

5-2017

What Can We Learn from Death and Dying? One Man's Experience

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Recommended Citation

Benson, Brooke K., "What Can We Learn from Death and Dying? One Man's Experience" (2017). *Master of Social Work Clinical Research Papers*. 704.

http://sophia.stkate.edu/msw_papers/704

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What Can We Learn from Death and Dying? One Man's Experience

by

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MSW Clinical Research Paper

Presented to the Faculty of the
School of Social Work

St. Catherine University and the University of St. Thomas
St. Paul, MN

In Partial fulfillment of the Requirements for the Degree of

Masters of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

The research explored a personal account of a man's experience of actively dying. From the findings, five major themes emerged describing the participant's experience of dying. The first theme, physical states, was sub-categorized by states of being, felt senses, and physical things. The second emerging theme, mental, was sub-categorized by emotions and cognitions. The third emerging theme, behaviors, was sub-categorized by actions and communications. The fourth emerging theme was spirituality and the fifth and final theme was time. The findings provide valuable insight into the process of death and dying, the emotions surrounding the process of dying and various aspects of living while dying (that is, how one person has described using his experience of dying to live more fully). By providing a rich, thick description of participant's experience, this research will aid helping professionals in the medical and social service field improve the quality of care for those facing the end-stages-of life, thus enhancing the patient's quality of life during those critical, final stages. Researching and understanding the process of death and dying can assist in reframing negative social constructs of death as a natural part of life. The findings also provide some lessons to live by.

Keywords: death and dying, subjective dying process, lessons from the dying, mortality, terminal illness, clients, social work, energy, present

Acknowledgments

I would like to acknowledge the following people for their support, encouragement, and guidance throughout this research study:

Dr. Michael Chovanec, MSW, Ph.D. LICSW, LMFT, thank you for your time and consideration throughout this process. Your expertise and experience was a great contribution to my efforts. It was a time-consuming project; thank you for sharing your time with me.

To my committee members Leigh Ostrander, M.A., L.P., SEP and Hilary Mueller, OTR/L, MSW, LGSW, you are two of the most capable, composed women I know and I feel privileged to have you on my committee. Your compassion and attention for others and the world around you, complimented and reinforced the authenticity of this research. Your time and consideration mean a great deal to me; thank you a thousand times.

To Derek, you were beside me throughout this project and absorbed emotions I could not hold at times; thank you for sustaining me when I needed you. This is a project you nor I will ever forget. Thank you for being a loving part of this.

And, to the participant, you have been a guiding light throughout our collaboration. I have so many words to say to you and yet, nothing to say at all because you know how I feel. My time with you is forever cherished, and you will remain with me in spirit, from now until the hereafter. I am not afraid because you are fearless and free.

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What Can We Learn from Death and Dying? One Man's Experience

Death is a part of life. Everyone, at some point, will face mortality; and in countless times throughout one's lifespan, many will bear witness to others facing death, the process of dying and issues of mortality. Examination of one's mortality can be overwhelming, especially for those who are facing death or those who are in the process of dying. Often, the end-stages-of life are beset with the fear of the unknown and the thought of impending death can be a source of overwhelming fear and anxiety for those facing it. The emotions surrounding death and dying constitutes the contemplation of it to be unappealing, overwhelming, and mostly avoidable. Zilberfein and Hurwitz (2003) define death anxiety as "our fear of death" further describing it as a "multifaceted concept that can include fears about the process of dying, death itself, and what happens afterward" (p. 300). Clarke, Korotchenko and Bundon (2012) assert that while there is a growing emphasis in gerontology and society alike on positive or successful aging, topics such as death and dying are frequently avoided or neglected in the research. There is nominal research regarding death and dying. It is an emanating topic not to be overlooked; moreover, it is a critical component of living.

Heightened awareness of death and dying can be associated with the increasing gerontological population. Youdin, Sussman, and Peak (2014) report that there will be more than 53 million people over the age of 65 and approximately 7 million over the age of 85 years of age by 2020. They further report "between 2008 and 2050, the American population over the age of 85 years is projected to more than triple from 5.4 million to 19 million" (Youdin, Sussman & Peak, 2014, p. 4). Furthermore, beginning in 2012, Youdin, Sussman and Peak (2014) cite an average of 10,000 older adults from the baby boom era began retiring each day.

The rising number of people who will be facing old age by 2030 makes it likely that supporting elderly persons with serious chronic illness will be a dominant challenge for health care in the next half-century (Lynn & Adamson, 2003). Owing to the considerable rise in the elderly population, social workers and helping professions alike, are called to meet the future medical and social needs of the elderly. Research regarding death and dying is relevant to the future circumstances facing the medical and social service fields.

