve?	<ul style="list-style-type: none"> • Symptom relief • Help to make critical medical and treatment decisions • Emotional, spiritual, and financial support for the patient and their family • Assistance in coordinating care 	<ul style="list-style-type: none"> • Symptom relief • Help to make essential EOL decisions • Emotional, spiritual, and financial support for the patient and their family • Assistance in coordinating care
Can you still get curative treatments?	Yes, if you wish	No, you must stop curative treatments to qualify for hospice.
Can you still get life-prolonging treatments?	Yes, if you wish	No, you must stop life-prolonging treatments to qualify for hospice.
Who is involved?	A doctor or nurse(s) specializing in palliative care, as well as other healthcare professionals such as your primary doctor, pharmacists, social workers, and counselors.	A doctor or nurse(s) specializing in hospice care, as well as other healthcare professionals such as your primary doctor, pharmacists, social workers, and counselors.
Where is it available?	Depending on where you live – Home care is sometimes available but often offered through a hospital or outpatient clinic.	<ul style="list-style-type: none"> • Your own home • A hospice facility • A hospital • A nursing-home • An assisting-living facility

Note: Adapted from Vandergrient & Weatherspoon (2020). What's the difference between palliative care and hospice care?

How is Hospice Care Provided?

Around 80% of hospice patients receive care in patients' residences—private homes, nursing homes, and other long-term care facilities—with the rest receiving care in a hospice inpatient facility or a hospital's acute units (NHPCO, 2020). When a preassigned representative family member decides to seek hospice care for the terminally ill relative, the hospice team follows up with assessments and necessary services and care tailored specifically for the patient (NHPCO, 2020). The hospice interdisciplinary team coordinates and provides around-the-clock care until the patient's demise.

The care plan includes two main components: pain management and symptom control. Both are methods to provide comfort without complete sedation so that the patient can remain comfortably present (Leming & Dickinson, 2020; Lowey, 2015). Figure 2 includes two physicians, the patient's physician, the hospice physician director, and trained volunteers, social workers, nurses, hospice aides, therapists (physical, occupational, speech, and others) if needed, and spiritual counselors, including the clergy, if desired.

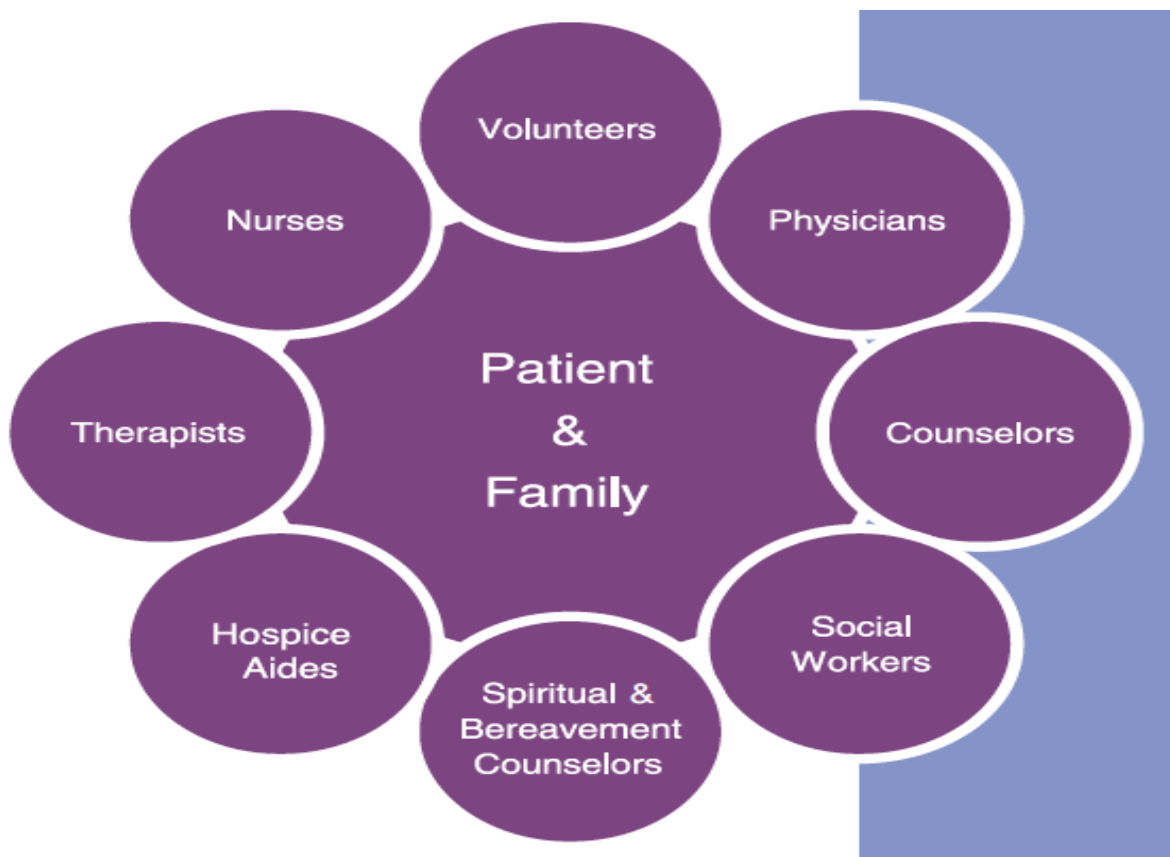
Services the Interdisciplinary Hospice Team Delivers

NHPCO (2020) lists eight hospice services:

1. Supply medical equipment and medication
2. Educate the family on how to assist the terminally ill patient
3. Regulate pain and other afflicting symptoms
4. Provide spiritual, emotional, psychosocial counseling to patient and their family
5. Assist with grief support and bereavement counseling before death

6. Provide grief support and counseling to surviving family and friends
7. Provide various therapy types to the patient as needed
8. Provide respite for caregivers and short-term inpatient care when symptoms become challenging to control at home.

Figure 1: Members of the Hospice Team Support



Note: Adapted from National Hospice Palliative Care Organization (2020). NHPCO facts and figures: Hospice care in America.

The level of care is customized according to the patient's pre-existing conditions. Due to the number of interdisciplinary team members involved in each terminally ill patient's care, the cost of hospice comfort care is considered excessive (Leming & Dickinson, 2020), averaging \$12,200 per hospice patient in 2018 (NHPCO, 2020) for two weeks or less. However, Leming and

Dickinson (2020) also consider the spending per hospice patient as very cost-effective compared to the cost of multiple hospitalizations plus the price of the accumulative cost of medication and time spent in hospital rooms. Nonetheless, other services are being made available for the dying patient and their families, expounded in the next section.

Current Challenges Individuals at the End of Life and Their Families Face

Regardless of the quality of EOL, every person in the U.S. deserves to have comfortable care. However, there is no guarantee for the following two reasons: first, the ratio of a hospice nurse to multiple (at least six) dying patients does not fully meet each dying patient's individual needs; second, a night shift nurse cannot overextend their time or energy to care for family members who struggle with various fears and grief (Diamond, 2019). The structure of hospice care for dying patients in their own homes, which may be spread throughout diverse communities and towns, restricts the comfort-care hospice promises to provide (Karnes, 2018, Krawczyk & Rush, 2020).

Cochran (2019) expressed concern that although hospices claim they provide ongoing comfort care, many hospice personnel's bedside visits tend to last an hour or less and rely primarily on family caregivers to care for the patient the remaining time. Cochran (2019) also claims that after the patient's death, the hospice bereavement team coordinator tends to transfer the supervision of the bereavement family to a new team member, which can be very unsettling to grieving families. Cochran (2019), therefore, promotes the hiring of EOLDs to give respite to grieving family members and provide seamless comforting care between the pre-and post-death period.

Another factor to consider is that only one out of four nurses feel prepared and confident to assist the dying and their families (Lowey, 2015). According to Lowey (2015), topics about

EOL in nursing textbooks constitute less than two percent. Both statistics seem appalling when palliative and hospice care is experiencing exponential growth in the U.S.

Another issue of concern is the influx of baby boomers reaching retirement age. They are already starting to request more comfort care than what hospice provides, such as extending the time of care that hospice caregivers may be allowed to provide (Cochran, 2019). When the healthcare system does not meet the needs for EOL comfort care in hospitals, palliative, and hospice care, interdisciplinary programs and advocacy groups will increase to fill the gap (Fersko-Weiss, 2017). Hence, the demands for palliative and hospice care will continue to rise (Commisso et al., 2017). An increase in healthcare demand may exceed the services palliative and hospice centers provide and overextend the time and availability of their staff. Fersko-Weiss (2017) witnessed this gap in the medical care system when he attended as a hospice clinician an overwhelming number of dying patients. He remembers being unable to aid them with an easier transition into the afterlife.

When the healthcare system does not meet the needs of dying patients, interdisciplinary advocacy groups such as the EOLDs begin to address the need for a more dignified way to die (Fersko-Weiss, 2017; Rush, 2020). EOLDs offer information about EOL services beyond what hospice care provides. For example, EOLDs help with advance care planning, revision of patients' legal documents and online accounts for survivors to review, and other decisions terminally ill patients need to make before losing their ability to speak for themselves (Van Eechoud et al., 2014; Krawczyk & Rush, 2020; Cochran, 2019).

How the EOLDs Roles Differs from those of Other EOL Professionals

The services of EOL specialists such as hospice nurses, hospice volunteers, counselors, therapists, funeral directors, EOLDs, and others are indispensable during the pre-and post-death

experiences of dying individuals and their families (NHPCO, 2020; Rawlings et al., 2019). I will explain how the EOLDs role differs from other EOL service providers: a) hospice nurses; b) hospice volunteers; c) counselors, therapists, psychologists, and psychiatrists; and d) funeral directors.

a) *Hospice nurses vs. EOLDs*—Hospice nurses attend to the medical needs of the EOL patient. EOLDs, on the other hand, do not provide any medical care. EOLDs do not take measurements of vital signs, give medications, conduct patient assessments, or follow medical orders for the patient’s medical needs (Fersko-Weiss, 2017). Although hospice nurses provide compassionate care and emotional support to their EOL patients and families, their available time to offer such help is scarce (Cochran, 2019; Rush, 2020). Hospice nurses prioritize medical assistance, have many other patients to care for, and other responsibilities to attend during their work shifts (Rawlings et al., 2020). Therefore, sitting by the bedside of a dying patient is very difficult to accomplish.

Hence, hospice nurses rely on hospice volunteers and people such as EOLDs to provide EOL patients extra time and extra personal care they wish they could give but cannot (Fersko-Weiss, 2017). Furthermore, many hospice nurses experience this gap in personalizing care and choose to serve as an EOLD, either professionally or in a volunteer role (Karnes, 2018). Their function as EOLDs gives them the flexibility and freedom to sit by the bedside of dying individuals and offer holistic care (Fersko-Weiss, 2017; Karnes, 2018).

b) *Hospice volunteers vs. EOLDs*—Most hospice volunteers are trained in the “No One Dies Alone” project and provide companionship sitting by the bedside during a patient dying process (Cochran, 2019). Cochran (2019) adds that volunteers agree to abide by the preset hospice regulations, which, although necessary, can limit how much and what kind of support they may

offer EOL patients. By contrast, EOLDs provide services outside of the scope of the hospice volunteers. For example, EOLDs may assist their EOL patients in fulfilling their wish to die where they want to die and in the way they wish to die (Karnes, 2018). According to Fersko-Weiss (2017) and Karnes (2018), many EOLDs begin their practice as hospice volunteers and continue to work alongside non-EOLDs hospice volunteers. Additionally, hospice volunteers are usually assigned to assist EOL patients who have no friends and family (Diamond, 2019). Whereas EOLDs have the freedom to help both those who are dying alone, as well as those surrounded by friends and family (Fersko-Weiss, 2017; Karnes, 2018).

c) *Counselors, therapists, psychologists, and psychiatrists* may diagnose and treat mental health issues for EOL patients. EOLDs do not diagnose or treat mental illness but may help EOL individuals and families recognize the signs of depression or anxiety and refer them to mental health professionals (Diamond, 2019; Fersko-Weiss, 2017; Karnes, 2018). EOLDs are trained in deep listening techniques and engage in active listening and compassionate support in conversations about death and dying with their clients (Fersko-Weiss, 2017).

d) *Funeral directors vs. EOLDs*—EOLDs do not operate as funeral directors. This service is not one of their main service objectives (Webster et al., 2018). As Webster et al. (2018) recount that “replacing the funeral director is not [the EOLDs] goal. Empowering families is” (p.1). Therefore, EOLDs offer home funeral guidance and support as an accessory service to their clients. EOLDs may present other available and legal funeral and burial options, such as home funerals and green burials (Fournier, 2018; Webster, n.d.). EOLDs also help their EOL patients consider their options before they die or help their grieving family plan the post-death arrangements (Webster et al., 2018). The following section will focus more on the description of EOLDs.

EOLDs: Who are the EOLDs?

EOLDs serve as a nonmedical bridge of care between the medical services of palliative and hospice care providers and patients and families. EOLDs fill in the gaps without appropriating the procedures hospice and palliative care practitioners provide (Gurevich, 2019; National End of Life Doula Alliance [NEDA], 2020, October 15). Although EOLDs provide nonmedical care, they ensure the dying individual receives the medical care they need from the healthcare team. EOLDs also offer comfort, holistic support, education, guidance, and emotional, spiritual, and practical care (Fersko-Weiss, 2017; Gurevich, 2019; Rush, 2020). Table 3 reviews the difference between hospice and EOLDs' services. Table 4 displays the overlap of services between EOLDs and the hospice team.

Table 3: Differences Between Hospice and End-of-Life Doulas

Hospice Team	End-of-Life Doulas
Plan medical care	Reinforces / complement hospice's medical care plan
Paid by hospice A Medicare benefit for people over 65 y/o	Privately paid by families Volunteer at hospices
Licensed roles	No national regulatory board
Care clearly defined and the same in all 50 states	Skillset may differ depending on previous occupation(s) and end-of-life doula training
Provide clinical care	Provide practical nonmedical holistic care

Note: Table 3 was adapted from NHPCO—Difference between Hospice and EOLDs services & Overlap of services between EOLDs and the hospice team.

Table 4: Overlap of Services Between End-of-Life Doulas and the Hospice Team

Overlap of Services Between End-of-Life Doulas and Hospice Team
End-of-life planning and guidance
Emotional and spiritual support and care
End-of-life vigil support
Ceremonial and funeral planning
Bereavement care

Note: Table 4 was adapted from NHPCO—Difference between Hospice and EOLDs services & Overlap of services between EOLDs and the hospice team.

Furthermore, EOLDs help the dying and their family reduce fear and anxiety by teaching them the natural stages of dying and how to decide on their EOL care; for example, EOLDs discuss what a “good death” means and support their plans, including funeral and burial (Fersko-Weiss, 2017; Gurevich, 2019). EOLDs do not serve to impose their personal beliefs, morality, or religion on the dying. Although they may explore spiritual and philosophical beliefs through active listening in conversation, they always respect the dying person’s religious desires for the context of their dying, including death rites (Gurevich, 2019).

EOLDs represent a new nonmedical way of approaching dying, death, and burial with more awareness and empowerment (Kaufman, 2020). EOLDs encourage dying patients to return home or stay home while receiving hospice services. The patient may receive more personable treatment at home and be surrounded by family and friends (Kaufman, 2020). Fersko-Weiss (2017) asserts that EOLDs transform how EOL patients die and how families experience their death. However, EOLDs are the least known and understood of all interdisciplinary teams in the nonmedical group (Rawlings et al., 2018, 2019).

The EOLDs

Present-day EOLD training programs base their modalities on the birth doula approach. According to Brennan (2019), the birth doula movement began in the U.S. around 1969 and became mainstream in 1992. The first EOLD program in the U.S. started in New York City in 2003 at Continuum Hospice by Henry Fresko-Weiss (International End of Life Doula Association [INELDA], 2020, October 15). Henry Fersko-Weiss also founded the International End of Life Doula Association (INELDA) in 2015 to train EOLDs and implement a different way to assist the dying at the end of their illness and lives (INELDA, 2020, October 15). EOLD trainers such as Fersko-Weiss hope to become a viable part of the healthcare system reimbursed by Medicare and insurance companies (Kaufman, 2020). Currently, their services are not covered by private insurance or Medicare. Some EOLDs negotiate to make direct work contracts with patients and their families; others choose to serve as volunteers (Brennan, 2019).

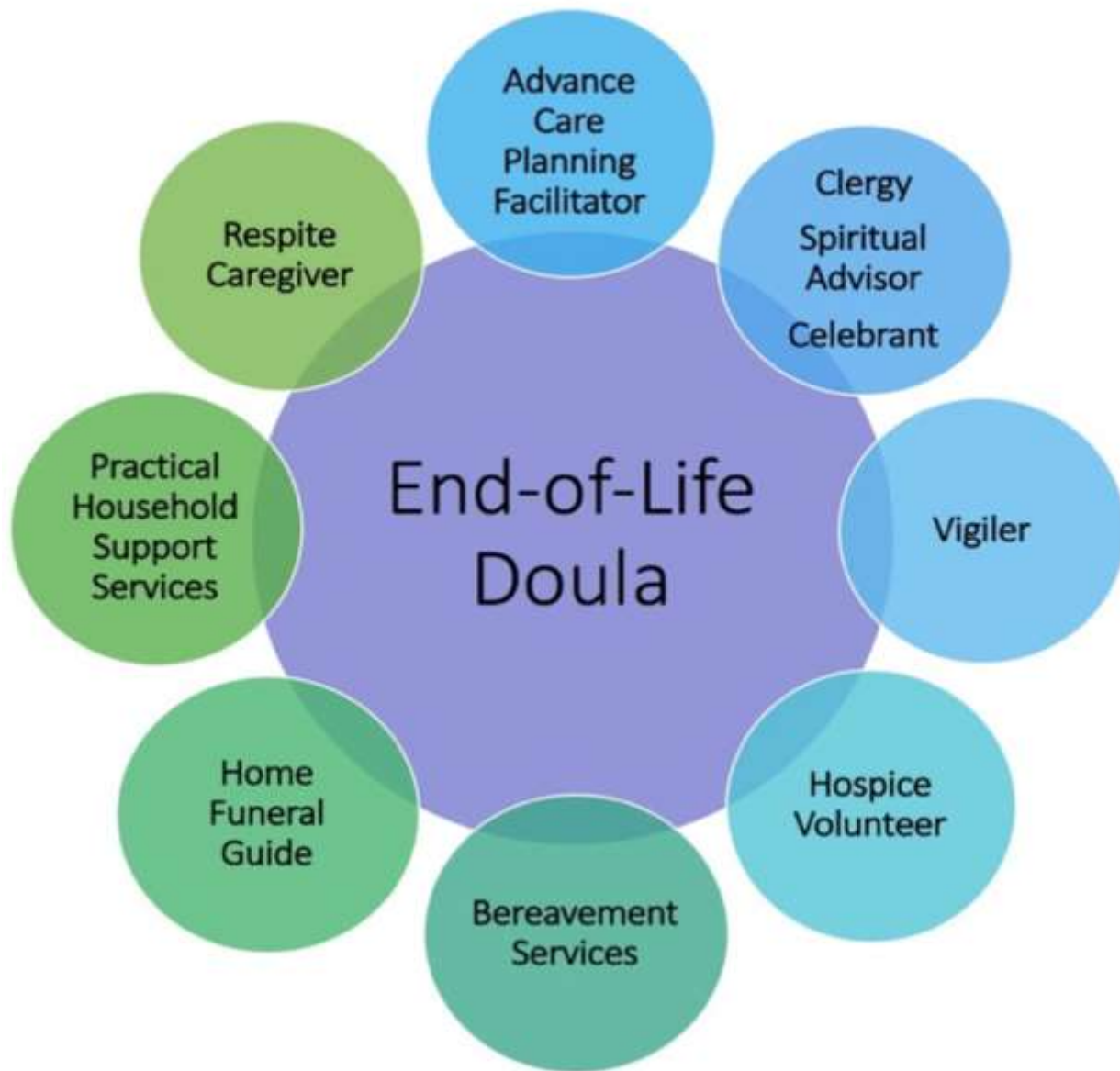
EOLDs are individuals from different occupational backgrounds who take training (in-person before COVID-19 and online after COVID-19's restrictions) from an EOLD individual trainer or an EOLD training organization such as The Dying Year, INELDA, Doulagivers, Lifespan Doulas, Going with Grace, and many others (Rush, 2020). Brennan's (2019) concern is as numbers of active EOLDs continue to increase, "there is a danger that each new player in the field will attempt to assert their brand by re-inventing and re-designing the role of the doula" (p. 217). Hence, unification is needed under one umbrella with established core requirements for functioning as an EOLD.