Along with the rising gerontological population, so is the cost of healthcare for the elderly. Hosseini (2015) cites a 2009 CAE Health Report indicating that the projected healthcare costs are reported to reach 34% of the gross domestic product (GDP) by 2040 which equates to a third of the GDP, while in 1960, the total healthcare spending was 5% of the GDP. Today, healthcare spending is approximately 19% of the GDP. These statistics are directly connected to the rise in the elderly population with 80 years of age and older being the fastest growing age group in the United States (Hosseini, 2015); the very age group which will necessitate more intensive and expensive medical care.

Kelly & Meier (2015) report the United States spent \$2.9 trillion on healthcare in 2013, and projections suggest that by 2040, one out of every three dollars spent in the United States will be spent on healthcare (Centers for Medicare & Medicaid Services, 2014). Furthermore, healthcare spending is highly concentrated among a small, seriously ill population approximating 5% of patients accounting for 50% of total healthcare costs (Kelly & Meier, 2015; The Lewin Group, 2010).

To more adequately frame the state of healthcare costs, Hosseini (2015) reports people aged 65 and older will consume four times more health services than their younger cohorts. Add 25 more years of age, which represents the fastest growing age group (80-year-olds and above)

and the number for healthcare services are overwhelming, with costs swelling beyond a sustainable rate (Black & Csikai, 2015).

It is valuable and worthwhile to research and explore death and the process of dying. Hosseini (2015) refers to a recognized ethicist, Daniel Callahan, who asserts that the future goal of medical science should be to focus and improve the quality of people's lives, not necessarily to lengthen lives. Research regarding death and dying explores the possible benefits of Callahan's assertions and beliefs that the primary goal of medical science should focus on the quality of the end-of-life rather than the length of life.

Hospice and palliative care are models of care primarily designed to focus on end-of-life quality. As a philosophy, hospice aims to focus on the quality of end-of-life care in the dying process by affirming life, not death, and by making the most of present quality of living; the purpose is to provide comfort, not curative care (Corr, 2016; White & Gilstrap, 2015). Social workers have been a vital part of the hospice movement since the first American hospice opened in 1974 (Nakashima, 2003).

Black and Csikai (2015) define the tenets of palliative care to view death as a natural part of living and affirming life by providing "the best chance to maintain the highest quality of life during an end-of-life course," and research has revealed palliative care has been associated to "enhanced patient satisfaction and reduction in health care costs" (p. 34). Although both hospice care and palliative care are associated with a better quality of dying, both continue to be an under-utilized benefit (Black & Csikai, 2015). They further report in 2012, 12% of hospice users were enrolled for the duration of the initial benefit period of 6 months, and more than one-third (36%) were enrolled less than 1 week and approximately two-thirds (63%) were enrolled less than one month (Black & Csikai, 2015, p. 35). White and Gilstrap (2015) contend that with the

continuing rise in life expectancy and the declining health status of the elderly, the health-care industry will be impacted, and hospice and palliative care will continue to meet the needs of the dying. Social workers, therefore, continue to play a vital role in education and care options for end-of-life decisions facing the elderly, dying patients and their families.

Research and education exploring the death and dying process will better prepare social workers and medical professionals to meet the needs of the elderly and dying. Fox (1981) contends that some of the core ethical principles in the field of social work, such as the right to self-determination, are in jeopardy owing to emerging death and dying moral and ethical issues. Social workers are advocates for their clients' interests, welfare and overall well-being. Fox (1981) speaks to the state of the social work field and to the training of social workers pertaining to death and dying, claiming that social workers are inadequately equipped "to think clearly or act effectively on behalf of the persons and the principles they represent" (Fox, 1979, p. 49).

It is critical, as social workers and helping professionals, to provide a holistic, integrative, quality of care for the elderly. Youdin, Sussman & Peak, 2014 (2014) refer to a process called gerodynamics. This is a psychosocial process that describes the experience of an older adult who confronts, concurrently, the conflicts and problems unique to the final stages of development in life while also facing problems of anticipated death and the final transition of life. From a systems perspective, the elderly population are experiencing changes involving a vast array of systems of biology, individual functioning, interpersonal functioning, social policies, cultural influences, and historical influences (Youdin, Sussman & Peak, 2014).