Some EOLDs also work as health professionals (palliative/hospice or volunteers, pastoral care, etc.). These multi-professionals working as EOLDs add to the role of lack of clarity (Rawling et al., 2019). As mentioned earlier, EOLDs lack regulation and are not subject to state laws; hence,

each trainer certifies their methodology. It is up to the trainee to compare training programs before enrolling (Rush, 2020; Brennan, 2019).

As a developing profession, it is logical that EOLDs lack credibility and stability within the EOL care industry, which may be a source of confusion for consumers and healthcare organizations (Brennan, 2019; Rawlings, 2018, 2019). For some patients and their families, valid accreditations are essential because they uphold EOLD's capability to provide quality care. There is uncertainty about the validity of EOLDs status among comfort care providers, which indicates a gap in information regarding how the leaders of the EOLD movement in the U.S. will accomplish EOLDs' formal certification. Brennan (2019) considers the need for unification among EOLD trainers a great responsibility because the number of EOLDs is increasing exponentially. Their popularity shows their appeal and demand for services among diverse families and communities in the U.S. (see Figure 2).

Figure 2: Overall Tasks EOLDs Perform When Supporting Those Reaching the EOL



Note: Adopted from *NEDA scope of practice*. (2020, September). National End-of-Life Doula Alliance. Retrieved from <https://www.nedalliance.org/scope-of-practice.html>

Table 5: An Example of EOLDs’ Scope of Practice

End-of-Life Doulas’ Scope of Practice:
First Stage
Work with family and dying person during the last months, weeks, or days of life
Provide education and information on diverse EOL choices and options
Clarify the interactions the EOL person wants with caregivers, family members, and others
Construe how EOL individual wants last days of life to look (room decoration), sound (kind of music), smell (types of essence, oils), light in the room (dim, bright), feel (light touch massage), readings they find comforting
Explain the physical and emotional nature of the dying process to caregivers
Deep active listening
Give emotional, spiritual, and some physical support
Explore the individual’s life meaning through a life review
Extract from life review the legacy they want to leave behind
Create a memory book, photo album, audio, or video, write letters, etc., to capture/express their legacy.
Being present and providing companionship
Second Stage
Vigiling—attending around the clock as much as possible (a team of three EOLDs works best)
Provide respite to family members
Facilitate resolve of EOL individual’s emotional issues, regrets, reflection through guided imagery

Table 5 (Cont'd)

Second Stage
Assist with simple physical care, e.g., help caregiver reposition EOL person's body, apply a warm or cold compress, etc. (obtain written agreement if the patient wants more physical care, e.g., provide medication under nurse or caregiver guidance, incontinence undergarment change, etc. with clear description of circumstances under which it will take place and a waiver of personal liability)
Inform family about the symptoms of the active dying process and imminent death and what to expect as the process unfolds
Reach out to the appropriate clinician to help with the active dying process
Do NOT perform medical assessment or intervention, regardless of EOLDs' licensure—it is outside of the EOLDs' scope of practice
Home funeral support, e.g., washing EOL individual's dead body
Third Stage: Reprocessing of Patient's Death & Early Grief of Family
Holistic support to the family through death, burial, cremation, and grief
Help the family reprocess the EOL experience of things said or not said, wishes unmet, etc.
Reframe experiences that have harmful emotional content
Share positive touching moments the EOLD witnessed to encourage uplifting reminiscence of the experience
Hold space
Do NOT establish an intimate relationship with those EOLDs served (see NEDA code of ethics in Appendix E)

Note: Table 5 displays the scope of practice most EOLDs execute in the U.S. It focuses on values, character mapping, identification of roles, and time lapses (Fersko-Weiss, 2017; Rawlings et al., 2018).

Table 5 depicts examples of EOLDs scope of practice, which resembles the table Rawlings et al. (2018) used. The information in Table 5 also describes some of the topics covered in most training programs for EOLDs. Regarding the diversity of training programs, Rush (2020) notes that some specialize in holistic care (which means EOLDs provide more than physical care by considering the emotional, social, and spiritual needs); others focus more on spirituality while still others emphasize practical matters. EOLDs may represent a new career path in the world of death and dying; however, the need for this profession has always existed (O'Brien, 2015; Gurevich, 2019).

Former Hospice Nurse Advocates for EOLDs

Barbara Karnes remembers the claim hospice care made 40 years ago: “We can support, comfort, and guide people and their families as the EOL approaches. No one needs to be alone anymore during this life moment” (Karnes, 2018, p. 2). She acknowledges learning the process people typically follow as they die from old age or terminal illness and admits it was a privilege to care for the dying and their families. She guided and supported them during their dying experience, which could take months, but for most people was weeks, days, or hours.

Karnes (2018) now claims that hospice care is not what it was 40 years ago. Hospice is subject to increased regulations of care and has become a contributor to the healthcare system. For example, insurance companies and Medicare now reimburse hospice care. Karnes laments that hospice EOL care is regulated by healthcare and is obliged to respond to the demands of the medical system. Cochran (2019), Fersko-Weiss (2017), Karnes (2018), and other experts in EOLD care report that hospice employees’ strict regulations of wages and hours of work tarnish if not void hospice’s claim that patients and families are not alone during the dying process. Every dying patients’ final breath is unpredictable, which seems to be the main reason hospice care does not

make good on their claim any longer (Karnes, 2018). The price of paying for unpredictable time is not cost-effective.

Therefore, hospice staff cannot accompany EOL patients throughout the unpredictable schedule that every dying process seems to take (Karnes, 2018). Hence, EOL patients and their families often find themselves alone as death approaches and at the moment of death, either at hospice facilities or at home. The lack of hospice nurses' "presence" (by "presence," Karnes means dedicated unrestricted time and gentle touches) at one of the most crucial times in a person's life has promoted the development of the EOLD care concept.

Karnes asserts that she provided primary physical comfort care and pain management when appropriate and used to say to EOL patients, "I cannot make this last life experience go away, but I can accompany you through your journey" (Karnes, 2018, p.2). Karnes (2018) compares her involvement with EOL patients to the present work EOLDS are doing as they support, guide, nurture, and offer presence during the unspecified times every death seems to take.

As a result, Karnes is currently proactively involved in supporting the EOLD movement. She endorses the NEDA, which has become the archetypal umbrella for the EOLD movement. NEDA is a new organization established in 2017 to give the emerging care concept—EOLDS—more stability and credibility (NEDA, 2020, October 15). Since NEDA's goal is to unify the various EOLD training programs under the same standards of EOL care and EOL operation guidance, although each EOLD training program varies in style, content, and beliefs, NEDA has created a unifying code of ethics (see Appendix E).

Karnes (2018) stated the following:

It is education, support, and tender guidance during that critical time of dying that brings comfort. Someone who understands what is happening during the dying process, that it is

not pathological, and it is not bad, turns an otherwise frightening experience into a sacred time, creating a sacred memory for the family. That is the goal, the mission of an end-of-life doula (p. 3).

Conclusion and Summary of the Literature Review

From this literature review, we have learned about trends in life expectancy, the death and dying system in the U.S., the aging baby boomers, the mortality rate, and the cost of dying. We also learned that Kübler-Ross's stages of dying theory instigated advocacy for better care for dying people and promoted the founding of hospice care and palliative care within the U.S. healthcare system. We became aware that there is a gap in existing services provided to people at the end of life. Individuals, such as Henry Fersko-Weiss, Marilynne Rush, Deanna Cochran, Barbara Karnes (who were mentioned in this study), and others who worked in healthcare, saw concerning gaps in the care of the dying. These individuals parted ways from the healthcare system to implement a different solution that promotes unconventional nonmedical holistic EOLD care. While the number of EOLDS in U.S. communities continues to grow, questions about their training and qualifications remain unresolved.

EOLDS assist individuals and their families through a holistic approach, providing emotional, spiritual, and nonmedical support, guidance, and companionship during an EOL patient's dying process. However, the general populace and healthcare providers are not fully aware of the holistic nonmedical services EOLDS offer. Thus, EOLDS need to learn how to talk about their services so that healthcare providers and the general populace know that they know their place within the EOL system. The purpose of this qualitative interpretive phenomenological study is to bridge the gap that currently exists in understanding the training qualifications EOLDS obtain to aid those who seek a peaceful death. Hence, this research aims to give trained EOLDS a

voice to articulate their lived training experiences, examine the content and quality of their training, and understand the training process.

Through interviews, field observations, field notations, and participatory observation, this study intends to describe the EOLDs' learning and developmental experience during their training. The outcomes of this study may elucidate community members and current health care providers about EOLDs' roles in the EOL field. Furthermore, the results of this study may provide EOL researchers a better understanding of this emerging group. Finally, families with loved ones experiencing EOL may appreciate how trained EOLDs offer them a more caring, comfortable, and peaceful dying process.

In the next chapter, I lay out the Heideggerian hermeneutic phenomenology framework of this study. Within this framework, I discuss its design and rationale, reflexivity, and role as a researcher. I will explain the general data collection procedures and analysis. I close the chapter with information on the four constructs of validity and reliability: credibility, transferability, dependability, and confirmability—and a description of the ethics implemented in this research study.

CHAPTER 3: METHODOLOGY

In this chapter, I present the Heideggerian hermeneutic phenomenological approach, which is also known as the theory of interpretation (Sloan & Bowe, 2014; Holloway & Brown, 2012; Peoples, 2020; Smith et al., 2009; Van Manen, 2014, 2016), and the most appropriate method to collect, analyze, and present the findings of this research. I present the selection of participants and provisions for follow-up interviews; then discuss the benefits and drawbacks of the use of software in hermeneutic phenomenological research. I also analyze the demographics of participants, examine the interaction and research procedures of the data collection and analysis, and connect the narrative of the participants' experiences to the theoretical framework. Finally, I clarify the importance of practicing self-reflection throughout the research process. This chapter closes with discussions about validity and reliability and the ethics framework.

Methodological Framework

Heidegger's hermeneutics, the theory of interpretation, focuses on capturing the phenomenon's *essence* or ethos of a lived experience through the participants' *lifeworld* (the everyday life that we lead) descriptions (Adams & Van Manen, 2017; Sloan & Bowe, 2014; Smith et al., 2009; Peoples, 2020; Van Manen, 2014). Heideggerian hermeneutics aims to "describe a phenomenon as it manifests itself to consciousness" (Holloway & Brown, 2012, p. 41). Van Manen (2014) describes the word *essence*, which is an essential word for hermeneutic phenomenologists, as the "grasp[ing] of the very nature of a thing" (p. 177). In other words, a participant partakes in much reflecting and thinking in attempts to find meaning or make sense of their experience (Colaizzi, 1978; Smith et al., 2013).

The concept of *essence* used in the hermeneutic framework originated in phenomenological philosophy (Creswell & Poth, 2018). The *essence* of a thing is how it is described, how it functions

in the lived experience, and how it reveals itself in our consciousness subjectively as a thing to be reflected upon (Adams & Van Manen, 2017; Van Manen, 2014; Peoples, 2020). However, to increase objectivity, Peoples (2020) advises phenomenologists to consider the participants' perspectives. When researchers look at phenomena through different participants' perspectives, they expand their understanding and knowledge of the experience (Peoples, 2020).

Furthermore, phenomenologists recognize that access to experience depends mostly on participants' contextual narratives of their phenomena and the researcher's interpretation of their account in understanding the phenomena or experience (Smith et al., 2009). Smith et al. (2009) add that hermeneutic phenomenologists operate in a dual role or "double hermeneutics" because they persist in "trying to make sense of the participant trying to make sense of what happened to them," hence sharing the same mental skills of sharing and interpreting (p. 3). Moreover, Peoples (2020) and Van Manen (2014) indicate that hermeneutic phenomenology is *idiographic* because it examines the factual details of what a lived experience was like for each participant. Phenomenology is also considered a philosophical approach to studying participants' lived experiences because it was engendered in Husserl's and Heidegger's philosophical tenets (Adams & Van Manen, 2017; Van Manen, 2014).

Both Edmund Husserl and Martin Heidegger (Peoples, 2020) are the foundational philosophers of phenomenology. According to Van Manen (2014) and Peoples (2020), both philosophies are uncomplicated guides for new phenomenologists on two fronts: (1) Husserl's theoretical framework is for transcendental or descriptive phenomenological studies, and (2) Heidegger's framework is for interpretive or hermeneutic investigations. However, both have different philosophical opinions on understanding (Peoples, 2020). For instance, Husserl's philosophical approach involves avoiding premature conclusions because nothing is to be assumed

when trying to understand a phenomenon; hence, a phenomenon is to be analyzed with conscious intention (intentionality) and full awareness of its existence (Peoples, 2020; Van Manen, 2014).

Husserl's *intentionality* idea is the central theme within his philosophy, which is also known as transcendental or descriptive phenomenology (Peoples, 2020). These concepts include setting aside personal biases or bracketing/framing or *epoché* moments of judgments until the researcher arrives at the *horizon* of the phenomenon's pure essence or, in other words, arrives in its full understanding (Peoples, 2020; Sloan & Bowe, 2014; Van Manen, 2014).

Heidegger's Philosophical Approach

The focus of Heidegger's philosophical approach is, in contrast, *Dasein* or "being there"-being present, being yourself, being-in-the-world within the circumstances of the self-own embodied existence (Creswell & Poth, 2018; Peoples, 2020, p. 32; Thomas, 2021; Wilson, 2014). Heidegger does not endorse bracketing (reduction, suspension, *epoché*) of biases because once the researcher begins to understand the interpreted phenomenon, all judgments and biases are automatically revised (Holloway & Brown, 2012; Peoples, 2020). Heidegger calls this process of understanding the *hermeneutic circle*, which is how people make sense of their world (Finlay, 2012; Peoples, 2020; Suddick et al., 2020; Van Manen, 2014). For example, phenomenologists leave their research world when engaging in an interview and go around the hermeneutic circle to the participant's *lifeworld* (Smith et al., 2009).

When researchers apply Heidegger's *hermeneutic circle* during data analysis, they begin with a global understanding of the entire transcript of the participants' original narratives and gradually switch to a version of "aha" moments or crucial points known as codes, which are then synthesized into themes (Sloan & Bowe, 2014; Peoples, 2020; Van Manen, 2014). The codes and themes represent the entire transcript, hence revealing the *hermeneutic circle* (the parts making

sense of the whole and the whole making sense of the parts), revealing a new understanding of the phenomenon (Finlay, 2012; Peoples, 2020; Van Manen, 2014).

The *hermeneutic circle* of understanding is also represented as a *spiral of understanding* because of changing or increasing comprehension as new data are introduced (Adams & Van Manen, 2017; Peoples, 2014). We interpret our world through constant revision as we learn new things through experience. Hence, as I moved forward with the data collection and data analysis, I committed to revising preconceived ideas I may have about the phenomenon under study by examining my biases and adjusting to the newly derived knowledge. Therefore, assumptions and biases that seem to add to the study's meaning are elucidated and described in this study. If there are reasons for using any assumption or bias, I will explain them in the context of this study.

Terminology

Heidegger's framework is for interpretive or hermeneutic investigations. Its common terminology is listed below:

- *Lived experience* or phenomenon experienced by the EOLD participants: "A unit in the flow of time...which is made up of parts of life, linked by a common meaning" (Smith et al., 2009, p. 2).
- *Dasein* means *to exist, to be there*, being *present*, being yourself, being-in-the-world within the circumstances of the self-own embodied existence. Heidegger uses it to refer to the experience of *being* that is peculiar to the human existence (Creswell & Poth, 2018; Peoples, 2020, p. 32; Thomas, 2021; Wilson, 2014); for example, as in the EOLDs being there, present in their lived experience.
- *Lifeworld* is the everyday life that we lead (Adams & Van Manen, 2017): the world of everyday experiences every EOLD participant has had.

- *Hermeneutic circle*: the parts making sense of the whole and the whole making sense of the parts, revealing a new understanding of the phenomenon (Finlay, 2012; Peoples, 2020; Van Manen, 2014). The hermeneutic circle of understanding is also represented as a *spiral of understanding* because of changing or increasing comprehension as new information is introduced during the data analysis process (Peoples, 2014).
- *Double hermeneutics*: hermeneutic phenomenologists operate in a dual role because they try “to make sense of the participant trying to make sense of what happened to them;” hence, both the researcher and the participants sharing the same mental skills of sharing and interpreting (Smith et al., 2009, p. 3).
- *Essence*: the “grasp[ing] of the very nature of a thing,” arriving with a full understanding of its meaning (Van Manen, 2016, p. 177; Peoples, 2020; Sloan & Bowe, 2014; Van Manen, 2014). The essence of this research study is the findings in Chapter 4 and the discussion in Chapter 5.
- *Idiographic*: the examination of the factual details of what a lived experience was like for each participant (Peoples, 2020; Van Manen, 2014).
- *Foresight or fore conception*: pre-understanding or preconceived knowledge about the phenomenon being studied from the researcher and the participants’ perspectives (Peoples, 2020).

Hermeneutics (the theory of interpretation) focuses on capturing the phenomenon’s *essence* of a lived experience through the participants’ *lifeworld* descriptions (Adams & Van Manen, 2017; Peoples, 2020; Sloan & Bowe, 2014; Smith et al., 2009; Van Manen, 2016).

Research Design and Rationale

I chose qualitative Heideggerian hermeneutic or interpretive phenomenology for this study because it would help generate knowledge that could be used to clarify a poorly understood phenomenon (Van Manen, 2014; Wilson, 2015); specifically, the lived nonmedical training experiences of EOLDs in the context of their perspectives on the phenomenon. As discussed in the literature review, little academic research has been conducted about EOLDs and their qualifications in caring for the dying. Due to the overall lack of information available, the approach to this research was also exploratory in nature. According to Stebbins (2001), exploratory research deals with a problem that has not been studied fully and needs clarification to gain insight and understanding to be better understood, as in the case of the main research question of this study.

I ventured into this research project with limited preconceived ideas of what I might find as I investigated the lived EOLD training experiences of participants or co-researchers. Smith (1994) asserts that “one enlists interested parties as coresearchers in a research project and it becomes a cooperative activity” (p. 255). Boylorn (2008) also considers participants as coresearchers, writing “qualitative research ... validates ... the experiences of participants, making them experts and therefore co-researcher and collaborators” (p. 601). Creswell and Poth (2018) and Boylorn (2008) compare this participatory position with the traditional form of research, in which the investigator can be viewed as a supreme authority figure while the participants merely represent the passive investigated beings. With this exploratory mindset, I aim to understand a participant’s lived experience and its meaning as described through reflective awareness on how a phenomenon affects their relations within their *lifeworlds* or daily living experiences (Matua & Van Der Wal, 2015; Van Manen, 2014; Wilson, 2015).

While some researchers may be inclined to use ethnography to identify shared patterns of a cultural group as they occur in natural settings (Creswell & Poth, 2018), this approach will not fit this study because the culture of a group is not the focus of this research. Instead, the focus of this study is to explore the lived training experiences of individual EOLDs. I also considered using a case study approach, which involves a detailed and in-depth depiction of an issue or case(s) within a real-life setting, including time and place (Creswell & Poth, 2018). However, a case study will not fully meet this study’s objective, which is to investigate the experiences as lived by the participants. I instead used the hermeneutic phenomenological methodology and followed Wilson’s (2015) practical steps of foundations of phenomenology, as shown in Table 6—foundations of phenomenology interpreted—in which each step describes the practical side of phenomenology as a framework for data analysis and reporting.

Table 6: Foundations of Phenomenology Interpreted

Foundations of Phenomenology		How this study will fulfill these phenomenology criteria (Creswell & Poth, 2018; Finlay, 2012; Matua & Van Der Wal, 2015; Van Manen, 2014; Wilson, 2015).
The overarching idea of the meaning	Phenomenologists design studies to discover the <i>meaning</i> of a phenomenon. Humans are naturally predisposed to experience their world as meaningful. <i>Meaning</i> is embedded in feelings, awareness, and actions.	I selected a phenomenological design to discover the <i>meaning</i> of the following phenomenon—the lived nonmedical training experiences of end-of-life doulas.