Nakashima (2003) suggests that while the central concern of social work writings, pertaining to terminal care in social work, continues to focus on coping and adaptation:

there are a growing number of scholars and clinicians in palliative care who support a new vision of death and dying from a boldly different perspective: death as a passage in life with an inherent potential for emotional healing and spiritual growth (p.367).

As the elderly population continues to increase, research gathered exploring and examining the final stages of life will be a critical factor in developing and advancing the quality of care provided by helping professionals, across disciplines, who work with the elderly and terminal patients. Progressive health care practices will, ultimately, enhance the end-of-life quality for patients, and families alike. The data gathered can also provide valuable insight for professionals when considering the best course of treatment for their patients, in addition to potentially informing patients and their preferred health care practices and directives at the end of life.

Hobart (2002) explores the expanding role of social work as it relates to death and dying, asserting that social workers, predominantly gerontological social workers, need to be “well versed” on issues related to death and dying due to the dramatic changes in the last century regarding how people die. Social workers play an integral role in nursing homes, hospitals, hospices, home health care and residential facilities; all environments where many clients are facing death and dying. Hobart (2002) cites that 75% of all people spend their last days in a hospital or medical center, (NCHS, 1991) and further asserts “advances in medical technology now challenge us as a nation to define quality end-of-life care and the right to deny heroic life-prolonging interventions” (p.182). Social workers need to possess knowledge about the psychosocial aspect of death and dying and require “familiarity with death and dying policy including state and federal laws, as well as service delivery and overall best practice standards” (Hobart, 2002, p. 182). In the ever-changing climate of medical technology and the ways and environments in which we die, it is essential for social workers to meet the varying needs of the dying, and those facing mortality.

There is also need for research exploring “fearful” or “negative” Western constructs of death and dying. Pollak (1980) suggests “old people in the United States live in a society which puts a premium on being young” further stating that the ideal self-image of an American is that of a young person with *youthfulness* being the embodiment of the American culture (p. 75). Pollak (1980) asserts that to be old in a society that idealizes youth essentially deems the elderly individual “a member of an undesirable, and undesired population” (p. 75). This research can provide insight into the process of death and dying, allaying fear and anxieties that accompany this process and potentially alter existing, negative Western social constructs of death and dying. Transforming these existing constructs can invariably improve the quality of life for people facing death and dying and contribute to a holistic quality of care provided by professionals working in the medical and social service fields.

The insight gained from this research will also contribute to a growing body of literature exploring death and dying: thanatology. Thanatology emerged as a science in the 1950's and is the study of death which employs an interdisciplinary approach to practice aiming to construct a scientific comprehension of death, its rites and its meanings (Fonseca & Testoni, 2012). Fonseca & Testoni (2012) refer to Kastenbaum's (1993) proposed alternate definition of thanatology as “the study of life with death left in” (p. 76). Implications of this research have the potential power to positively influence the way in which we choose to live, enriching the quality of life for the living. Kellehear (2014) reminds us “dying is not to be conflated with death in one important and crucial way—dying is living. The dying are not the dead” (p.53). Fonseca & Testoni (2012) further assert that death studies and the reflections of death must integrate the concepts of life and death in efforts to redefine death and its symbolic significance in Western societies.

Through exploration and examination, the fear and anxiety surrounding societal and cultural perspectives of death and dying can be diminished, and a new, advanced understanding (and ultimate acceptance) of death as a natural occurrence can emerge. Nakashima (2003) asserts “even the prospect of dying, which is one of the unquestioned causes of human misery and suffering, can be reframed and approached in a way that is affirming, empowering, and liberating (p. 375). Zilberfein & Hurwitz (2003) declare “to understand dying is, after all, to understand how best to live” (p. 300). Qualitative research examining the accounts and experiences of people facing the end-stages-of life support this research agenda. Best-selling books such as "Tuesdays with Morrie" offer precedent for interviewing people about their experience of dying and for publishing such conversations. Nakashima (2003) asserts “Accounts of the generative process of dying have always existed but were private, barely noticed, and largely inconceivable to the general public,” further asserting that healing and transformative accounts of dying, like *Tuesdays with Morrie*, are becoming more evident indicating that there is some evidence in American culture for the social reconstruction of death and dying into a “more fulfilling and meaningful paradigm” (p. 374).

The purpose of this research is to explore a personal account of a man's experience of actively dying. Through the examination of his experience, valuable insight will be gained into the process of death and dying, the emotions surrounding the process of dying and various aspects of living while dying (that is, how one person has described using his experience of dying to live more fully). This research will aid helping professionals in the medical and social service fields improve the quality of care for those facing the end-stages-of life, thus enhancing the patient's quality of life during those critical, final stages. Researching and understanding the

process of death and dying can also positively inform the ways in which we live our lives and assist in reframing negative social constructs of death as a natural and meaningful part of life.