Table 7: (Cont'd)

Foundations of Phenomenology		How this study will fulfill these phenomenology criteria (Creswell & Poth, 2018; Finlay, 2012; Matua & Van Der Wal, 2015; Van Manen, 2014; Wilson, 2015).
Person and world	How far can you investigate a person's lived experience objectively? Are you even aware of your assumptions and preconceptions?	I plan to invest time collecting and analyzing participants' phenomenon's lived experiences by practicing ongoing self-reflection to keep assumptions and preconceptions at bay.
The continuous sequence of lived experience	Some implicit knowledge may never be uncovered, but the knowledge that we can access by focusing on thoughts, feelings, and practices can be both described and interpreted.	I will focus on the essence of the phenomenon lived through by participants to extract a common meaning of it and find its universality (e.g., grief is universally experienced)

Table 8: (Cont'd)

Foundations of Phenomenology		<p>How this study will fulfill these phenomenology criteria</p> <p>(Creswell & Poth, 2018; Finlay, 2012; Matua & Van Der Wal, 2015; Van Manen, 2014; Wilson, 2015).</p>
Critical ingredients of phenomenological research	<p>A research question driven by curiosity informs the design of a study.</p> <p>Participants need to be interested in and committed to exploring their lived experience, and this helps generate useful quality data. A practical hermeneutic framework can increase the quality of the findings.</p>	<p>I plan to gather descriptions of experiences (not opinions or intellectual interpretations) of the phenomenon then interpret it. The descriptions will include “what” participants experienced and “how” it was experienced.</p>
Cues and clues in the literature	<p>Phenomenology focuses on a particular experience or the object of a person’s perception, rather than individual biographies, social norms, or attitudes, although these elements often emerge.</p> <p>Keywords include “lifeworld,” “essence,” and “lived experience.”</p>	<p>I will (1) explore a phenomenon with a heterogeneous group of participants who have all experienced holistic nonmedical EOL training and (2) summarize the “what” and the “how” of the phenomenon with detailed description and interpretation.</p>

Table 9: (Cont'd)

Foundations of Phenomenology		<p>How this study will fulfill these phenomenology criteria</p> <p>(Creswell & Poth, 2018; Finlay, 2012; Matua & Van Der Wal, 2015; Van Manen, 2014; Wilson, 2015).</p>
Limits and limitations	Phenomenological research cannot produce a theory. It demands high personal engagement from everyone, and trust may be a limiting factor.	After transcribing the interviews, I will generate themes from the analysis of significant statements, develop structural descriptions, share results with participants, revise, and report the phenomenon's essence.

Note: Adapted from Wilson (2015, p. 39) A guide to phenomenological research.

Despite some variety in phenomenological research designs, phenomenologists in general abide by a few foundations or principles that I also followed:

- (1) Select a hermeneutic phenomenological design to discover the meaning of the phenomenon through participant selection, interviews, data analysis, findings, discussion, and conclusion.
- (2) Collect accounts of *lived experiences* of the phenomenon through email and phone interviews with seven participants (not in-person as originally planned).

(3) Aim to gather descriptions of experiences (not opinions or intellectual interpretations) of the phenomenon by staying focused on the participants' lived training experiences.

(4) Maintain openness and develop an in-depth understanding of the phenomenon through constant self-awareness, which is paramount during data collection and data analysis (Finlay, 2012; Matua & Van Der Wal, 2015; Van Manen, 2014; Wilson, 2015).

By abiding by these listed phenomenological principles, I focused on discovering the lived experiences of participants.

Role of the Researcher and Reflexivity

In this section, I explain my role as the researcher and discuss three ways self-reflection is used in hermeneutic phenomenological research: (1) as a tool for understanding the lived EOLD training phenomenon to improve the overall trustworthiness of the study, (2) as a medium to keep all my obvious and subtle biases in check, and (3) as a *dwelling-with* technique, which will be explained shortly.

1. Self-reflexivity used as a tool to understand phenomena

Pool (2018) emphasizes that self-reflection is the cornerstone of the Heideggerian interpretive phenomenology. Based on Pools (2018), Spence (2017), Van Manen (2014, 2016), and Wilson (2015), the interpretive approach calls for self-reflection to address assumptions and pre-understanding about the phenomena throughout the research process. Van Manen (2014, 2016) explains that self-reflection is needed to improve the validity and trustworthiness of the study. Hence, self-reflection (a) allows phenomenologists to be more receptive to the idiosyncrasies and subtle assumptions of research participants; (b) contributes to the creation of meaning as the understanding of the phenomenon that arises from data; (c) allows a deeper understanding of the phenomenon through constant refocusing; (d) validates and refutes participants' perceptions in

order to find meaning that reflects universal human experiences; for example, grief (Pool, 2018; Van Manen, 2016).

Self-reflection was therefore a salient activity during the data collection and analysis process as I recognized myself in the participants and the participants in myself (Van Manen, 2014). For example, during the interview with the participants, I perceived that their virtual (simulated) in-person death and dying exercise in the time of their training left them with a profound impression of the “possibility” of their own demise. Their experience of this event recalled how I also felt when I did the same exercise during my in-person EOLD training. Thus, I recognized myself in them and vice-versa. Pool (2018) notes that it takes self-introspection to reveal the humanness of others in relation to oneself to disclose the true intention of the interaction. Therefore, reflexivity becomes an ongoing awareness of self in relation to the other or a deep introspective activity to recognize another (the participant) and construct knowledge that leads to accurate research analysis (Pool, 2018; Van Manen, 2016).

2. Self-reflexivity used as a medium to keep biases at bay

Suddick et al. (2020) and Pool (2018) remind phenomenologists that it is during the research data collection and results period that the potential for bias usually occurs. Holloway and Brown (2012) believe that self-reflection encourages researchers to confront their biases and examine the influence of their past experiences in present meaning-making interpretations. Peoples (2020) states that self-reflection fine-tunes researchers’ humanness so they may capture the essence of the phenomenon and interpret it as it is at that moment in time.

I intensified my self-reflection throughout the data collection analysis and interpretation by making my preconceived ideas about the lived EOLD training experience more explicit and revisable through journaling. Therefore, I was conscious of my personal biases as I (a) reviewed

the interview transcripts; (b) grouped the transcripts into units or chunks of relevant information; (c) created themes based on the relevant units or chunks made; and (d) kept the purpose of the study and research questions in mind when describing the themes. I was also mindful of Heidegger's teaching that once the phenomenologist begins to comprehend the interpreted phenomenon, all judgments and biases are automatically revised (Holloway & Brown, 2012; Peoples, 2020; Van Manen, 2017). According to the Heideggerian hermeneutic phenomenological approach, the *bracketing* or the suspension of judgments to focus on the studied phenomenon (also known as reduction, suspension, or *epoché*) of biases was not a vital component of this study because biases cannot be wholly set aside or bracketed (Peoples, 2020).

3. Self-reflexivity as a dwelling-with technique

Self-reflection also requires the *dwelling-with* technique, which refers to the process of setting aside time aside to reflect and purposely avoid writing while *dwelling with* the data before and during the study (Pool, 2018; Van Manen, 2014, 2016). The purpose of *dwelling with* is to slow the pace of self-reflection, heighten awareness, and increase insight into participants' lived experiences (Creswell & Poth, 2018; Van Manen, 2014). The intent of this intense process of interpreting the essence of a lived experience is to accept the inseparability of emotion, thought, writing, and language to construct meaning (Pool, 2018; Smith et al., 2009; Van Manen, 2014, 2016).

As I examined and reflected on my background, gender, age, social status, character, motives, actions, personal views on death and dying, and status as a former EOLD training participant, I recognized the influence my collective perspectives may have had in the EOLD participants' lived experience narratives. Therefore, I monitored any potential biases that could be projected on the data collection, analysis, and reporting by practicing the *dwelling-with* technique,

then jotting down personal reflections and possible assumptions regarding the study. Self-reflection helped me recognize assumptions and promptly revise them as new information arose from the meaning of participants' lived experiences during the hermeneutic circle of data collection and analysis (Van Manen, 2014, 2016). The following section will explain the setting and recruitment process of participants.

Setting and Recruitment

Due to the 2020 governmental nationwide mandate to restrict all human contact to minimize infection and death caused by COVID-19, my original plans to recruit and interview participants in-person from areas around Lansing and Ann Arbor, Michigan, were switched to recruiting remotely from locations throughout the U.S. using emails, Zoom, and phone calls to contact and interview participants. The setting and recruitment were done in the following order:

Step 1: Initial contact via telephone or email with nine potential participants from diverse ethnic groups and genders (based on their public biographical information on trainers' websites). Seven of them agreed to participate. Two failed to respond despite several attempts to make contact.

Step 2: I asked the seven participants who agreed to participate (a) permission to email them the research participant information and consent form that explained the research details including possible risks, rewards, and freedom to remain or exit the research at any time (a \$25 gift for participating was also mentioned) and (b) the best day and time to call them back for a recorded interview that would be kept as an audio memo for nine months before being permanently deleted.

Step 3: Protecting participants' information. As mentioned in the consent form (see Appendix A), the recorded voice memos were saved in a password-protected digital file on a

password-protected computer. I was the only person who knew the participants' true identity and referred to each participant with a pseudonym (P1, P2, etc.) in numerical sequence addressed on all signed consent forms, data, voice memos, and other identifiable information collected solely for this research project.

There were two main criteria for participants or coresearchers for this study: the completion of an EOLD training program and consent to be interviewed. Furthermore, as the observer and contributor to this phenomenological study, I did not include any participant who had a personal or professional relationship with me so to avoid and uphold any position of power within our relationship which could mar the study results (Peoples, 2020).

I selected participants from directories of EOLD trainers' websites, such as NEDA's <http://www.nedalliance.org/doulas-by-state-a---m.html>, *lifespanandoulas.com*, and *inelda.com*. According to my original plan, I enlisted, interviewed, and analyzed the data of three participants at first, but since I did not reach saturation—which is the criterion for judging when to stop sampling because no additional data is being found—I recruited six more. However, two prospective participants chose not to participate. Smith et al. (2009) recommend a small sample size because it allows more time for microanalysis of similarities and differences of participants' experiences. I recruited seven ($n = 7$) adult participants / co-researchers.

Six out of seven participants attended a hybrid training, which is a combination of online but mostly in-person instruction. The hybrid EOLD training sessions occurred before the COVID-19 pandemic. In early 2020, all trainers moved their training programs completely online due to COVID-19. Hence one participant, (P2) was the only one who did his full EOLD training online during 2020.

Participants

In this section, I describe the participants' demographic information including age, gender, ethnicity, and education. I also list the name of the EOLD training program, the length and cost of each training, and participants' current career status as EOLDs (see demographic questionnaire in Appendix B). Some of the demographic information was posted in the EOLD trainers' public website directory. Nonetheless, participants provided additional information regarding when and how they were trained in-person, the cost, and their current working status as EOLDs. Their in-person training cost was in addition to the cost of airfare, car rental, lodging, and meals. Participants also revealed other personal information voluntarily during the interview. I noted such information in my field notes as the participants spoke and filled their demographic forms afterward (see Table 7 for easy reference). The demographics reveal variation in age, gender, and ethnicity.

Table 10: Participants' Demographic Data

Participants	Age	Gender	Ethnicity	Education	Training Organization --- Present EOLD career status	Length and Cost of EOLD Training
P1	65	F	African American	Some college	Lifespan Doulas --- Hospice Volunteer	20 hrs./\$700*
P2	31	M	Caucasian	Graduate	Going with Grace --- Setting up own EOLD business	72 hrs./\$1600

Table 11: (Cont'd)

Participants	Age	Gender	Ethnicity	Education	Training Organization --- Present EOLD career status	Length and Cost of EOLD Training
P3	66	F	Caucasian	Graduate	Conscious Dying Institute & INELDA --- Setting up pay scale for services	8 full days/\$2,300* and 3 days/\$850*
P4	69	F	Caucasian	Two Masters	Doulagivers Institute --- Hospice Volunteer	20 hrs./\$3,500*
P5	41	F	Caucasian	Bachelor	Sacred Passage --- Setting up pay scale for services	8 full days/\$2,300*
P6	36	F	Hispanic	Ph.D.	Earth Traditions & The Death Midwife --- No plans as an EOLD	24+hrs./\$750* and 30 hrs./\$750*
P7	62	M	Caucasian	Bachelor	INELDA --- Hospice Volunteer	3 full days/\$850*

Note: *—Plus the cost of airfare, car rental, lodging, and meals (In-person and before COVID-19); EOLD: end-of-life doula.

Data Collection Procedures

The data for this qualitative study were collected using individual interviews with people who had attended EOLD training. After receiving the agreed consent form from the seven participants, we conducted the interview on the agreed day and time. After a few minutes of exchanging pleasantries, I announced that I would start asking seven RQs and recording their answers to each of them as voice memos. The list of RQs was as follows:

- Could you describe something about your EOLD lived training experience that made an impression on you?
- Did your EOLD training have an impact on your desire or decision to aid the dying?
- Was there anything you were aiming at when you first started your EOLD training? During your training? Afterward?
- What were you experiencing before your EOLD training? During? Afterward?
- Did you discuss the essence of what you were experiencing either with yourself or someone else before, during, and/or after your training? What did such discussions mean to you? What came out of them?
- What difference(s) can you detect within yourself after your EOLD training?
- What made the whole lived training experience easy or difficult for you? Enjoyable or disagreeable?

According to hermeneutic phenomenological research, the main and most important question can be distilled to one: What is the *lived experience* of *X*? The seven research questions include or imply the *lived experience* statement; for example, Question 1: “What is the non-medical, holistic *lived* EOLD training *experience*?” Some of the interview questions had follow-up queries to clarify or elaborate on what participants had said, for example, Question 5: “Did you

discuss the essence of what you were experiencing either with yourself or someone else before, during, and/or after your lived training? What did such discussion mean to you? What came out of them?” (see RQs interview protocol in Appendix C). I supported the participants’ narratives by approving aural presence and/or sub-questions to clarify or elaborate on a questionable expression. None of the questions provoked any inconvenience during our interaction.

All participants were interviewed for an average of 30 minutes and followed a semi-structured protocol. I shared the key aspects of the research studies with the participants via the consent form they read and signed beforehand. According to Pool (2018), the sharing of key aspects allows the participant to expound on their answer or discuss additional information that may end up being relevant to the study. Peoples (2020) and Van Manen (2016) state that participants’ personal feelings and opinions tend to change due to new experiences they may encounter as they advance in life. For example, participants might believe an event happened a certain way, yet when the experience is discussed among other observers, this perception may not be as accurate as first described.

Hence, when participants shared an opinion, I asked them to elaborate on their narrative so I could discern the essence of their experience better. For example, when Participant 7 (P7) expressed feeling disappointed that he perceived that EOLD trainers using their continuous training programs mainly for profit because they have discovered that they can, I remained quiet until he revealed that his main concern was the quality of training EOLD trainees were getting. P7 is in the position of hiring EOLDs and wanted them well trained. His narrative did not directly indicate nor suggest that all EOLD trainers were acting dishonestly.

I also kept in mind that phenomenological studies are about explaining experiences; hence, I used questions with “yes” or “no” answers to help clarify or to avoid assumptions about their

experiences. Peoples (2020) states that it is essential to keep this aim in mind during interviews because many participants tend to speculate and theorize about their lived phenomena, which are not the focus. Hence, I summarized, rephrased, and asked follow-up questions.

Follow-up interviews usually occur after the first readings and reflection on the data, in cases which further clarification may be needed after the analysis. Although the possibility of a follow-up interview to clarify preliminary information was mentioned during the interview, no further follow-up interviews were needed. As the interview ended, I reminded participants that I would be transcribing and analyzing their voice memos following a protocol of privacy and confidentiality as written in the consent form they signed.

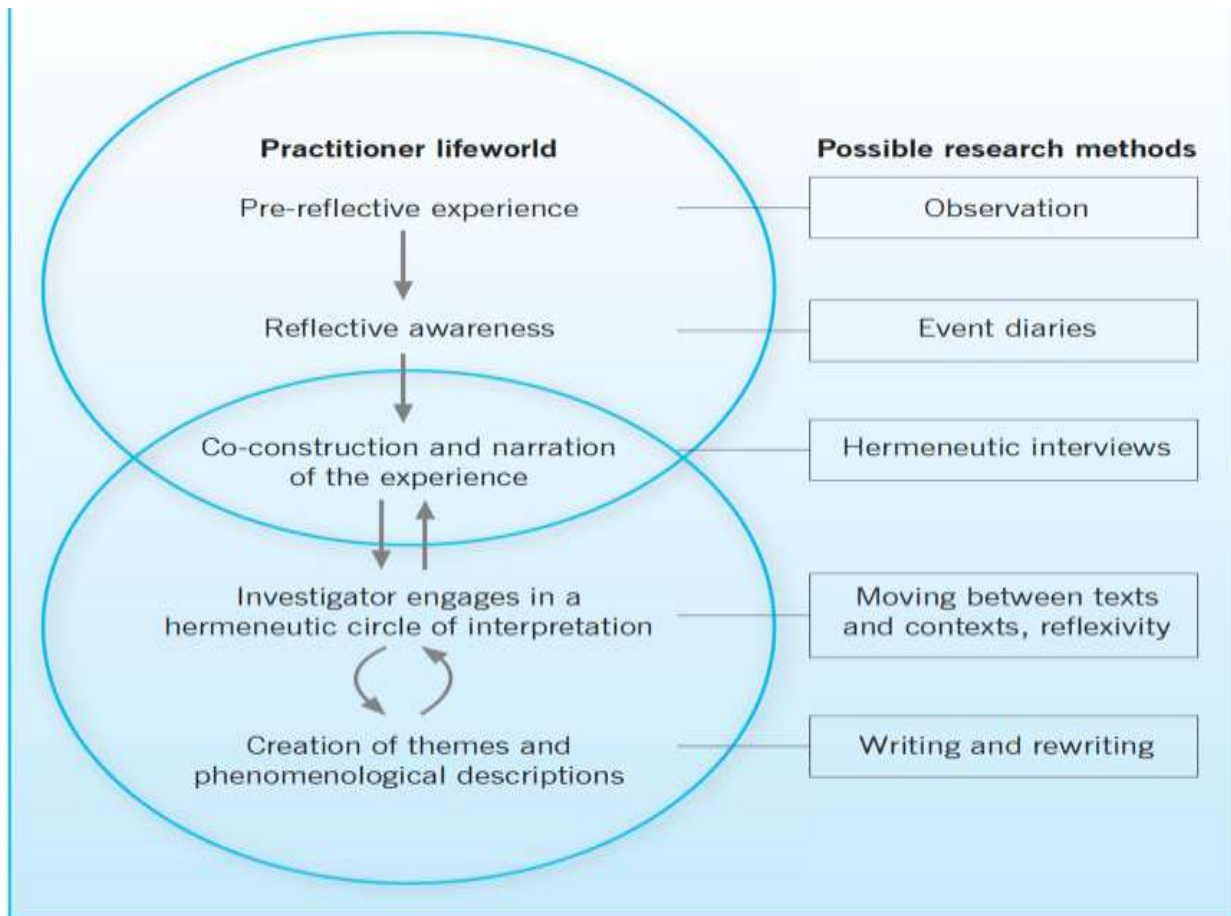
Data Analysis

Figure 3, called “Fusion of horizons,” shows the process of turning each participant’s *dasein* of their *lifeworld* (being present within their everyday world context) into themes and phenomenological description and interpretation. The result is the expansion of the researcher’s and participant’s understanding (Wilson, 2014, p. 32). The “fusion of horizons” figure depicts in more detail the researcher’s process of immersion into the data. It also involves: (a) the reading and re-reading each participant’s interview transcripts, participatory and field observations, and field notations; (b) the applying of intuition; (c) the refining of thoughts and ideas through discussions; (d) the building of thematic representation; and (e) the hermeneutic circle (spiral) ending in the creation of themes and discussion (Wilson, 2014, p. 32).

Through the process of acknowledging the overlap or fusion of horizons between the researcher’s and the participant’s experiences, it seemed easier to acquire a more accurate research technique for the data analysis (Wilson, 2014). Wilson (2014) affirms that “it is impossible to understand experience by being detached” from the data analysis process (p. 30). Hence, I

embraced the fusion of horizon and its components, including the hermeneutic circle of understanding, which is not a self-perpetuating circle but is instead more of a spiral that is formed as we learn about new facets of the participants' experience.

Figure 3: Turning Participants' Lifeworlds into Phenomenological Description and Interpretation



Note: Figure 3 – “Fusion of Horizons” was adapted from Wilson (2014, p. 32).

The Use of Qualitative Data Analysis Software

Peoples (2020), Sohn (2017), Van Manen (2014), and other phenomenologists do not recommend the use of qualitative data analysis software (QDAS) because it may distract from the wholistic details of a participant's transcript, thereby compromising the meaning of the phenomenon being studied. Transcripts, according to the leading phenomenologists, represent

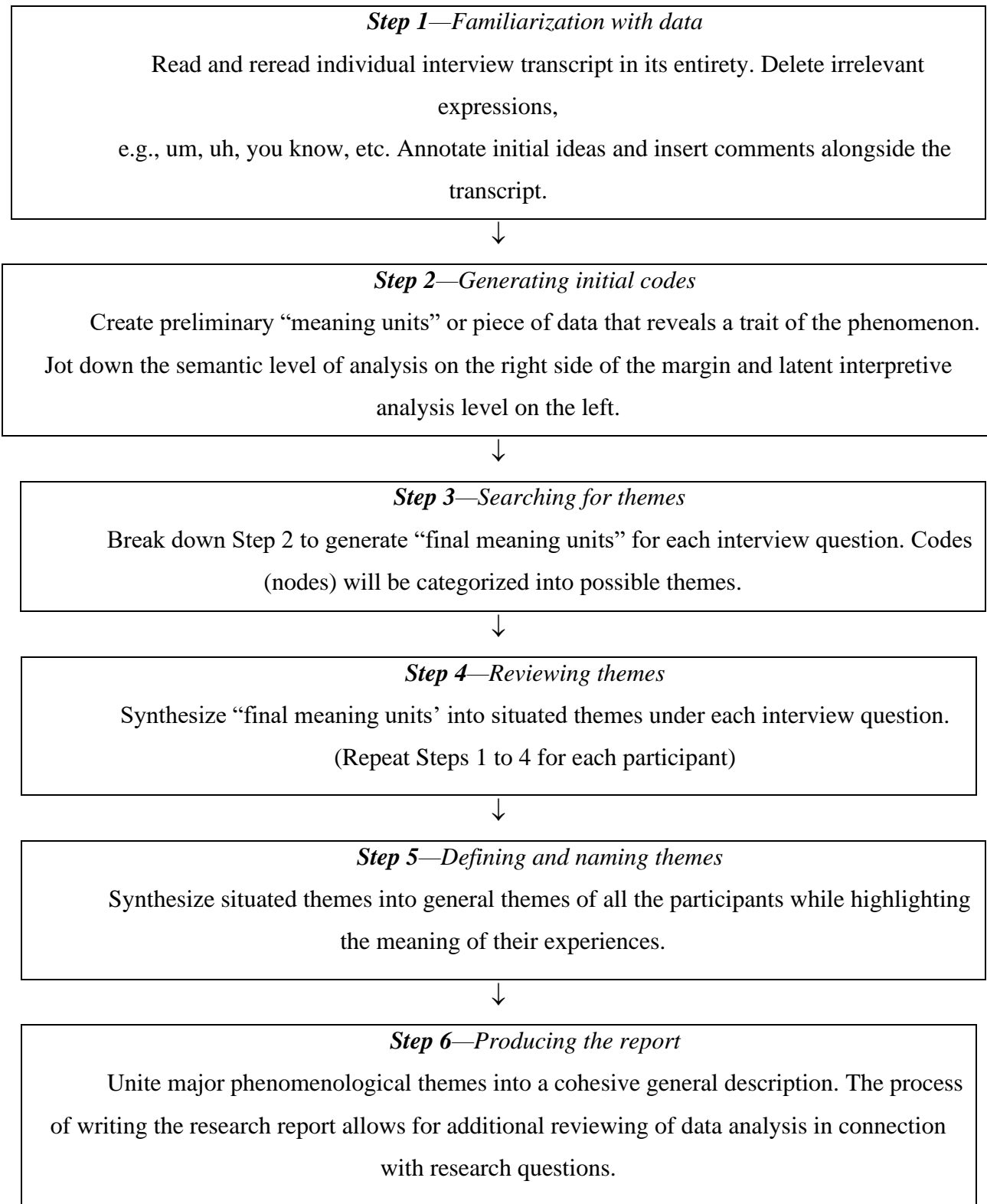
living and breathing human beings. Thus, finding the core meaning or essence of an experience without the use of QDAS entails re-reading each transcript several times, manual coding, and relistening to each participant's recorded vocal inflections carefully (Peoples, 2020). I chose to not use QDAS and completed my data analysis as explained above.

General Data Analysis Steps

Peoples (2020) encourages researchers to keep the context of the whole phenomenon while investigating its components. As we have already learned, a phenomenon's experience may be dissimilar from other comparable experiences (People, 2020). Peoples (2020) recommends that phenomenologists embody themselves within the participants' spoken details so that they can rise above or transcend "the mundane nature of each description" and find the core or essence of the phenomenon (p.58). My goal was to describe salient themes of the experience so that others who have had similar experiences can quickly identify it and understand it, e.g., grief. To analyze the phenomenological data correctly, I immersed myself in each participant's descriptions of the phenomenon, hoping to transcend or decipher its meaning. After I transcribed the participants' voice recorded interview answers based on the participants' responses to the seven interview questions (see Appendix C), I followed the steps described in Table 8.

Peoples (2020) proposes that the most consistent way to report phenomenological study results is to follow the step-by-step process of data analysis outlined in Table 8. Table 8 shows a flow chart of six steps adapted from Peoples (2020, p. 59) in conjunction with the six phases of thematic analysis from Braun and Clarke (2006, pp. 87-93—See Appendix E). These general steps of phenomenological data analysis may facilitate thorough data analysis and replication of the research.

Table 12: Phenomenological Data Analysis and Thematic Analysis Flow Chart



Note: Table 8 shows a flow chart adapted from (Peoples, 2020, p. 59) in combination with the phases of thematic analysis from (Braun & Clarke, 2006, pp. 87-93).

Step 1—Familiarization with Data

The recommendations from Finlay (2012), Matua and Van Der Wal (2015), Van Manen (2014), Pool (2018), Wilson (2015), and other leading phenomenologists to maintain openness through self-reflection are crucial. Self-reflection was of paramount importance during data collection and data analysis.

To acquire an in-depth understanding of participants' phenomenon and facilitate my meditative self-reflection state, I did the following: (1) as a music-therapist who knows about the therapeutic value of music, I listened to renditions such as Max Richter's "*Dream 3 (in the midst of my life)*," (2) practiced breathing techniques to relax, (3) practiced the well-known Pomodoro technique, which involves taking 5 to 10 minutes breaks after 25 minutes of focused work. These practices helped me achieve short respites from the analysis phase and left me feeling that I had gained fresh insights into the data.

Once a phenomenologist begins to comprehend and gain new insights into the participants' interpreted phenomenon, judgments or biases are automatically revised (see Figure 3 for the use of the hermeneutic circle or spiral; Holloway & Brown, 2012; Peoples, 2020; Van Manen, 2017). Knowing this helped me relax and gave me the confidence needed to stay focused on analyzing the data. Thus, I read and re-read each individual interview transcript in its entirety, deleted irrelevant expressions—e.g., um, uh, you know, etc.—annotated initial ideas, and inserted comments alongside the transcript.

Example of Step 1:

Original transcription:

Participant: We did really like in-depth emotional work on ourselves and we... then we did practices with each other. And so, it was like a lot of internal work, you know, and ah ... but also a lot of like self-awareness work and then like actual practices that would give us the tools to work with people who are dying.

Revision:

We did in-depth emotional work on ourselves. Then we practiced with each other. The aim of the self-awareness practice was to give us the tools to work with people who are dying.

I also followed the six self-reflective steps listed below, as suggested by Pool (2018, pp. 250-251). While I immersed myself in the procedures of Steps in Table 8, for each participant's transcription of Step 1, I also practiced the following:

(1) Planned time for self-reflection period and established a physical writing space. According to Pool (2018), this activity creates a sense of self-discipline and commitment procedures, which are critical for the study's successful outcome.

(2) Avoided premature interpretations, explanations, or generalizations and refocused on embodied physical sensations and aligned them with reflective prompts.

In addition, and as advised by Pool (2018), I also dwelled with *dasein's* lifeworld-based questions and feedback; for example, what did the participant mean when he said frustrated? How did it feel physically and emotionally for me during the interview? How does it feel now looking back on it? Pool (2018) says that periods of stillness and restraint prepare the phenomenologist for subsequent phases of analysis.

- (3) Embraced my ongoing internal critique and probing questions to become comfortable with the vulnerability felt in self-reflection.
- (4) Wrote within the *lifeworld* modalities or the mode of everyday experiences of each participant and explored the possible meaning of those experiences.
- (5) Evaluated and organized the meaning units or significant statements to draw attention to repeated patterns. I then designed a table to illustrate tentative themes after discussing and revising the elements in it (see Tables 9 and 10). Once I reached saturation of well-supported themes, I moved on to the next step.
- (6) Created a tentative overarching series of results by summarizing interpretations to facilitate hermeneutical reduction and concise meaning of participants' lived experiences (see the example in Step 6).

After engaging in Step 1 as shown in Table 8, (see the example above, p. 64) to see how Step 1 was developed for each participant), I sent each participant their individual revised transcript in a Word document for revision and feedback. All seven participants responded acknowledging the validity of their transcriptions. One participant made suggestions to add additional but inconsequential information she forgot to mention.

Step 2—Generating Initial Meaning Units or Significant Statements

The second step in this method is to create preliminary “meaning units” (Peoples, 2020, p. 60) or “significant statements” (Colaizzi, 1978, p. 59), which are pieces of data that reveal a trait of the phenomenon being investigated while focusing on the research topic. In addition, and as suggested by Braun and Clarke (2006), I noted the semantic level of analysis on the right side of the margin and potential interpretive analysis level on the left.

Example of Step 2:

Participant 2 (P2) said, “I learned about what I want for my own idea of a good death for myself and others in my community and the world.”

I divided P2’s “significant statement” into two meaning units, (a) what I want for my own idea of a good death for myself, and (b) others in my community and the world. The (a) meaning unit portrays P2’s acceptance of his own mortality. The (b) statement reveals his heightened desire to assist others.

Participant 5 (P5): “I experienced internal growth to help dying individuals.”

I also divided P5 statement into two sections: (a) experienced internal growth, and (b) help dying individuals. The 1st (a) meaning unit describes P5’s view of her experience as an EOL trainee receiving practical training. The 2nd (b) meaning unit is viewing her role as one who provides care to others.

Step 3—Searching for Themes by Generating Final Meaning Units for Each RQ

I decomposed all the initial or preliminary meaning units formed in Step 2 to generate “final meaning units” for each interview question and then categorized them into possible themes. Each theme was imbued by my own “deeper” understanding of each participant’s description.

Example of Step 3:

RQ 1: Please describe your experience or the nature of your EOLD training. Participant 2 initial meaning units derive from his experiential virtual dying exercise during his lived training experience:

Participant 2 (P2): Initial meaning unit 1— “I gained clarity over my fear of death and the dying process.”

Initial meaning unit 2 — “I learned what to do to have a good death for myself and others.”

Final meaning unit or significant statements: Positive understanding and acceptance of death and dying.

Table 13: Final Meaning Units or Significant Statements

1. Intuitive pull to do EOL work (felt a deep calling to do this work)
2. Increased sense of purpose and mission in life
3. Acceptance of own mortality
4. Heightened my desire to help others
5. Catalyst to face one’s soul, one’s very being
6. New positive understanding and acceptance of death and dying
7. A safe space to express myself before others
8. I have changed as result of this training
9. Became more compassionate toward others
10. Got the tools to work with the dying
11. A call to action was stimulated
12. It is an honor to care for the dying
13. Self-awareness of own mortality
14. Higher tolerance for life’s inconsistencies
15. Improved relationship with self and others
16. Engaging more in death and dying conversations
17. Higher levels of awareness
18. Prompted changes in one’s behavior, thinking, attitudes, and life-action priorities
19. Acknowledge the importance of deep active listening
20. Inspired to volunteer at hospices
21. Understand what holding space mean
22. Understanding death and dying helps communities and society at large
23. I work in the EOL field and the training resonate well
24. What I learned continues to unfold in unimaginable ways

Table 9 (Cont'd)

25. Being an EOLD demands dedication and lots of work
26. EOLD trainers speak about death with a different tone in a more relaxed manner
27. EOLD training requires introspection to reach one's own clarity about death and dying
28. Attending an EOLD training does not make you a death professional
29. Profound experiential training was necessary because the dying phase is not the same for each person
30. A wonderful and powerful experience but very emotional with lots of tears
31. My EOLD training group were 60 white folks, 58 females, and 2 males—EOLD training sessions need more outreach to more diverse racial, gender, and cultural communities.
32. Being the only non-white person in the group, I had to speak up for observed racial inequalities in the medical system
33. Seek an EOLD trainer carefully because they'll teach you EOL care as they deem effective
34. Trainer seemed trustworthy and competent
35. The training covered all aspects of doula work, from being at the bedside, to the funeral, and to grieving with the family afterward
36. The training demands time and self-absorption to do it right

Note: Table 9 presents significant statements extracted from participants' protocol and transcriptions.

Step 4—Reviewing themes

I synthesized the final meaning units into situated themes under each interview question (Peoples, 2020, p. 61). Then I repeated Steps 1 to 4 for each participant. The “situated themes” are a reiteration of each participant's storyline, which I organized thematically under each research question. I used direct quotes to highlight thematically the meaning of each participant's experience as they expressed it to me during the interview.

Example of Step 4

A final meaning unit: have intuitive pull or attraction to do EOL training

P1— “I was experiencing an urge and spiritual or intuitive pull to do EOL services and needed the training. I was sure I could learn it and become good at helping others.”

P4 — “The training confirmed and validated what I always wanted to do, which was to work with the dying. Now, I have the tools and know what to do.”

P6 — “I have always been interested in the rites of passing and in the practices around the death in cemeteries since I was a child. Therefore, for a long time I considered taking an EOL training.”

Step 5—Defining and Naming Themes

After Step 4, I synthesized situated themes into general themes while highlighting the meaning of their experiences. My aim was to sort out the data from the situated themes by highlighting the meaning of all the participants’ EOL training experiences from most, many, and some into general themes (see Table 10—categorizes the general themes from most to some).

“Most” = saturated theme

“Many” = 50% saturated theme

“Some” = theme that was unsaturated yet still relevant although a consensus was not established on the research question.

Interview Q2: *Has your EOLD training had an impact on your desire/decision to aid the dying?*

“Most” participants were grateful for the training because it validated their desire to know how to aid dying individuals. “Many” participants thought their primary impact from the training was a better understanding of death and losing the fear of dying. “Some” said their EOL training showed them how to support dying family members and other people in their communities.

Table 14: Table of General Themes

General Themes	P1	P2	P3	P4	P5	P6	P7
Predisposed to taking the training	√	√	√	√	√	√	√
Experienced transformation	√	√	√	√	√	√	√
Explored own death narrative and embraced it	√	√	√	√	√	√	
The call to do this work (aid the dying) is validated by the training	√	√	√	√	√		
Improved relationship with self and others	√	√		√		√	
Question future of end-of-life doulas					√	√	√
Disapprove of some aspects of the training process						√	√

Note: The checkmarks in Table 10 categorize the general themes from most to some.

Interview Q6: *What difference(s) can you detect within yourself after you completed the EOLD training?*

“Most” felt they gained an increased sense of purpose and mission in life by filling the gap of helping others die with dignity. “Many” detected more ease talking about death and dying with self and others. “Some” became aware of the importance of planning their own demise.

From Situated Themes to General Themes to Cluster of Themes

In this section, I moved beyond the participants’ statements—from what they said to what they meant. In other words, I moved beyond what was given to me in the original data and at the same time, intentionally stayed with it by relistening to their recorded answers. This process allowed for the emergence of significant general themes that were common among the participants’ protocols. To validate these themes, I referred to the original protocols by asking two questions: (1) is there anything transcribed in the original protocols that is not represented in the situated themes moving forward to the general themes? (2) Is each general theme saying anything that is not implied in the original protocol?

These questions were necessary to validate the themes. Otherwise, Colaizzi (1978) warns, the preceding steps must be revised and made right or else the work must start all over. Moreover, since a few general themes still shared similarities, I synthesized them further by clustering them under more overarching themes while referring them back to the original transcriptions in order to validate them. A summary of the final cluster of themes is presented in Table 11. I expound on the components of each overarching cluster of themes in the next two chapters.

Table 15: Cluster of Themes

<p>I. Being ready to attend an EOLD training</p> <ul style="list-style-type: none">• One must be predisposed to attending an EOLD training.• One must be willing to engage with the experiential side of EOLD learning.• One must be ready for social change in oneself, one’s community, society at large, and in the world.• The trainer must appear trustworthy and competent.
<p>II. Validation of the EOLD training</p> <ul style="list-style-type: none">• Promotes self-awareness, resulting in one becoming open to change• Fosters acceptance of one’s own mortality to eventually assist others to accept theirs• Unveils what is of central importance for participants• Presents the possibility of asking for payment for EOL services

Note: EOLD: end-of-life doula.

Step 6—Producing the report with a comprehensive description of results

The aim of this last step is to integrate the major phenomenological themes into a comprehensive description of the research. The process of writing this report allowed me to have an additional reviewing of the data analysis in connection with the research questions within the theoretical framework (Peoples, 2020). Therefore, my goal in this section was to discuss the themes that were implied in all or most of the participants’ narratives of their lived EOLD training experiences. Sometimes I used the indefinite pronoun “some” to address a topic where the responses from the participants varied.

Brief Description of Results

Regardless of the content, context, and price of the different EOLD trainings attended by the participants, the subject matter seemed to focus on their inner framework (inner self) related to their lifespan, mortality, relationships, compassion, grief, meaning of life, and benevolence toward self, others, community, society, and the world. At times, the participants' self-focus attention may have felt soothing, painful, fortifying, or threatening (in the case of their virtual dying activity). Consequently, the participants then may have trusted and accepted the trainers as competent if not as brilliant facilitators for what they illuminated in their inner selves, as many of them acknowledged in their narratives of verifiable restructuring of attitudes, perspectives, changes, and transformations.

None of the participants openly said they did not appreciate the practical exercises or the trainers for shedding light upon their self-awareness and revealing, perhaps a little too much of their fears regarding dying and death. Nonetheless, at the end, participants felt significantly more able to cope with death and dying after their lived EOLD training program than before.

Connecting the Researcher to the Theoretical Framework

As mentioned above, I used the Heideggerian hermeneutic phenomenology framework (Holloway & Brown, 2012; Peoples, 2020; Sloan & Bowe, 2014; Smith et al., 2009; Van Manen, 1997) to analyze the data. Here, I examine the process I engaged in by using this framework. Among the terms and meanings requiring use in this framework are the following: *dasein*, foresight or fore-conception, and hermeneutic circle of understanding (Peoples, 2020):

1. Dasein

To expound on the concept of *dasein* or being there, I asked and answered two related questions:

a. How did my *dasein* affect the research? My *dasein* or “being there” affected the research in a logistic manner because I preemptively planned to put aside preconceived ideas that I may have had about the phenomenon throughout the entire data collection process, the analysis, and interpretation. For example, I had attended three EOLD training sessions (one hybrid before the pandemic, and two solely online), and I am somewhat familiar with the particular context and content of each of them. I deliberately committed myself to respecting each participant’s lived training experience, regardless of how outrageous they may have appeared to me.

For example, P4 was critical of EOLDs who charged money for their EOLD services. I intently listened to her, in full awareness (*dasein*) that she is retired and has no need for monetary support. She had confessed this to me earlier. Younger EOLDs may still need to put food on their table, clothes on their back, and a roof over their heads. Hence, intending to make a profit as an active EOLD in the EOL field bears witness to their basic needs for sustenance and survival along with their call to serve.

I was also conscious of possible personal biases as I

- (a) reviewed the interview transcripts,
- (b) grouped the transcripts into meaningful units of relevant information,
- (c) created clusters of themes based on the relevant units made, and
- (d) kept the purpose of the study and research questions in mind when describing the themes.

All data collection with participants was executed fully online. Hence, each participant being-in-the-world as training in-person with others did not apply in this case.

b. How did the research affect my *dasein*? Wilson (2014) stated, “it is impossible to understand [a lived] experience” by being detached from the data analysis process (p. 57). Hence,

my desire to explore and understand the research process and its outcome was the motivation and driving force to practice *dasein*, to being fully present and in full use of my sensory and intuitive faculties. Furthermore, the persistent self-question of how to have a peaceful death with or without a well-trained EOLD present was another effective motivator to practice *dasein* throughout the data analysis.

2. Foresight or Fore Conception

Pre-understanding or preconceived knowledge about the phenomenon being studied. What was my preconceived knowledge about the EOLD training? Based on the three independent EOLD training sessions I had participated in before and during the pandemic, I understood some of the concepts and procedures the trainers used. However, aside from playing harp music as a volunteer for those in transition at one of the local hospitals in my area, I have no practical EOLD experience working with the dying in the manner that most participants in my research did. Five out of seven were already working in the field of elderly care and hospice care before their EOLD training.

As such, their individual lived training experiences are just as unique as mine was. I highly respect (1) their preunderstanding or preconceived knowledge of their lived EOLD training experiences, (2) their distinctive way of processing learning, and (3) their use of knowledge afterward, which, in my opinion, every participant is entitled to self-manage. Therefore, regardless of my preconceived knowledge and my lived EOLD training experiences, the variety, and distinctive protocols of the participants in my research seems fitting, and I honor that.

3 Hermeneutic Circle of Understanding

The expression of becoming involved in the hermeneutic circle of understanding becomes more of a spiral as researchers learn new facets of participants' lived experience (Wilson, 2014;

Creswell & Poth, 2018; Van Manen, 1997). To expound on this concept, I asked myself the following question:

How were my understandings revised as I analyzed the data? Since my goal was to revise and upgrade my current conceptions with more relevant ones, I engaged in self-reflection, journaling, revising personal biases and thoughts, and contended with these projections back and forth until I sensed a release or what Gadamer (2013) calls an agreement of meaning or essence revealed, clarified, and acknowledged. I became deeply involved in the hermeneutic circle or spiral of understanding as I discerned new aspects of each participant's lived experience.

For instance, before I read and analyzed each participant protocol, I was oblivious to the fact that (a) their lived EOLD training experiences had a common yet sensitive mortality-related thread; (b) most of them were afraid of death and dying and candidly admitted as much; (c) they felt a "divine" call to aid the dying and care for grieving families; and (d) they felt drawn to serve others in their families, communities, society at large, and the world.

Validity and Reliability

According to Peoples (2020) and Creswell and Poth (2018), there are four constructs to validity and reliability: credibility, transferability, dependability, and confirmability. Therefore, to ensure that (1) my study is credible and the findings trustworthy, transferable, generalizable, and dependable, (2) my findings can be replicated and confirmed, and (3) my research is unbiased, I discuss how I implemented these strategies in the study by presenting them under the following subheadings: credibility, transferability, dependability, and confirmability.

1. Credibility

To ensure that the research findings were credible, I first checked the participants' membership under the EOLD trainers' members directory publicly available websites, e.g.,

nedalliance.org before contacting them. The completion of their EOLD training was the main requirement to participate in this research study. After I interviewed the participants, I transcribed and provided clear and accurate descriptions of their experiences and emailed them to them for verification. I also used prolonged engagements and observation in the field of study by attending three different EOLD training sessions and note-taking. Hence, when the participants discussed the same kind of practical exercises they did during their training, their credibility was once again validated by my own narrative of the events. Creswell and Poth (2018) have observed that spending time with participants in their natural environment imbues the researcher with a better understanding of participants' cultural context. I was able to distinguish the important from the irrelevant as I sought to present the results of the study with validity and credibility.

2. Transferability

Transferability is the extent to which research findings are generalizable to other populations (Creswell & Poth, 2018). The insights obtained from the lived EOLD training experiences of these participants may be like the insights of other aspiring EOLDs with similar lived experiences. However, phenomenologists should consider the setting, the participants, and participants' experiences before generalizing any findings (Peoples, 2020). This was a small study with a small sample size that aimed to focus on the deeper subjective experiences of the participants rather than making general assumptions (Colaizzi, 1978). Other leading phenomenologists such as Smith et al. (2009) have also recommended the use of a small sample size because it allows more time for microanalysis of similarities and differences of participants' experiences. However, the findings could be utilized to formulate hypotheses with similar populations and may offer insights for those serving in the EOL field.

3. Dependability

I provide in Chapter 3 a detailed explanation of the research process followed to maintain the dependability of the study, by doing things such as taking measures to follow a rigorous data collection from analogous sources. For example, I obtained informed consent, audio-recorded the interviews, and documented and reflected on impressions during the process of collecting and analyzing data. Hence, it is probable that repeating the steps of this research for additional investigation into the same lived experience within a similar context could yield equivalent findings.

4. Confirmability

Firstly, I had participants read their transcripts for accuracy and confirmability. As mentioned in the section on dependability, I provided in this chapter a detailed audit trail to enable replication of the study and the following of each step as it was described. Furthermore, my advisor and research committee members who are not directly involved with my research procedures will evaluate both the data analysis and the findings to decide whether the results reflect the data accurately. Their involvement and input will fulfill all constructs of validity and reliability.

I also chronicled and reflected on my subjective biases to anticipate any personal projections in my quest for understanding each participant's lived experience. I repeated this process of thought revision and journaling until the meaning or essence of each participant's experience became clear (which is the hermeneutic circle in action). Pool (2018) and Van Manen (2014, 2016) claim that the intent of this process of interpreting lived experiences is to accept the inseparability of thought, emotion, language, and writing in constructing meaning.

Ethics Framework

In addition to the four constructs of validity and reliability: credibility, transferability, dependability, and confirmability (Creswell & Poth, 2018; Peoples, 2020) elaborated above, this section gives information about the ethical considerations that presided over this study. The ethics segment of this research complies with the expectations and guidelines of the MSU Institutional Review Boards (IRB). Its clearance number is STUDY00004609. This study was completed with the cooperative participation of seven consenting adult coresearchers.

A copy of the informed consent was emailed to the participants to read and sign before I scheduled an interview session with each of them (see copy sent to them in Appendix A). Participants were also informed about the risks and benefits, including the reasons why they might or might not want to be part of the study. I provided my personal home address, cell phone number, and my academic email and degree status, just in case they should have wanted to discuss or ask me any questions they might have had. I also included MSU's Human Research Protection Program address, phone number, and email address. The intent of providing transparency was that participants would feel safe and protected. Hence, they were empowered to make an informed decision in agreeing to participate or even to stop at any time after they had already started. I would have accepted their decision with equanimity.

The participants also knew ahead of time that they would be asked seven questions related to their lived EOLD training experience and that I would record their answers and return them to the participants after transcription to have them revised if necessary. There were no foreseeable risks of participating, and none of the participants reported having any issues. The most likely inconvenience to them may have been the time and effort that it took them to answer seven questions related to their EOLD training. Despite that, they understood the potential benefits of

taking part in the study. One of the benefits presented to them was that they would help others understand how trained EOLDs provide informed support, guidance, and comfort to dying individuals and their families in coping with grief and impending death.

Regarding confidentiality and anonymity, participants were aware that their recorded answers were safely stored in WD Smart-Ware Software and locked in a safe box at my home. As also explained in the written consent, participants knew that I would keep the recordings for nine months before deleting it permanently. In addition, according to Pool (2018), confidential information may be accidentally revealed, and emotional sharing could be distressing, I made every effort to protect the privacy of and reassure participants if it was needed. To restate my commitment to protect participants identity and input into this research, I did the following:

- Participants were not identified by name. All documents pertaining to each of them were labeled with a pseudonym. I chose P for each participant connected to a number from 1 to 7; for example, P1, P2, etc.
- I saved each participant's recorded interview in my computer hard drive with a secret code used to access the file and completely erase it after nine months, along with shredding all physical and hard-copy field notes.
- I endeavored to report all findings accurately. However, realistically speaking, any data interpretation is not fully objective (Pool, 2018); therefore, participants were contacted again to validate the findings, and they responded with full approval.
- I agreed to use the data appropriately in the best interest of the participants and the EOLD group they represent.

Conclusion and Summary of Methodology

In this chapter, I presented the research method and my role as the researcher. I clarified the importance of continuous self-reflection before and during the phenomenological data analysis. Besides discussing the selection of participants and provisions for follow-up interviews, along with their demographic information, I explained the research procedures, interview questions, and the data collection and analysis I followed.

I discussed in detail each step of the general data analysis as well as the benefits and drawbacks of using QDAS in phenomenological studies. I also evaluated my participation through the lenses of the Heideggerian hermeneutic theoretical framework. I closed this chapter by analyzing how validity and reliability with its four constructs guided the steps to accomplish this phenomenological research, in addition to how the ethics for this study also influenced its design. The findings are discussed in the next chapter - Chapter 4.

CHAPTER 4: FINDINGS

In this chapter I present the research results linked to the interviews, field observations, field notations, and participatory observation. As stated in Chapter 3, the results from the analysis of the training experiences of seven EOLDs interview transcripts were intimately sieved through the hermeneutic phenomenological framework. At the forefront of this process was the ever-present reason and purpose for this study: (1) give trained EOLDs a voice to articulate their lived training experiences and (2) analyze those experiences to understand what and how they obtained their qualifying skills to serve in the EOL field and aid those who seek a peaceful death.

In this section I also followed the idiographic approach to analysis. “Ideography is concerned with the particular” or the details of the phenomena under study to understand it from the perspective and context of the participants (Smith et al., 2009, p.29). Here I present the results of the analysis, which include two overarching themes and their respective subthemes. Colaizzi (1978) warns that this is a challenging process due to the tendency to honor the voices of all participants. I intend to heed his warning.

Overarching Themes and Subthemes

A. Being ready for an EOLD training program

1. One must be predisposed to attending EOLD training
2. One must be willing to engage with the experiential side of EOLD training
3. One must be ready for social change in oneself, in one’s community, society, and in the world
4. The trainer must appear trustworthy and competent

B. Validation of the EOLD training

1. Promotes self-awareness, resulting in one becoming open to change

2. Fosters acceptance of one's own mortality to eventually assist others in accepting theirs
3. Unveils what is of central importance for participants
4. Presents the possibility of asking for payment for EOL services

In this chapter, I also leaned on Colaizzi's (1978) advice, "the researcher must refuse the temptations of ignoring data or themes which don't fit, or of prematurely generating a theory which would merely conceptually-abstractly eliminate the discordance of their findings thus far" (p. 63).

Findings

The essence of the lived training experiences of EOLDs are encapsulated in two overarching clusters of themes. The first one that emerged from the research analysis is prospective trainees *being ready for EOLD training*. The second one is that their lived experiences revealed *empowering properties EOLD training* seems to possess. Both clusters of themes with their respective encompassing subthemes are presented here sequentially.

A. Being Ready for EOLD Training

The assertion of *being ready*, in this context, conveys an image of knowing that one is prepared mentally and physically for the next step, project, or objective. Most participants identified an awareness of being ready and well-equipped to add value to a new venture. Some of them added enthusiasm and some wit to their *being ready*. For example, Participant 2 (P2) had just lost his job due to COVID-19 and was understandably devastated. Yet, when the opportunity to attend an EOLD training presented itself, he took it. He said he was ready for it and the undertaking proved to him that it was the right thing to do. His narrative, upbeat attitude, and the voice modulation he used during the interview were enthusiastic and passionate.

Most of the participants also displayed readiness with enthusiasm, e.g., P3 who is an accomplished veteran in the EOL field, has worked in palliative and hospice care most of her adult

life. She was one of two participants out of seven who attended two EOLD training sessions (see Table 7, pp. 61-62). She said, “I revel in all of that. I’m so glad that I had both kinds of training—the more cognitive training as well as the [more] experiential. I’m really glad I had both.”

While doing the research interviews, I also noticed that the participants wanted me to know what attracted them to the EOLD training. The emphasis on justifying their attendance ran throughout the duration of the interviews but was more noticeably after questions 1 and 4. Question 1., which was “Please describe your lived experience or the nature of your EOLD training.” When participants waited a few seconds to respond, I used the following prompt: “Please try to recall and describe something about your EOLD training experience that made an impression on you or in some way affected or influenced you.” Question 4. was “What were you experiencing before your lived EOLD training? During? Afterward?”

Although neither questions 1 nor 4 asked participants to give a reason for their attendance at an EOLD training, question 4 seemed to elicit a reason more than Question 1. Lacking an explanation that a trained psychologist or linguist could give regarding the semantics of these verbal exchanges, I can only ponder that if I were to replicate this research in the future, I would switch question 4 to 1 before conducting the interviews. Hence, the first subtheme, “One must be predisposed to attending an EOLD training” was initiated and fully produced by the participants.

1. One must be predisposed to attending an EOLD training.

All the participants testified to a predisposition to attending an EOLD training. They expressed being ready or feeling an allure toward the training. Some reported feeling “called” one way or another to attend an EOLD training of their choice to either enhance their current offerings or to create a new path (see the list of training organizations in Chapter 3, Table 7, pp. 57-58).

Participant 1 (P1), a chaplain at her local hospice, wanted to enhance her volunteer work and felt a strong “call” to attend an EOLD training. Her desire was to learn what a death doula could or could not do and why. For example, she wanted answers to questions that arose during her lived EOLD training experience, questions such as, “What do the dying need from an EOLD that a hospice staff can’t supply?”

P3, on the other hand, had been working in hospice for over 30 years. Her friends invited her to attend an EOLD training with the idea of enhancing their skills with a holistic nonmedical approach. She admitted to attending the training more out of curiosity but also acknowledged that she was already looking for something different. “I was looking for ... an even better experience than just drugging a person out of their symptoms.... Therefore, I attended out of curiosity. Once I started, I liked it and it still continues to resonate with me.” Eventually she attended another EOLD training program and reported that she learned different yet valuable information from each. “I’m still doing the work as I was taught at the trainings ... it continues to unfold for me in ways I can’t really explain how.”

Both P1 and P3 were already familiar with the EOL field and have had a strong background in the palliative and hospice care industry. They were both curious and predisposed to participate in a lived EOLD training experience along with P5, P6, and P7. They testified to being ready to attend to enhance their current offerings. Both P2 and P4 felt “called” to attend an EOLD training to create a new path in their lives—P2 as a young professional switching career and P4 as a recent retiree looking for a new vocation to give of herself to others. P4 hoped to volunteer her time in the EOL field, because she felt a strong “call” to do so:

Before my training, I just knew that this is what I wanted to do. I heard someone talking about it and as soon as she mentioned the word end-of-life doula. I was like, oh whatever

that is, that's what I want to do. And I know that during the training I experienced the same thing, a knowing that this is where I want to be. I know this is the place I need to be and should be.

Unlike the rest of the participants, P2, P4, and P6 did not have background in the medical assistance industry. Next, the following subtheme regarding the participants being ready or willing to immerse themselves fully in all aspects of the training touches on a more succinct yet impactful experience for them.

2. One must be willing to engage with the experiential side of the EOLD training.

Johann Wolfgang von Goethe's well-known statement, "Knowing is not enough, we must apply. Willing is not enough; we must do" (Philosiblog, 2021, March 25) describes this subtheme well. Indeed, one must be willing to engage with the experimental, hands-on side of the EOLD instruction to walk away with knowledge that is applicable to certain situations in a chosen life journey. This practical side of learning recalls the kinesthetic-tactile style of instruction, which is highly in vogue in educational classrooms and beyond. Its effectiveness is credited to the amalgamation of the senses—especially tactile, auditory, and visual. The use of real-life variables may produce an effective multisensory learning experience that can easily transfer to real-life situations. For example, I have found that EOLD trainers who were able to apply experiential learning in their in-person EOLD training curriculum positioned themselves on the cutting edge of teaching. Hands-on learning may lead to a deeper understanding of a concept when engaged with through personal experience. That is the gist of this subtheme.

Before the pandemic, there had been a virtual dying exercise which was required in most of the in-person EOLD training curriculums. This virtual exercise seemed unfamiliar to most new trainees and took many of them by surprise. I know since I—the researcher—was one of them at

one point. I was a naive trainee who attended an in-person EOLD training before COVID-19. The goal of the exercise was for the participants to undergo a shift in how each of person related to death and acquire a certain level of comfort with death and dying. During the interview for this research project, a few participants alluded to it; however, they did not voluntarily provide many details. For instance, P2 said the following:

I found that exercise very useful and growth inducing in my life. I would say, the introspection that this course required to get me to have more clarity around death and the dying process is really the gold nugget of it all. It is the thing that challenges you to think greater for yourself and that also means you've got to do some big work around yourself. Therefore, I would say, it was the most difficult and yet also the most rewarding work from this course.

Notice that P2 did not openly talk about the experiential learning scenario described in the above paragraph. He referred to the virtual dying exercise as “that exercise.”

When P3 compared the teachings of the two training sessions she attended, she spoke highly of the first one because it offered more experiential or hands-on learning:

Well, the Conscious Dying Institute is profound training because it is not linear thinking. It is very experiential. Therefore, you lay on the floor and you learn breathing techniques and that kind of stuff. [Here she switched the topic to comment on her second training. Then she resumed as follows]. I would say, it has allowed me to ask deeper questions of myself around my own end-of-life and maybe be more prepared for those stages within myself. You know, maybe address even deeper levels of anxiety or fear ... I think we all have death anxiety. I don't think that's relegated to just a few people. I think it is in all of

us and how we work with that throughout our lifetime or careers is important. Therefore, maybe go a little bit deeper in that for me. I think that might have happened.”

P3 alluded to the exercise by commenting on the effects it might have had on herself. When I listened to P3’s recorded voice memo, I observed her tone of voice sounding a bit matter-of-fact. I wondered if her seeming indifference about this teaching exercise could be related to her strong palliative and hospice background. She might have already witnessed the dying of many patients. However, these self-inquisitions did not elicit a follow-up interview on my part.

P5’s tone of voice, on the other hand, was more animated, as she seemed to have fully engaged with, if not embraced, this experiential side of the EOLD training. P5 admitted to performing a considerable amount of internal self-awareness work during the hands-on exercises. When I asked her to tell me more about it, she said,

One exercise we did was looking at ourselves in the mirror and thanking our bodies for the life we’ve had with it and then journaling about it. But the virtual dying exercise was the most challenging. We were supposed to imagine that we were in the emergency room dying. Since we couldn’t talk, we wondered who was going to be with us, which family members were being part of our experience, and what was going on around us.

I imagined myself dying and wondering what my family members would be going through. How my dad would show up. What would come to the surface for him. Imagining my family there and all these emotions that come up. All the drama that can surface because of how everyone in the family has interacted with each other for years and years and years. What would show up emotionally for those closest to me as I was dying? Just imagining oneself in that situation, was emotional yet powerful. I cried a lot during this exercise.

From an observational field perspective, I, the researcher, also participated in an in-person EOLD training before the pandemic and did the virtual dying exercise. P5's response brought flashbacks of my own experience as I volunteered to be the dying person in the group. I remembered becoming anxious and chiding myself for volunteering to be the dying person. I started trembling and almost choked without crying openly. I found it extremely challenging to imagine my own demise and to think of leaving my loved ones behind, forever. I did not sleep well that night, as I realized I needed to work on my own virtual dying process if I were to assist anyone in their dying journey. The next subtheme of being ready for an EOLD training relates to the participants' readiness to promote change in their surroundings through human interactions and relationships.

3. One must be inclined toward social change in oneself, in one's community, and in the world.

The expression that "one must be inclined towards," in the sense of being prepared or ready for change in oneself, the community, and in the world, indicates and includes all people, as shown in the following paragraphs. The EOLD movement for a "good" or planned death is an emerging field of holistic nonmedical care among paraprofessionals, and as such, EOLDs are experiencing growth to address the surging need for a more holistic and dignified way of dying (Van Eechoud et al., 2014; Fersko-Weiss, 2017; Cochran, 2019).

P1 expressed that she saw the need for more education about death and dying in her own community and started conversations with people by facilitating a Death Café once a month.

Since most people I know and have known won't talk about death, are afraid of it, and choose not to think about it, I became sure that I could be helpful to them in this way. And that in doing so, I would also help myself, my community, and society at large.

P1's initiative is the effect of her leadership and readiness to invest in her community and produce positive social change.

P3 verbalized her admiration for one of the two training sites she attended, "One of the things that impressed me so much [about the training] was the emphasis put into end-of-life doula [work] being a community service." P3 refers to the Conscious Dying Institute, which is one of the two EOLD training sessions she attended and one which she spoke very highly of the instructor, "the main teacher is just a creative genius." P3 considers the leader of this organization to be a role model to hundreds of EOLD trainees who have attended this training. This EOLD training leader uses conscious awareness to induce social change. P3 also observed that "death doulas speak about death with a different tone and in a more relaxed manner, like this is okay, death happens to people and it's normal." She went on to express her way of investing in social change, "I believe that death is something we should talk about more often, especially during the COVID-19 pandemic times. Therefore, talking about death is a normal thing for me now. I do it all the time."

P6 encouraged family caregivers who sustain loved ones in transition as situations that a whole community could benefit from if more people were doing it:

This work is important in terms of our loved ones and those who live around us but also as the backbone of the community as it has been done from when humans started to live on this planet. Something we all know about life is that we're going to die. Death is part of every culture. Yet we all have this fear of death and we don't talk about it. We should talk about it as an important part of living. Being in the role of supporting death and dying conversations and supporting the families as they support the person doing the transition is very important.

Although P6 validated the unifying community work EOLDS do and supported conversations about death and dying among loved ones, families, and in communities, she did not engage in a proactive initiative herself.

The above participants' statements illustrate their awareness of being part of a holistic nonmedical care movement that seeks acceptance of the inevitability of death and social change. Five out of seven participants were already engaged in the EOL field and were proactively involved in their communities as career clinicians. Most of them have initiated conversations on death and dying. The rest of them were planning on getting involved; for example, P5 wanted to start conversations about her own parents' death and dying:

Therefore, to be able to have conversations with my mom or my dad about what their end-of-life wishes are. To come into that space and really hold it and feel like I would be prepared to help and be there with them.

After accepting one's own mortality, as most participants experienced during their lived EOLD training, family members are the logical starting point to initiate conversations for change. Those same participants may gain the resolve to initiate change in their communities, which may possibly reverberate throughout society. If the message for change gains critical mass in different pockets of society, then the possibility of generating a mindset shift about accepting one's own mortality worldwide would seem like a new age of enlightenment.

The next and last subtheme of the overarching theme of "being ready for an EOLD training" will focus on the findings pertaining to participants' expectations of their lived EOLD training experiences in connection with their chosen trainer.

4. The trainer must appear trustworthy and competent.

Education and knowledge about the EOL were highly valued by all participants. They wanted to see evidence of the trainer(s)' commitment, competency, and trustworthiness. These character traits are also sought by prospective employers in business operations. Hence, the EOLD trainees were in the position of hiring the trainers and it was imperative to obtain a return on their investment in time, energy, and financial resources. Four participants were content with their choice of EOLD trainers. Two participants hesitated to speak positively of their trainers. P7 seemed to have experienced buyer's remorse. P7 was the outlier in the group and his keen observations attest to the developmental infirmities of a young EOLD movement. I expound more on P7's contrary comment below. P1's observation and recommendation start the next lines.

P1 wanted to learn from trainers who worked in the medical field and were already experienced death doulas. She sought EOLDs who "understood intricacies, complexities, and subtleties" of the death and dying process. P1 wanted to learn from the best because she was concerned about the risk of harming patients physically, psychologically, and/or emotionally. To prevent such occurrences, she researched for the "best trainer" and according to her, she found one. P1 was so confident about her find that she had some words of wisdom for prospective EOLD trainees,

I'd encourage anyone who's interested in EOLD to find a knowledgeable trainer who provides inexpensive online training or the most complex expensive studios training. Whatever is a fit for their methods and/or budget, or who they are. Simply choose the program and the instructor they resonate with because they'll be learning the EOL care as the trainer sees it more effective. Therefore, check the trainer's success in their field and trust your own intuition.

Although P1's unsolicited advice to find a trainer that fits the needs of a prospective EOLD may seem unnecessary because that is what most people would do before paying for a training, this study showed that a few participants were not fully satisfied with their choice of EOLD trainer. P2 expressed solidarity with the values and mission of his trainer:

Somebody showed me the video of [the trainer] and I felt totally called to this work ... my training has only been a source of inspiration, motivation, and safe space to express myself, question my experiences, and strengthen my love for this work.

During the recorded interview, P2 showed enthusiasm about the knowledge he had gained in his lived EOLD training experience. He started his own website to offer services of legacy work to potential clients. The meaning of legacy work, as explained in Chapter 2, is the intimate work EOLDS do with their EOL clients. It encompasses (1) exploring the patient's life meaning through a life review; (2) extracting from the life review the legacy they want to leave behind; (3) creating a memory book, or photo album, audio, or video, writing letters, etc. to capture or narrate their legacy for beloved survivors. P2 described being coached by his trainer for this phase of his new EOL career.

P4 was also impressed with the training and expressed admiration for her trainer,

"I trusted her. She was very knowledgeable, competent, and taught it in a logical progressive manner. She covered all aspects of the doula work: from being at the bedside to the funeral and to grieving with the family afterwards. She gave me time to think, assess, and journal in between lessons. I found the whole experience very intellectually enjoyable.

It was worth the time. It was worth the money. It was well worth the entire experience."

P4's positive expression about her trainer and her lived EOLD training experience stands in contrast to P7's statement below.

Here P7 describes an aspect of the training and trainers that he feels needs correction,

...the knowledge I gained in over 20 hours of training did not make me a professional in death and dying. Trainers need to be more sensitive about this topic [of professionalism] which they woefully miss giving out to their students. I have met students who were released from the training with wonderful aspirations and full of energy to do good things. It saddens me that they are being misled this way.

After the scheduled interview recording with P7, he reported having a conversation with his trainer about his concerns. He hoped the leader had made changes in this respect in his future training sessions.

B. Validation of the EOLD Training

The list of benefits EOL patients received from trained EOLDs is presented in detail in Chapter 2 (see Table 5, EOLDs' scope of practice, pp. 36-37). Most dying individuals need care in two main areas: (1) comfort of the whole person: physical, mental, emotional, and spiritual, (2) completing mostly legal documents to help survivors know what to do with patient's belongings, power of attorney, investments, life insurance, bank account(s), online subscriptions, and other important matters to the individual. The following subthemes demonstrate the empowerment the lived EOLD training bestowed upon the participants. There were four focus areas, which will be presented sequentially.

1. Promote self-awareness - Resulting in one becoming open to change

Maharshi and Godman (1985) wrote about awareness as being another name for "you."

Since you are awareness there is no need to attain it or cultivate it. All you must do is to give up being aware of other things that are of not-self. If one gives up being aware of

them, then pure awareness alone remains, and that is the Self (p. 12). “Till awareness is awareness of itself, it knows no peace at all” (Maharshi et al., 2011, p. 7).

EOLD participants’ training experiences seemingly triggered a heightened self-awareness as they testified in their narratives of becoming empowered to make changes in themselves regarding goodwill for self and others. Maharshi and Godman (1985) taught that the self-awareness or self-realization of one’s own “infinite” existence, even if vague, is grounding and therefore uplifts the self (soul) to loftier grounds. It is in this subliminal state that the conscious self may expand its wings (horizons) as it connects to its eternal source. This nonphysical omnipresence of eternalness is from whence the self obtains its inspiring perceptions to make its material world a better place to be.

Most of the participants seemed to have experienced self-awareness at different points in time during and after their EOLD training. For example, after the training, P2 eulogized his experience as follows:

The training was a source of inspiration, motivation, and a safe space to express myself. I just feel more in tune with my sense of self. I’m more aware, more carefree, and more-or-less stress-free. You know, I just feel lightweight again, like a kid, and it’s a blast.

P2’s sense of inner joy along with his happy expressions affirmed what Maharshi & Godman (1985) teaches regarding joy and happiness: both joy and happiness are byproducts of fleeting blips of self-awareness one experiences. P2 also maintained an enthusiastic attitude and transparency throughout his recorded interview.

P5, on the other hand, demonstrated her self-awareness in a more subdued manner. During the training, she felt an intense desire to reach out to her parents and have that dreaded discussion about their EOL, and she was ready: “I feel I’m ready. Yeah, just being able to be there for my

family ... I had a lot of discussions with my mom about my [EOLD] experience. She became curious about what I was learning.” P5 indicated that now her mother also has the desire to explore and talk more about death.

Another aftereffect of self-awareness is the expansion of one’s horizons which may lead to increased ability or willingness to change. P6 shows this aftereffect by expressing her changed mindset of goodwill toward others:

I’m more connected with my own wishes and desires and with my role as a daughter, sister, and wife. As a wife in terms of knowing what my husband wants. I’m way more aware of my role and the importance of thinking and planning ahead of time, which it’s something that I haven’t really known how important it is until after the training.

P7 also confided an aspect of himself that he was not fully aware of needing improvement until he attended the EOLD training. His lived EOLD training experience boosted his self-awareness to the point of inspiring him to make the world a better place to be in by holding space for others:

The training increased my sensitivity, particularly around the term called “holding space.” Holding space means that you are not there to solve anything. You’re not really doing anything, but simply, and more so being comfortably present with whatever unfolds with the dying person or their loved ones. I walked away from the training knowing the importance of active listening by potentially asking open-ended questions and holding space for them.

The holding space for others was a concept mentioned by most participants as a selfless desire to be present physically, mentally, and emotionally to support others. It seems that holding

space for others is an altruistic act connected to self-awareness. The next subtheme focuses on another form of change in self, which was also stimulated by the lived EOLD training experience.

2. Foster acceptance of one's own mortality then assist others to accept their own.

This subtheme of participants accepting their own mortality to help others accept their own remind me of airline attendants mandating passengers to wear their oxygen masks. A segment of the announcement focuses on passengers with a child or children or someone who requires assistance. The accompanying parent or adult is then required to first secure their own mask before assisting others. This analogy vivifies the salient nature of experiencing EOLD training through the lens of self-first. Those who attend EOLD training may then appreciate their experience of transformation that prepares them to provide the assistance they were “called” to do.

Alua Arthur, an EOLD trainer, explains the acceptance of one's own mortality, noting that “the single most effective, most important trait for somebody's success and effectiveness as a death doula is building your own personal relationship with death and dying because when you do that, then you can tell which [misgiving or fear] is yours, as opposed to what belongs to somebody else” (personal communication, February 22, 2021). She continues, “Look, this work can be tough. It bares your soul, but people can only meet themselves as deeply as you've been willing to meet yourself, which means that if you are not willing to go to those places within yourself, that makes you [feel] unworthy or not vulnerable or any of those things, you're not going to be much use to anybody else” (personal communication, February 22, 2021).

Alua's sobering observations are reflective of participants' comments about being predisposed to attending an EOLD training. The participants testified of consciously wanting to be trained to either enhance their current career performance or to create a new path comforting

and supporting those at the EOL. Therefore, accepting the reality of their own mortality can be seen not only as an important step in their learning but as a process they were willing to master.

P1 articulated that during her EOLD training, she willingly embraced her mortality and was now comfortable assisting others:

The very first thing that I benefited from the training was that I embraced death in my personal life and in my personal belief. Once I was sure what death was not, I didn't need to avoid or be afraid of the unknowns any longer. I think that's the primary thing that training underscored for me ... Now that I understand death and dying, I know I'm helping people understand it, and I would like to believe I'm also helping society at large.

P1 expanded her reach of ministry to helping "society at large" after coming to terms with her own comfort with death and thus also demonstrating an expansion of benevolence and goodwill toward humanity. P4 also experienced a transformation regarding her mortality while attending the EOLD training:

I don't feel afraid of death anymore. Initially I was like, who wants to talk about death? But now I find myself talking about death all the time ... I'm much more aware of the transitory beauty of life and how important each moment is to live and be the best that I can be ... I'm also more compassionate toward those who are dying and those who are grieving. Therefore, I've finally realized within myself that I have much more to give to others than I thought possible.

P4 seemed to have taken ownership of her own death and dying which has enhanced her empathy for those at the EOL and her potential to contribute more to others.

When P3 shared about her journey facing her own mortality, she also gave credit to the EOLD training for her transformation:

I would say that [the training] has allowed me to ask deeper questions of myself around my own end-of-life and maybe be more prepared for those stages within myself... and, you know, maybe address even deeper levels of anxiety or fear. I think we all have death anxiety. I don't think that that's relegated to just a few people. I think it's in all of us and how do we work with that throughout our lifetime or careers is important.

P3 is clear about her commitment to study herself more deeply and come to terms with her relegated fears and anxieties about death. She added:

I know [the training] has given me the tools to attend to my present elderly clients and their families. Now I know how to hold space for them that feels right ... I have a heightened desire to upgrade the services I offer them.

P3's new personal relationship with death has allowed her to reform and enhance her services to her patients and families.

The participants' narratives seem to convey that the development of their personal relationship with death and dying was the most important experience during their lived EOLD training. The acceptance of their own mortality may not mean participants were completely liberated from the fear of death and dying but instead that they have done their introspective work and feel ready to show up to meet their patient needs. As stated in Chapter 2, Fersko-Ross (2019), Gurevich (2019), and other leading EOLD individuals emphasize the importance of reducing fear and anxiety about death for patients and their families as one of the EOLDs responsibilities to teach their clients. However, the EOLD literature does not highlight the same reduction of anxiety and fear as a crucial step toward becoming an EOLD as EOLD trainers emphasize during their hands-on training sessions. The next subtheme is also one of the EOLD training outcomes.

3. Unveil what is of central importance for participants.

Each participant reacted in their own unique ways about what they considered to be the most important aspect of themselves and of an observed circumstance. For instance, they analyzed their own situational conditions in conjunction with what could be lying ahead for them after their lived EOLD training experience. P6, for example, reconsidered her initial interest in becoming an EOLD as a potential career. After learning at the EOLD training what being a doula entailed, she assessed the pros and cons and decided that it was too much work and thus that it was not for her:

I realized that if this work involves individualized components about a person, you can't have right or wrong answers because people's beliefs are different, families are different. During the training, I felt, "I'm going to be able to do this work no matter what." After the training, I realized I must live it, experience it, do it the first time, and then the next. I felt this is actual work, that once you do it in a community and then establish it by inserting your own culture while you do it, involves dedication and lots of work.

P6's reconsiderations were based on her self-judgments or values of what is important to her in life. She included in her decision her work ethics, her sociocultural awareness, and, therefore, her professional duties to maintain the cultural integrity of individuals and families within their own communities. P6 was the only participant who decided against becoming an active EOLD after completing the training. The other participants decided to move forward serving others as EOLD; however, each one had a different concern regarding the profession. For example, P3 was concerned about EOLD certifications, while P7 was curious about the intrinsic motivations that attracted trainees to the EOLD training.

What was fundamental or of central importance for P3 was the topic about EOLDS' certifications (touched on briefly in the literature review, p. 39). P3 speculated about the future of

EOLD within the field of EOL. She assessed it in two ways: (1) as a validated and accepted profession among the medical-based EOL field, which would be organized and overseen by a legal accrediting entity; and (2) as a para-profession that remains one that is developing and lacking credibility and stability within the EOL care industry but remains independent and open to developing in creative ways. P3:

What's going to happen is that it [EOLD] will get organized to the point that requires a national certification and that will take out some of the creativity of this initial start-up just like other disciplines have done it. But at the same time, there will be at least a standard. Therefore, when somebody says I'm a certified doula, we will know what that means, the clients will know, the families will know. Yeah, so I think overall I'm in favor of that.

P3 concluded in favor of accreditation. In other words, EOLDs should be officially certified to project an aura of credibility to their clients. I will elaborate more on this topic in the next chapter.

In the case of P7, he came across as an observer of human behavior and was curious about what motivates participants to attend an EOLD training:

It was interesting for me to see what motivated some people to be there [at the training]. Some people had a lot of experience with end of life. Other people had never experienced anything having to do remotely with dying. However, I found it to be worthwhile and enjoyed having the camaraderie of meeting other people who were like minded.

P7's previous narratives throughout this chapter revealed that he came into the training already equipped to serve as an EOLD. He has worked in elder care for over 30 years and had witnessed numerous deaths. However, he attended the INELDA EOLD training more in the likes of an undercover agent. He observed the way the trainer(s) executed their curriculum and course

modules and how they taught their materials. He wanted to assess the outcome of their teaching because he was concern about the quality of the teachings since he was in the position of hiring trained EOLDs.

The final subtheme of the overarching theme, “validation of the EOLD training” will focus on a sensitive, yet seemingly, still unresolved topic EOLD participants discussed during their training and discussed with me during their scheduled interviews: being paid for providing EOL services.

4. Present the possibility of asking for payment for services.

The lived EOLD training participants experienced also brought to light the financial aspect of their EOL services. Some participants disclosed that while attending their EOLD training they felt uncomfortable when the trainer brought up the subject of charging for their EOLD services. Most were ambivalent about it. Three of them had strong opinions against it and voiced it from different angles. For example, P4 was adamant about and critical of trained EOLDs who charge for their services. She argued,

Before going into this work, I knew one hundred percent that I’d never do it for money. I was never going to make it into a business. You know, it’s really very humbling to sit with someone who’s dying, and as a volunteer, I almost always sit with people who are actively dying. People are losing a loved one and are grieving and I don’t charge for helping them. So, I only work as a volunteer.

P4’s strong sentiments on the financial aspect of EOL represent her unique station in her lifespan. Because she was retired, “the whole [training] experience was easy in the sense that I was retired, and I could just devote the time to it...” P4 also had the belief that “...with end-of-

life, the people who need you come to your life and tell you. Therefore, I don't feel the need to have it as a business."

P6 expressed her concern about the trainer investing valuable training time to talk about the financial side of EOLDS services:

I personally felt somewhat uncomfortable with the ways in which [the trainer] was so focused on turning this into a business model to make a profit. I wasn't that interested in that. I mean, I bet it's necessary for some people. I only wished that instead of spending two hours talking about the business side of that, we could have spent two hours talking about something else to expand on other end-of-life concerns.

P6 addressed this issue from her own perspective of how she viewed the teaching format and the EOLDS charging for their EOL services more of an inconvenience that did not pertain to her.

P3 spoke from her position of having attended two training sessions and considering offering EOLD services for profit. She considered the possibility of starting a doula business and having a support group to rely on:

You see, most people don't know what a doula is or does. And they don't necessarily want to pay for the services. Therefore, it is not easy to start a doula business by yourself when you don't have a cohort. It takes time, energy, focus, and patience. Having a group of people to support your walk through it is very helpful.

P3 referred to having plans to provide EOLD services and was exercising patience and investing energy to bring it to fruition. She knew that one of the challenges in starting her business was the general public's lack of knowledge about EOLDS, and according to her, their unwillingness to pay for services.

These contrasting viewpoints among attendees reflect the various ways the EOLD training empowered them to find their voices and talk about their own take-aways from their lived training experience. As they serve the people in their communities as volunteers or as paid paraprofessionals, each participant eventually may find their own niche of services their community needs, therefore empowering not only themselves but also those they serve. On that account, they are also fulfilling their original call to becoming EOLDs.

Whether EOLDs serve as volunteers or as paid professionals, their approach matters as a representation of what they have to offer from their EOL knowledge base and practical know-how. Most importantly, it is their personal choice to either give their EOL services away as a humanitarian gift or to have monetary exchange for their services. In Chapter 2 we learned that some EOLDs negotiate to make direct work contracts with patients and their families; others choose to serve as volunteers at hospices and elder care centers (Brennan, 2019). In the following section I will examine the EOLD participants' lived training experiences viewed through the Heideggerian hermeneutic phenomenological framework: *dasein*, foresight or fore conception, and the hermeneutic circle of understanding.

Connecting Participants to the Theoretical Framework

To analyze the participants' experiences when using a hermeneutic framework (Holloway & Brown, 2012; Peoples, 2020; Sloan & Bowe, 2014; Smith et al., 2009; Van Manen, 1997), I used three terms: *dasein*, foresight or fore-conception, and hermeneutic circle of understanding (Peoples, 2020):

1. Dasein

Being there. Peoples (2020) suggests asking the following three questions related to participants' *dasein* to help us analyze it:

a. How were participants' being-in-the-world with others? Six participants were more acutely aware of experiencing *dasein* during their lived training experience. They voiced appreciation for attending their EOLD training in-person before COVID-19. Some elaborated on the benefits of in-person training; for example, doing hands-on practical exercises in groups, forming close, long-term friendships as they spent time face-to-face in transparency with each other, and other benefits. For example, P7 thought that having an in-person training in contrast to a Zoom call was an advantage, implying somehow that individuals taking the training online during the pandemic in 2020 were missing the experience of *dasein*: the equivalence of "being there" in-person with its benefits of enhanced learning and opportunities to network with others.

The uncertainties caused by COVID-19 may have also encouraged EOLD trainers to offer online training. P2 was the only participant in my research who attended a training session online. He voiced contentment with the online camaraderie he formed with other co-online participants. However, when I listened to the recorded interview with P2, his effusive tone of voice reveals more enthusiasm when he describes a meaningful liaison formed with his instructor than when he declared "contentment" with friendships formed with coparticipants. Hence, P2 seems to validate the merits of *dasein* with others.

b. How did participants find themselves in situations that were not of their making? Most participants expressed openness to learning the material in whichever way the trainer deemed fit. For example, despite P7's extensive experience in the field, he expressed respect toward the trainer, even though he had some doubts about the validity of what he was being taught.

c. How did participants actualize or fail to actualize their *dasein*? All participants actualized their being there/*dasein* in one form or another by benefiting from the instructions they received during their lived EOLD training experience. Their declarations of positive inner changes each

experienced regarding death and dying were the proof of this. For instance, P2 declared experiencing total transformation after navigating “the metaphysics of death and dying through introspective heart-work, emotional sharing, and ... hold[ing] space around death and dying” and P5 admitted shedding lots of tears while participating in a virtual dying exercise, “I imagined myself dying, wondering what my family members would be going through ... There were lots of tears and it was very emotional, yet powerful ... I feel I’m ready. I got the tools.”

2. Foresight or fore conception

Pre-understanding or preconceived knowledge about the phenomenon being studied. What was each participant’s preconceived knowledge about certain experiences or situations and how did this knowledge change? All participants had a transformation of some sort. For the sake of brevity, I will only comment on two of their testimonies.

P3 illustrates the change she experienced over her preconceived knowledge and it changed after her lived training experience.

I’ve been doing hospice and end-of-life care most of my career. Therefore, I’ve had a fair amount of experience with dying people. But I was looking for an even better experience and not just drugging a person out of their symptoms ... During the training I realized that a lot of the Doula work came out of our medical model’s gap ... [which] can only provide certain services but can’t provide a lot of this Doula stuff because they just don’t have the time per person.

P2 described his pre-COVID-19 pandemic experience and how it all changed during his EOLD training. “...before the training, I felt purposelessness, panic, and confusion. I was just very lost ... COVID19 shut down both the artistic and hospitality field. [Now] I’m doing this training...

and have a sense of wholeness ... I don't feel the panic or purposelessness I had before. It's just not there. I have clear direction in my life."

3. The hermeneutic circle

The hermeneutic circle is the understanding of the whole by reference to its parts and vice-versa; hence, neither can be understood without referencing the other in a circular manner (Finlay, 2012; Peoples, 2020; Van Manen, 1997). However, according to Wilson (2014), the hermeneutic circle of understanding becomes more of a spiral as new facets of participants' lived experiences are learned. To explore this topic, I will answer the following question:

How did participants revise their interpretations or understandings about different situations in their experiences? Participants revised their interpretations or understandings from the vantage of their unique personal platforms. For most of them, the transformative effect was visceral. The illustrations given on page 90 under "Revealing the power of EOLD training" disclose different degrees of participants' personal transformation during and after the training. Most of their revisions occurred after facing and accepting their own mortality during the virtual dying exercises in their respective lived EOLD training contexts.

Conclusion and Summary of Findings

The lived EOLD training experiences of the seven participants provided insight into the phenomenon through the essential themes extracted from the data analysis. Two clusters of themes emerged from the participants' interviews: (1) predisposition to attending an EOLD training, and (2) the training empowered EOLD trainees to serve others. Each theme had four subthemes related to the lived EOLDs training experiences. The results of this study offer insights into the making or empowerment of hundreds of EOLDs who hold certificates of attendance from a variety of EOLD training organizations in the U.S., plus more worldwide. I also included the participants'

experiential input considered under the hermeneutic theoretical framework. Chapter 5 presents my discussions, conclusion, and future directions for research in the death and dying field based on this study's findings.

CHAPTER 5: DISCUSSION AND CONCLUSION

The purpose of this qualitative interpretive phenomenological study was to fill the gap that currently exists in understanding the training qualifications EOLDs obtain to aid those who seek a peaceful death. The objectives of this research were twofold: first, to give trained EOLDs a voice to articulate their lived training experiences; second, to examine and understand what qualifying skills they obtained, as well as how they obtained them to serve in the EOL field and feel capacitated to aid and support those at the EOL. In the following paragraphs, I discuss the literature review findings, the phenomenological framework, and its application in my discipline of study. I also interpret the findings and close the chapter with discussion of the strengths, limitations, and implications of the study, along with recommendations for future research.

Discussion of Findings

Table 16: Overarching themes and subthemes

<ul style="list-style-type: none">• Being ready to attend an EOLD training<ul style="list-style-type: none">- One must be predisposed to attending an EOLD training- One must be willing to engage with the experiential side of the EOLD learning- One must be ready for social change in oneself, one's community, society at large, and the world- The trainer must appear trustworthy and competent
<ul style="list-style-type: none">• Validation of the EOLD training<ul style="list-style-type: none">- Promote self-awareness, resulting in one becoming open to change- Foster acceptance of one's mortality to eventually assists others in accepting theirs- Unveil what is of central importance for participants- Present the possibility of charging for EOL services

I presented the content of Table 12 in Chapter 4 and identified the themes and subthemes as pertinent. I will discuss and interlace them with the literature and the phenomenological framework in this chapter

I used seven research questions (see Appendix C) during the interview to collect, analyze, and interpret the findings in this study. The seven participants, who were in practice my co-researchers, as Creswell and Poth (2018) and Boylorn (2008) also call them, were as engaged in the research topic throughout the interview process as willing to participate in much reflection. They strived to find meaning or make sense of their EOLD lived training experience. The mental processes to recapture and redefine a lived experience or phenomenon are called the hermeneutic circle of understanding explained in the methodology chapter (Colaizzi, 1978; Smith et al., 2009; Van Manen, 2014). The main research question was, “what is the holistic nonmedical *lived training experience* of EOLDs?” The findings demonstrate an overarching correlation between two clusters of themes and their respective subthemes (see chart above):

Being Ready to Attend an EOLD Training Session

The findings reveal that being ready to attend EOLD training was fundamental for all the research participants. Moreover, they conveyed their readiness with enthusiasm. I found it interesting that although six out of seven participants had taken the EOLD training several months before my research interview, they were just as enthusiastic as P2, who had just taken it in the summer of 2020. Their confidence and enthusiasm about being “called” to do the training and providing EOL care were still as vivid and relevant for them. The following paragraphs will discuss the four main components of the overarching theme “being ready to attend an EOLD training” sequentially. The second overarching theme with its subthemes will follow.

One must be predisposed to attending an EOLD training. The finding showed that the participants' strong desire to attend an EOLD training became one of the main characteristics of their lived training experience. This finding also should be considered concerning Rawlings et al. (2018, 2019, 2020) comments on the exponential number of individuals taking EOLD training in Australia, Canada, the U.S., and Europe. The predisposition to attending an EOLD training is also a tendency that some leaders in the EOLD movement, Brennan (2019), Fersko-Weiss (2017), Gurevich (2019), O'Brien (2015), Rush (2020), and others have documented.

The participants talked about a magnetic-like attraction to attend the EOLD training. They referred to such appeals as simply having felt a "call" or "calling" to equip themselves to serve the dying through EOLD training. This study supports evidence of this "call" from Rawlings et al. (2020) from previous observations on their results with their Australian research participants. Thus, since the initial objective of this research project was to identify what qualifies EOLDS to do their work, we may infer that those who are "called" to the EOLD work also feel a calling to attend EOLD training to learn how to provide comfort to those with EOL needs.

One must be willing to engage with the experiential side of EOLD learning. During the participants' training, the practical side of the EOLD learning seemed to have been another critical turning point for many of them. Since five participants (P1, P3, P4, P5, and P7) work or volunteer in hospice care and eldercare and have had a different level of exposure and experience attending EOL individuals' deaths, the main experiential exercise—that is, the virtual dying—also affected them differently. For example, the virtual dying activity was more impactful for P1, P4, and P5, who had less experience attending the dying than P3 and P7, who had over 30 years of experience. All the participants, including P2 and P6, who did not have any experience working in the helping professions, communicated experiencing a significant shift in facing some of their fears, anxieties,

lack of preparation for death, and inability to express emotions during the experiential side of the EOLD learning.

The participants' vulnerability expressed during the dying activity seemed to reflect what Brennan (2019) refers to as one of the main challenges that terminally ill dying individuals face either with or without assistance. Hence, participants' training activities revealed the interplay between who they were during the training or even before their training and who they would become afterward. Alua Arthur also comments on the importance of this transformation (see her comments in Chapter 4, p. 99), supporting the necessity of these experiential activities during the EOLD training. These experiential exercises with participants' narratives were examined in-depth in Chapter 4, pp. 100-104.

One must be ready for social change in oneself, one's community, society at large, and the world. From the literature in Chapter 2 pp. 33-35, we have learned that the EOLDs already function both as volunteers and as paid paraprofessionals in hospices and elder care facilities in their communities (Fersko-Weiss, 2017; Gurevich, 2019). In Rush's words, "the basic belief of community-dwelling is that health and well-being is everybody's business" (personal communication, April 12, 2021). Perhaps EOLDs are already involved serving not only in their communities but influencing society through the Zoom platform for speaking engagements, educating, training, and reaching audiences worldwide, as is the case with some EOLD leaders such as Alua Arthurs (personal communication, February 22, 2021) and Merilynne Rush (personal communication, April 12, 2021).

Observers may also see social change emerging as an organic community need that community dwellers fulfill—for example, hot meals for the elderly—or seen from the top-down as a mandated change ordered at the district or state level healthcare restrictions due to a pandemic.

These social changes may permeate their way through community into society and continue expanding as an ongoing phenomenon worldwide, requiring deep listening while having those difficult conversations about EOL choices (Greenfield, 2009).

Some participants stated that their EOLD trainers inspired them to engage in social change in their community to bring about change in society and the world eventually. Participants: P1, P3, P5, and P6 were thankful that their trainers made them aware of the importance of investing their resources in the form of time and skills provided to their communities. For example, giving death education via Death Café or a “death over dinner” platform in community centers, volunteering in their local hospices and elderly care facilities, and other activities. Brennen (2019) claims that the popularity of EOLDS is already growing because of satisfied family members of the diseased in diverse communities in the US. This observation also seems consistent with Nelson’s (2015) data regarding EOLDS being a movement born from a community-based startup, as Henry Fersko-Weiss’ first EOLD model for doula work in a neighborhood hospice in New York city (INELDA, 2021, April 25).

Participants’ execution of social change could start a domino effect as they enact positive changes within themselves, accepting their mortality and then transferring it to others when they volunteer and interact in positive ways in neighboring communities (Häsler et al., 2020). Hence, the findings of this study regarding participants’ interest in social change seem possible because the nature of EOLDS’ work is to lessen the burden of dying and death. Such a lofty mission could easily be coupled with sociocultural transformation (Hässler et al., 2020).

The trainer must appear trustworthy and competent. The findings revealed that the participants felt called to attend an EOLD training session; therefore, they valued their trainer’s qualifications and expected them to be competent and trustworthy. However, the participants

voiced different satisfaction levels about their trainers after attending the EOLD trainer's instructions. Perhaps, a more positive EOLD training outcome would occur if participants were more proactive investigating available online information about EOLD trainers' prior experience, the efficacy of their curriculum, and the opinions of former trainees.

Finding an EOLD trainer should be the same process commonly used to find an expert on any given topic, such as asking personal contacts for recommendations or searching online. Gleim (n.d.) recommends first determining one's expectations of an EOLD training program and then evaluating the trainer's qualifications. Furthermore, it may be beneficial to know the differences between various EOLD training programs. For example, some emphasize holistic care, which considers the patient's emotional, social, and spiritual needs (Gurevich, 2019). Other training programs may specialize in spirituality and others in practical issues (Rush, 2020). Another possible approach to finding a more compatible EOLD trainer with the trainee's likings would be to rely on NEDA's list of trainers (<http://www.nedalliance.org/trainer-directory.html>). Brennan (2018), Cochran (2019), Fersko-Weiss (2017), Karnes (2019), Gurevich (2019), and other leaders of the EOLD movement seem to believe that the NEDA leads the way in the U.S. for inquiries related to EOLDs.

However, I maintain that the diverse settings, trainers, and forms of training the participants attended did not detrimentally affect the participants' experiences or the study results. The participants' interview narratives seemed to show that their EOLDs lived training experiences were equally educational and introspective as most of them expected. In conclusion, and as verified by the results of this study, none of the participants could seriously deny or ignore the powerful catalytic effect and transformation the lived EOLD training experiences produced in them.

Validation of the EOLD Training Programs

During the data analysis period, I noticed that the EOLD training enhanced the participants' self-awareness. They seemed willing to accept their mortality and embrace the challenge to pursue their "call" as EOLDs and still support themselves (Pool, 2018; Van Manen, 2014, 2016; Smith et al., 2009). In the following paragraphs, I will sequentially explore the four focus areas of the overarching theme "revealing the power of EOLD training."

The lived EOLD training experience promoted self-awareness resulting in participants becoming open to change and moving forward with their visions or plans. For example, the findings show that six out of seven participants decided to talk more about death and dying with others and serve as EOLDs to their families, communities, society, and the world (see participants' testimonies in Chapter 4, pp. 99-101). According to Ackerman (2021) and Maharshi and Godman (1985), self-awareness is based on the idea that people are not their thoughts but the entity observing their thoughts as a separate being. Nevertheless, the aftereffect of self-awareness is perhaps the main reason why participants became empowered, accepted change, and inclined to make altruistic decisions.

Promote self-awareness, resulting in one becoming receptive to change. The findings also showed that participants' heightened self-awareness led them to be more specific in updating the services they were already providing to their EOL patients, as in the case of P3 and P7. For example, after understanding the meaning of nonmedical, holistic care from a practicing EOLD perspective, P3, who worked in the medical field for over 30 years, became open to attending her patients in these new ways. P7 also said that he acquired a new understanding of the meaning of holding space and decided to practice it with his patients. In general, the training restructured participants' outlook about EOL and motivated them to provide more generous services to EOL

patients and move forward as transformed EOLDs. Perhaps they were now more focused on the effect of the training in their personhood, including positive attitudes toward others, according to Colaizzi (1978), due to heightened self-awareness.

Foster acceptance of one's mortality to eventually assists others in accepting theirs.

Participants' heightened self-awareness also seems to have led them to accept their mortality so that they could subsequently help others accept theirs. We learned in the findings chapter that coming to terms with one's own death prepares us to meet EOL individuals' fears and anxieties about their own death and dying process with more equanimity, presence of mind, and knowledgeable compassion (A. Arthur, personal communication, February 22, 2021).

Perhaps facing and accepting one's mortality gave participants the impression of empowerment that seemed to have equipped them to become involved in assisting others. Six out of seven (P1, P2, P3, P4, P5, and P7) participants intended to do so in addition to other life responsibilities. At the same time, some of these participants chose to remain in the same line of work they had during pretraining. Those who did so (P3, P5, and P6) reported observing a heightened post-training self-awareness of one's own finite existence that seemed to permeate their general decision-making. However, P6, as described earlier, chose not to serve as an EOLD at this time.

This study supports previous observations (e.g., Fersko-Weiss, 2017; Gurevich, 2019; Rush, 2020) about possible transformation during the dying of someone who finally understands what is happening during the dying process. Such a transformation by someone who finally understands what is happening during the process of dying "may turn an otherwise, frightening experience into a sacred [moment] and create a sacred memory for the family" (Karnes, 2018, p. 2). Another possible interpretation of accepting one's own mortality to assist others in accepting

theirs could be that, perhaps, the physical and emotional effort participants invested in experiencing their virtual dying and death was the prevailing rite of passage in the lived training experience phenomenon that converted EOL-trainees into EOL-Doulas.

This strong relationship between EOLD trainees and their experience of facing and accepting their demise also appeared to be the empowering component that led them to do what they do best for EOL individuals and their families—provide compassionate care. Such transformation connected to their virtual dying experience was also mentioned by Alua Arthur (personal conversation, February 22, 2021). In addition, some EOLD leaders, such as Karnes (2018), Cochran (2019), Fersco-Weiss (2017), and others who were mentioned in the literature review, also discussed such transformation but without connecting it to any experiential training activity.

Unveil what is of central importance for participants. Participants attended an EOLD training of their choice, envisioning changes in themselves and others in the realm of death and dying. They demonstrated being ready through their vision to lead the change and make their situational surroundings better in their families, communities, and beyond. The EOLD training may have unveiled what is of central importance for each participant within their chosen goals: seeing others as recipients of their EOL services. If that were the case, then others would seem to validate their understanding and the effects of the lived EOLD training to serve. Each EOLD participant might become part of the nonmedical movement leading to transformation in death and dying (Fersco-Weiss, 2017; Gurevich, 2019). Each of them may have learned to portrait death and dying (1) as a natural ending of a human life's journey and (2) as a salient rite of passage deserving attention and acceptance within families, communities, society, and the world at large. Others might allow EOLDS to see themselves as different people, yet on the cutting edge of the death

industry. Although they are called to attend the dying and their survivors with compassion, they have no vestige of morbidity.

Present the possibility of charging for EOL services. Online instruction due to COVID-19 presents a new instructional challenge for EOLD trainers to contend with in their programs – online virtual training. As a result, all in-person EOLD trainings were canceled. However, the participants’ readiness to cover the cost and expenses associated with the EOLD trainer’s prerequisites appeared to prove participants’ commitment to attend an EOL training regardless of the format (see in Chapter 3, Table 7, pp. 57-58, the range of prices participants paid).

Since participants reside in different states in the US, many attended in-person training. In addition, they traveled long distances to take part in other EOLD training groups in different cities at different times. Yet all participants seemed content with the logistics of attending their training whichever way possible and at any cost. Two participants, P3 and P6, each already attended two training sessions. A few participants alluded to being open to attending other training sessions led by different leaders. However, these findings must be interpreted with caution because they may represent the socioeconomic status (SES) of a self-selected group who felt “called” to attend one or more EOLD training sessions. Therefore, more research on this topic that includes a greater focus on SES as an obstacle to EOLD training may be needed.

Nonetheless, when researching the topic of turning EOLD services into profitable para-professions, the findings reveal division among the participants. Two participants were opposed to charging for their services, one was considering it, and another mentioned it in passing. Three did not voice their preferences. Thus, the possibilities of charging or not charging for services remain an open discussion and one of the unique challenges trained EOLDs face. For instance,

Brennan (2019) has published a book, *The Doula Business Guide*, now in its third edition, which suggests an existing need among EOLDs to provide EOLD services with a charging scale.

Summary of Findings

The purpose of this study was to understand the value and effect EOLDs' training has in preparing trainees to provide practical yet compassionate care during an EOL patient's dying experience. Therefore, we venture to declare two answers: 1) the all-important, profound "call" to attend an EOLD training and 2) the act of facing and accepting one's mortality. Therefore, the EOLD training appears to have an immense effect and value in preparing participants to provide practical yet compassionate dignified care during an EOL patient's dying experience and postmortem family care. The list of contributions EOLDs offer to the EOL individuals and their families has been provided in the literature review, in Chapter 2, pp. 36-37.

As I close the discussion about the focus areas under the findings overarching themes, it seems that to receive the full benefit of an EOLD training, one must be willing to participate in their experiential virtual dying exercise and other hands-on applications. That is, during in-person training rather than remotely, as some participants preferred it. The findings also seemed to highlight the effect of different transformative training experiences EOLDs experienced in relationships with others, and their EOL service outreach in communities, their society, and the world at large.

Limitations

The findings in this study are subject to at least three limitations:

First, in hindsight, the interview research questions could have revealed more information about participants' lived training experience phenomena. For instance, during the data collection phase, I practiced meditation before engaging with the salient task of interviewing each participant.

As Creswell and Poth (2018) call them, the experts, and the data owners. My meditation process involved viewing each participant in self-reflection with appreciative mindfulness to contribute to this research (Van Manen, 2014, 2016). However, my meditation was not always done with tranquility nor accomplished before the participants' scheduled time.

Second, there could have been more age, gender, racial, and socioeconomic diversity in this study (see demographic data Table 7, pp. 57-58). The participants' demographics showed significant variance in ages (from 31 to 69), with 4/7 over the age of 60, and in gender (5 females and two males) and ethnicity (5 Caucasians, 1 African American, 1 Hispanic). Dissatisfaction with such inequalities in the EOLD field was voiced by two participants, P6 and P7. Nonetheless, neither explained why the trainees were mainly Caucasian, over 50 y/o and primarily females. P7 said the following regarding the gender, age, and racial breakdown he observed in his EOLD training group,

I trained with 60 students, 58 were females, and there were two males. As a male, I am very much in the minority presently in EOL work. I hope that will change because I believe there's a real value for specific inpatients at EOL to have a male experience, just as valuable as the female experience. The other thing that stood out to me aside from the gender breakdown was that the group was vastly white women, 50 y/o and older. They probably made up 95% of the attendees, and that's just an observational fact of those who attended the training. There needs to be more of a diversification culturally, racially in terms of outreach. But as I indicated, the [EOLD] training seems to be aimed at white people willing to pay for this. We, as a society, would benefit from having more racial diversity and an understanding of how other cultures deal with EOL differently than white folks do.

As a former EOLD trainee, I can also attest to P7's observation regarding gender inequality in groups of EOLD trainees. The only in-person training I attended had 63 attendees, and three of them were males. This observation aligns with Watts et al.' (2021) study documenting that females are typically overrepresented in the EOL care workforce. However, various minority ethnic groups were represented; nonetheless, most were Caucasian and over 50 y/o.

Furthermore, P6, who attended an EOLD training program different from P7's, expressed the same sentiments regarding gender and racial diversity as P7 did. In contrast, however, she did speak during her training concerning the inequality and the challenges some minority groups endure in some racially divided medical centers:

I appreciated all the things that the group of primarily white women shared. However, when we discussed inequity or how the medical system treats white people versus people of color, I had to speak up. I knew that I was in a group of sensitive, caring white people. Even in that context, they were blind to explicit racial inequalities and discrimination, even in things like the training. However, we talked about advocating for ourselves in a medical setting, which is not the same as when you're a person of color. For example, when you don't know the language or even in legal contexts when you're here undocumented, what happens? Therefore, being the only non-white person in the room, I felt that I was put in that position [to speak up]. That was one of the hardest experiences I remember having at the training. If I were to do it again in the future, I would probably choose a non-white trainer.

Interestingly, only two out of seven participants in this study voiced their concerns regarding diversity, inclusion, equality, and justice for all. Perhaps, EOLD trainers may also be concerned about the same social inequalities they seem to attract in their EOLD training gatherings. Moreover, these observations confirm Merilynne Rush's concerns about social

inequality. As a result, she is taking the initiative to combat it within the EOLD movement by speaking about it and encouraging weekly Zoom interactions among EOLDs with different backgrounds, ages, gender, and racial diversity. (personal communication, April 12, 2021).

When I contacted prospective participants during my data collection phase, my goal was to keep it diverse in age, race, and gender, which are the obvious observable characteristics viewers see on the public EOLD trainers' websites where I found them. I also looked for diverse educational levels, which some participants shared in their online profiles, while others did not. The seven participants who became co-researchers in this study were the ones who willingly chose to participate. In addition, most of the participants spoke of the cost of the EOLD training without much concern. However, some of them (P1, P3, P5, and P6) mentioned potentially attending one or more additional training sessions, which suggests some level of financial freedom in being able to support their wants. Hence, this study is limited in answering questions about the interplay of race and balance of age, gender, and socioeconomic distribution in the lived experience of EOLDs' training.

Third, the data in this study is only reflective of a small number of participants (Smith et al., 2009) and therefore cannot be generalized to all practicing EOLDs beyond this context: the setting, the participants, and their experiences. However, Smith et al. (2009) have stated that generalizability is not a significant limitation since that is not the purpose of a phenomenological study.

To summarize, it is essential to note that this study only provides a glimpse into the current, lived training experiences of EOLDs. I recognize that this emerging holistic nonmedical EOL practice is evolving rapidly, and the leaders of the EOLD movement continue to upgrade their group portfolio, e.g., the formation of NEDA's code of ethics for all practicing EOLDs (see

Appendix E). Therefore, this list of limitations and others not mentioned are only considered relevant to answering the research questions within the present context. However, the stated limitations did not undermine my analysis nor findings. In reviewing the literature, the reports by Colaizzi's (1978), Van Manen's (2014), and Smith et al.'s (2009) reports have shown that research can never exhaust the investigated phenomenon since no person can be exhaustively researched; therefore, research can never be complete.

Implications

The fact that I attended three EOLD training sessions with the primary intention of expanding my knowledge of my chosen EOL field of research indicates a deep-seated sense to do this research project with some understanding of the field. However, I did not have the genuine “call” most EOLD trainees in this study had. Therefore, this study's contribution is mainly due to the seven EOLD trained coresearchers whose direct responses to the interview research questions gave us the answers we sought in the purpose statement section in Chapter 1. Furthermore, we now know that the EOLD training programs may have promoted participants' transformation to serve EOL individuals and their families. Therefore, qualifying EOLDs to be, perhaps, welcomed in the medical-led EOL field and the private sector as volunteers or paid paraprofessionals. In addition, since we have learned that most of those who attend EOLD training sessions were genuinely “called” to do the EOL work and felt prepared to serve in that capacity, we may recommend EOLD training programs to those aspiring to become an EOLD.

The need for traditional and non-traditional EOL service providers was brought increasingly into view by Cochran (2019) and Henchoz et al. (2019). Prior studies have shown a cultural shift occurring due to the rise of an aging baby boomer population gradually approaching the threshold of death (Cochran, 2019; Kortess-Miller, 2018; Rawlings et al., 2019). Since the

findings have shown that trained EOLDs seemed to have a genuine vocation to assist EOL individuals and their grieving families with nonmedical holistic care, around the clock if necessary, the EOLDs come into play within the plans of some members of this cultural shift. The EOLDs “call” and readiness for training appear to have prepared them to offer individualized services to accommodate the diversity of EOL patients and their families in various communities with potentially distinctive cultural needs. For example, Fersko-Weiss (2020) speaks of serving his Jewish community with equanimity since he understands their specific spiritual and cultural needs.

Recommendations

Since the findings conveyed that the EOLD trainees felt “called” and accepted their mortality, further research could verify whether being “called” and accepting one’s mortality are valid factors in qualifying EOLDs to lead EOL patients into the peaceful death they desire. Furthermore, prospective researchers intrigued by EOLDs’ work may want to hear further from the EOLDs’ patients and their families regarding their reaction to the care received. Finally, we could conduct a similar investigation with those in the EOL clinical care who interact closely with the EOLDs.

The emphasis in these possible investigations could be to continue verifying and validating the EOLDs’ nonmedical holistic care as beneficial when facilitated either in-person or via Zoom, as during the COVID-19 pandemic. Hence, it seems imperative to continue to validate EOLDs’ qualifications to contribute to the exponential need for EOL care and enhance their capacity to efficiently provide the consumer-driven comfort care that the baby boom cohort may require.

Conclusion

I inquired in this study about the lived training experience phenomenon of the EOLDs to understand how they obtained their qualifications to aid those who seek a peaceful death. After

using a hermeneutic phenomenological method to examine the narratives of seven participants' lived training experiences, the analysis showed two main results. First, participants have a strong "call" to attend an EOLD training. Second, the participants' virtual acceptance of their mortality transformed and empowered EOLDs to assist others on their dying journey.

Although previous studies about the EOLDs clarified who they are and what they do to assist EOL individuals, this study dug more deeply into how EOLDs acquire their qualifications during their lived training experience and its essential components. As such, this study took a different path from other scholarly studies previously conducted. To my knowledge, this study is the first hermeneutic phenomenological framework research that has explored the EOLDs' lived training experience phenomenon by itself.

It is possible that the results of this study would vary if we were to double the number of participants and modify the focus and number of the interview research questions. Future phenomenologists could consider investigating the leaders of the EOLD movement and what motivates them to train EOLDs. Future researchers may also explore how EOLDs are transforming the way people die in diverse cultural and ethnic communities.

Regardless, the findings suggest EOLDs experience validation of their calling to serve by facing and accepting their mortality during their lived training experience, implying their readiness to serve. It is imperative, then, that the general populace and the clinicians working in EOL (1) be open-minded of the holistic nonmedical services EOLDs offer, (2) accept them as a specialized group of paraprofessionals "called" to honor people's quality of life at the end of their life's journey, and (3) that families with loved ones experiencing EOL may appreciate how trained EOLDs offer them a more caring, comfortable, and peaceful dying process.

APPENDICES

APPENDIX A: Research Participant Information and Consent Form

Study Title: A phenomenological inquiry into the lived holistic nonmedical training experiences of end-of-life doulas (EOLDs)

Researcher and Title: Angela M. Rozeboom—Graduate student

Department and Institution: Human Development and Family Studies—MSU

Contact Information: rozebo11@msu.edu Personal—rozebooms@gmail.com (970-904-6067)

Sponsor: N/A

BRIEF SUMMARY

You are being asked to participate in a research study. Researchers are required to provide a consent form to inform you about their research study to convey that participation is voluntary, explain the risks and benefits of participation, including why you might or might not want to participate, and empower you to make an informed decision. You should feel free to discuss and ask the researchers any questions you may have.

This research study is about the lived nonmedical training experience end-of-life doulas (EOLD) execute when caring for the dying before death. Your onetime participation in this study will take about 45 min of your time. The researcher will ask you to answer seven questions related to your initial nonmedical end-of-life doula training experience.

There are no foreseeable risks for participating. The most likely inconvenience to participate in this study is the time and effort that will take you to answer seven questions related to your training as an EOLD.

The potential benefits to you for taking part in this study are (1) helping educate others about the availability of EOLDs training programs and (2) promoting awareness of the emerging EOLDs who are transforming the way people die in the United States. Both activities will empower you as a leader in the EOLD movement. Your participation may also help understand how trained EOLDs provide emotional, spiritual, physical, and informational support and guidance to dying individuals and survivors in coping with impending death and grief.

PURPOSE OF RESEARCH (*This is a required element of consent*)

The purpose of this study is to explore the qualifications EOLD acquire through face-to-face (before COVID-19) and online training to provide support and guidance to dying individuals and their surviving loved ones. The research objectives are to evaluate the end-of-life training and identify the qualifications that help reduce fear, anxiety, inability to express emotion, and unpreparedness for dying and death. It addresses questions focused on participant(s)' lived holistic nonmedical training experiences.

WHAT YOU WILL BE ASKED TO DO (*This is a required element of consent*)

Procedure: The researcher will ask you to accept the consent for onetime voluntary participation in a 45 min remote interview regarding your EOLD training experiences. The following is an example of the questions: “In retrospect, what value do you think the whole training experience had for you?” The nine interview questions planned may have follow-up questions to clarify or elaborate on what you have said. For example, “How has your approach changed over time?” “Can you tell me more about that?” etc. You are free not to answer or even end the interview if you encounter any riskiness or discomfort with the topic.

The researcher will record all your answers as voice memos and will transcribe and thematize them later. The voice memos will be safely stored in WD Smart Ware Software and locked in a safe box at my home. The researcher will keep the voice memos for 9 months and then delete them permanently.

POTENTIAL BENEFITS (*This is a required element of consent if there are any potential benefits*)

Two potential benefits: (1) You may experience empowerment due to your generous contribution of knowledge that others may gain. (2) Your participation will also help promote awareness of EOLD in communities and expedite their emerging numbers to assist the increasing number of people aging and dying in the baby-boomer cohort.

POTENTIAL RISKS (*This is a required element of consent if there are any potential risks*)

There are no foreseeable risks to participate. The most likely inconveniences are the time and input effort that will take you to answer nine questions related to your past training experience to become an EOLD.

PRIVACY AND CONFIDENTIALITY (*This is a required element of consent*)

The researcher will not identify you by name. The researcher will (1) label you with an alternative fictitious name in all signed consent forms, data, voice memos, and identifiable information collected solely for this research project; (2) transfer all documents mentioned into a “My Passport Mac” hard drive; (3) keep for 9 months in a personal safe box stored at researcher’s home; (4) delete permanently all electronic data after nine months; and (5) shred all physical/hard copy field notes.

YOUR RIGHTS TO PARTICIPATE, SAY NO, OR WITHDRAW (*This is a required element of consent*)

You have the right to say no to participate in the research study. You can stop at any time after it has already started. If you choose to stop the interview, the researcher will not criticize you or penalize you with any negative consequence.

COSTS AND COMPENSATION FOR BEING IN THE STUDY (*This is a required element of consent*)

You will receive a \$25 Starbucks gift certificate for participating in this study.

CONTACT INFORMATION (*This is a required element of consent*)

If you have concerns or questions about this study, how to do any part of it, please contact the researcher (Angela M. Rozeboom; 1185 McClelland St SW Grandville, MI 49418; rozebo11@msu.edu 970-904-6067).

Suppose you have questions or concerns about your role and rights as a research participant or would like to obtain information or offer input or would like to register a complaint about this study. In that case, you may contact, anonymously if you wish, the Michigan State University's Human Research Protection Program at 517-355-2180, Fax 517-432-4503, or email irb@msu.edu or regular mail at 4000 Collins Rd, Suite 136, Lansing, MI 48910.

DOCUMENTATION OF INFORMED CONSENT.

Your signature below means that you voluntarily agree to participate in this research study.

Signature_____ Date_____

Signature of Assenting Child (13-17; if appropriate) _____ Date_____

You will be given a copy of this form to keep.

A signature is a required element of consent—if not included, a waiver of documentation must be granted by the IRB.

APPENDIX B: Demographic Questionnaire

Participant's name: _____

Date: _____

Directions: Please fill in the blank or circle the response that best describes you.

1. Year you were born: _____
2. What is your ethnicity? _____
3. Level of education:
 - a. High school _____
 - b. Bachelor's degree _____
 - c. Graduate or professional degree _____
 - d. Ph.D. _____

Relationship status

4. Single _____
5. Marital
 - a. Married _____
 - b. Separated _____
 - c. Divorced _____
 - d. Widowed _____

EOLD Training

6. What is the name of the EOLD organization(s) where you received training?

7. Duration of training in days _____ or in hours _____
8. What was the cost of your training? _____

Employment status as an EOLD

9. Are you currently working as an EOLD?
 - a. Yes, full-time employment
 - b. Yes, part time employment, in one location __, in multiple locations__
 - c. No, I am currently between jobs
 - d. I am self-employed
 - e. Other, please specify _____

APPENDIX C: Interview Protocol

(Qs adapted from Colaizzi, 1978, p. 58; Peoples, 2020, pp. 53-54)

1. Please try to recall and describe something about your lived EOLD training experience that made an impression on you or in some way affected or influenced you.

2. Has your lived EOLD training had an impact on your desire/decision to aid the dying?

Prompt: What is it that allows you to feel sure that it made an impression on you?

If so, give an example of how the EOLD training had an impact on your desire/decision to aid the dying.

3. Is there anything that you were aiming at when you first started your EOLD training?

What? And during your training? Afterward?

If so, give an example of how your EOLD training had a helpful impact on your views about training to aid the dying.

4. What were you experiencing before your EOLD training? During? Afterward?

5. Did you discuss the ethos of what you were experiencing either with yourself or someone else before, during, and/or after your training? What did such discussion mean to you?

What came out of them?

6. What difference(s) can you detect within yourself after your EOLD training?

7. What made the whole lived training experience easy or difficult for you? Enjoyable or disagreeable?

- Is there anything you wish to add?

APPENDIX D: Phases of thematic Analysis

(Adapted from Braun & Clarke, 2006)	
1	<p><i>Familiarization with data:</i></p> <p><i>Data Collection:</i> Semi-structured individual interviews will be conducted. Basic ideas and inquiries will be developed.</p> <p><i>Field notes:</i> During the interview process, notes will be taken and participants' opinions and experiences before and after the interviews will also be documented.</p> <p><i>Transcribing:</i> Transcription will be completed by the author</p> <p><i>Reading, and re-reading, noting down initial ideas:</i> This early exploration will be conducted by reading the digital copies of the transcripts and inserting comments along the transcripts from the Word program.</p>
2	<p><i>Generating initial codes:</i></p> <p>Transcripts will be printed, and coding features of interest will be done by hand. This systematic process will be implemented across the data set, categorizing the entire data in the appropriate code(s).</p> <p>At this stage, the semantic level of analysis will happen on the right side of the transcript margin and a latent (interpretative) level of analysis will be conducted on the left side of the margin.</p> <p>Themes will be identified and later condensed and reorganized.</p>
3	<p><i>Searching for themes:</i> (NVivo was not used for this study)</p> <p>NVivo 12 software program will not be utilized for the task of searching themes.</p> <p>After uploading the transcripts, a second round of coding will occur using the software for creating nodes and tree-nodes.</p> <p>The codes (nodes) will be categorized into prospective themes and grouped together the data related to each prospective theme. At this point, the nodes will be reorganized and re-categorized.</p> <p>At this stage, the evolving-prospective themes regarding their category and name will be refined.</p> <p>A thematic map of the themes will be drafted by hand and digitally.</p>

4	<p>Reviewing themes:</p> <p>Congruence of each theme with each of the coded extracts and all the data set will be reviewed.</p> <p>Initial field notes will be revisited. The notes will help to support the analysis process, as initially documented participants' experiences are anticipated to be corroborated.</p> <p>Continuation of refining the thematic map by classifying and re-classifying themes that are similar or that are not related to the research questions.</p> <p>Finally, major themes and sub-themes will be identified.</p>
5	<p>Defining and naming themes:</p> <p>At this phase, the analysis will continue to attain an increased refinement of each particular theme, as well as the general narrative that the data are perceived to be transmitting.</p> <p>More distinctive concepts and names for each of the themes will be reached.</p>
6	<p>Producing the report:</p> <p>The process of writing the research report will allow an additional chance for reviewing the data analysis as the narrative of the results section is told.</p> <p>For illustration purposes, a careful selection of persuasive and powerful extracts will be selected. This will be a challenging process due to the inclination to honor the voices of all participants.</p> <p>Then, the chosen extracts will be revised and analyzed, making connections between analysis and research questions.</p>

APPENDIX E: National End-of-Life Doula Alliance Code of Ethics

(<http://www.nedalliance.org/code-of-ethics.html>)

Purpose

The National End-of-Life Doula Alliance (NEDA) supports end-of-life doulas (EOLD) by offering this Code of Ethics as a working guide to standards for appropriate behavior and practices in business and research. Our goal is to encourage EOLD practices that exhibit compassion, integrity, consistency, and competency across all platforms and approaches by providing clear ethical expectations of practicing EOLDS.

Definition

End-of-life doula—a trained individual who provides nonmedical, holistic support and comfort to the dying person and their family, which may include education and guidance as well as emotional, spiritual, or practical care.

Code of Ethics

NEDA as a membership organization, provides the highest ethical standards to guide our members' conduct. NEDA members agree to:

- Act honestly, truthfully and with integrity in all their transactions and dealings
- Avoid conflicts of interest
- Appropriately handle actual or apparent conflicts of interest in their relationships
- Treat every individual with dignity and respect
- Honor confidentiality
- Deal fairly and with total transparency with money matters
- Comply with both the spirit and the letter of the law
- Act responsibly toward the communities in which they work and for the benefit of the communities that they serve
- Be responsible, transparent, and accountable for all their actions

Conduct

- EOLDS maintain the highest standards of conduct in their service to others
- EOLDS do not engage in nor condone acts by others that may constitute sexual harassment

Confidentiality

- EOLDS protect information received in confidence from individuals, families, caregivers, and involved professionals.

- EOLDs share information only with written permission or when all efforts to obtain permission have been exhausted and only if the information may inform a situation that is life-threatening (as in the case of communicable disease).
- EOLDs take necessary precautions to safeguard electronic (including social media), written, and spoken communications with anyone involved, including extended family and professional colleagues.
- EOLDs continue to protect the privacy of individuals and involved parties after death occurs.
- EOLDs obtain written consent to disclose details of cases for the purpose of educating others and take care to disguise names and details.
- EOLDs are careful when sharing confidences with colleagues, respecting the privacy of all involved.

Conflict of Interest

- EOLDs do not accept gifts from suppliers, organizations, or businesses that in any way set up a reciprocal expectation.
- EOLDs do not show favor to clients for personal benefit.
- EOLDs are aware of conflicts that may arise between their role as consultant, the families they serve, and other professionals.
- EOLDs are free to consult with other professionals provided that the consultation does not place the consultant in a position of conflict of interest and providing that all concerns of privacy, informed consents, and confidentiality are met appropriately.
- EOLDs avoid conflicts of interest that interfere with discretion and impartial judgment. If a real or potential conflict of interest arises, they take reasonable steps to resolve the issue in a manner that reflects the best interests of the person(s) served.

Completion of Duties

- EOLDs have a duty to complete services as contracted according to the terms of agreement.
- EOLDs unable to conclude the contract will give ample advanced notice, help the family find a replacement, and refund any fees for services that were incomplete.
- EOLDs are strongly encouraged to provide contracts in the form of a detailed proposal, including aims, activities, costs, timescales, and deliverables.

Communication

- EOLDs accurately describe training, expertise, and credentials when representing themselves to the media or other outside entity.
- EOLDs always represent the end-of-life doula profession in a responsible ethical and professional manner.
- EOLDs maintain high standards of scholarship and objectivity when presenting information regarding end-of-life issues and practices.

Duty of Care

- EOLDs have a duty to care for others that first does no harm.
- EOLDs keep the highest standards of practice and conduct at the forefront of all service to others.
- EOLDs treat others with the same level of dignity and respect.
- EOLDs take great care in communicating when collaborating with other EOL professionals.

Education

- EOLDs provide accurate and timely information to the public, including individuals, families, communities, support networks, and other professionals as needed.
- EOLDs accurately represent their level of training and credentials and attempt to provide educational material that is unbiased and consistent with universal EOLD tenets.
- EOLDs make every effort to participate in continuing education to stay informed and active in the EOLD community.

Equality and Discrimination

- EOLDs exercise fair and objective judgment when providing quality services to all, regardless of age, color, race, gender, sexual orientation, lifestyle, religion, national origin, marital status, political belief, or mental or physical disability.

Legal Compliance

- EOLDs comply with the spirit and letter of the law.
- EOLDs know the legal ramifications and consequences of acting beyond the scope of practice as defined by NEDA and all local, state, and federal laws.
- EOLDs are responsible for knowing and abiding by the laws and regulations that directly and indirectly affect their services.
- EOLDs adhere to the highest standards when dealing with public officials and may not accept, offer, provide, or solicit any special treatment or favor from those in law enforcement, political, or other regulating or enforcement office.
- EOLDs are responsible for knowing what after-death services can and cannot be legally charged for and acting accordingly to protect the rights of families.

Fees for Services

- EOLDs may charge for pre-death services and bereavement services: any postdeath care of the deceased's body must be on a consultation basis only and must conform to FTC regulations regarding the practice of funeral directing.
- EOLDs provide complete detailed cost information in writing prior to beginning service.

- EOLDs do not solicit funds from clients separate from the contract for services; once the agreed-upon financial transaction is concluded, the client is under no further financial commitment, obligation, or responsibility to the EOLD.
- EOLDs neither offer, seek, nor accept payment of any kind for referral services.

Professionalism

- EOLDs treat colleagues with respect, integrity, sensitivity, and collegiality.
- EOLDs provide transparent, detailed information to clients in writing about the services they offer/will offer.
- EOLDs cooperate with other professional groups.
- EOLDs are aware of the limits of their competency limits and do not misrepresent themselves as having training, experience, or qualification beyond those they possess.
- EOLDs exhibit respect for colleagues and trainers of all affiliations and training programs.

Research

- EOLDs designing and conducting research comply with the Belmont Report's areas of research ethics, including respect for person, beneficence, and justice.
- EOLDs do not design or conduct research without appropriate training (see NEDA Research Best Practices).
- EOLDs do not participate in research that entails a real or perceived conflict of interest.
- EOLDs employ a recognized informed consent process in all research.
- EOLDs seek approval from an Institutional Review Board (IRB) or ethics committee before initiating research projects.

Volunteer Services

- EOLDs who volunteer services are held to the same standards as those who charge a fee for service.
- EOLDs volunteer their services when conducting after-death care.

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