This study is designed to investigate how exploring and understanding death and the process of dying can inform and influence the practices and quality of care provided by professionals working with those facing death and positively impact the ways in which we live. The research question “what is the personal experience of dying and what can it teach us as professionals and as humans?” will be explored. I propose to explore these question through a qualitative, exploratory case study of a man and his experience of actively dying from stage IV lung cancer. Questions will be asked in a series of three unstructured interviews.

Much is to be learned from death and the process of dying. In Thorson's (1996) article *Qualitative Thanatology*, he asserts that not everything can be quantified which is specifically applicable to research in the social sciences. Furthermore, he believes it would prove useful to examine various qualitative research efforts including case studies and historical approaches “to broaden our perspectives and understandings of the elements of care for dying persons” (p.179). The purpose of this research is to contribute a case study to the literature of death and dying by exploring the experience of a man actively dying and discovering how that experience can positively inform future care for the elderly and dying, help to reconstruct negative social constructs of death and dying, as well teach us lessons as to the ways in which we live our lives.

A context will be formed through an examination of existing literature. To provide a frame of reference, the work of anthropologist Ernest Becker is applied; specifically, his theory of generative death anxiety. Existing literature regarding thanatology, social constructs of death and dying, specifically hoaning in on Western/American attitudes towards death and dying, subjective experiences of dying and experts in the field of death and dying will also be reviewed.

Literature Review

Death is a part of life. Everyone, at some point, will face mortality; and in countless times throughout one's lifespan, many will bear witness to others facing death, the process of dying and issues of mortality. Lewis (2014) asserts that people are frequently inundated with literal and symbolic reminders of their mortality whether hearing about the death of someone close, or receiving the diagnosis of a chronic illness. Examination of one's mortality can be overwhelming, especially for those who are facing death or those who are in the process of dying. Often, the end-stages-of life are beset with the fear of the unknown and the thought of impending death can be a source of overwhelming fear and anxiety for those facing it. The emotions surrounding death and dying constitutes the contemplation of it to be unappealing, overwhelming, and mostly avoidable. Zilberfein, & Hurwitz (2003) define death anxiety as "our fear of death" further describing it as a "multifaceted concept that can include fears about the process of dying, death itself, and what happens afterward" (p. 300).

The Root of Death Anxiety

Using an anthropological approach, and employing anthropologist Ernest Becker's theory of generative death anxiety, Liechty (2013) purports that human motivation, as a species, is a survival mechanism; and that very survival mechanism is in direct conflict with the prospect of dying. Thus, the result of death anxiety in humans. Fear of death and our unwavering awareness of mortality is embedded in us as humans. Feifel (1990) writes "To die is the human condition, and reflection concerning death exists practically among all peoples...realization of finitude has been a powerful concern and shaping force" (p. 537). Ernest Beker's concept of unconscious death anxiety and how it influences human attitudes and behaviors laid the foundation of what was later termed by social psychologists as "mortality salience hypothesis" (Liechty, 2012).

Becker's hypothesis contributed to the development of the terror management theory (TMT). TMT "posits that anxiety and fear are associated with mortality salience (MS) or the state of awareness of one's eventual death" (Lewis, 2014, p. 413). Orit & Adi (2010) assert that this very knowledge of one's finitude and potential vulnerability is a fundamental source of anxiety and a powerful motivator that determines much of human behavior.

Liechty (2000) points out that Becker made two important observations: human beings, alike with all living things, have a basic drive to continue existing; and humans, unlike other living beings, have a brain with a developed cerebral cortex. This intellectual capacity involves the development of self-consciousness which affords humans the ability to "think of ourselves as objects projected into the past, present and future environments" (Liechty, 2000, p. 126).

Herman Feifel's work is often observed as "marking the beginning of the modern study of death, varying referred to as death studies or thanatology" (Doka, Heflin-Wells, Martin, Redmond & Schachter, 2011, p114). Feifel suggests "humanity's most distinguishing characteristics, in contrast to other species, is its capacity to grasp the concept of a future and inevitable-death" (Feifel, 1990, p. 537). This cognitive capacity also developed an awareness of the human condition: one's own mortality. Human's cognitive capacity exceeds the passive adaptation to the environment; they possessed the ability to adapt to the environment befitting their own survival needs. Human's cognitive capacity allowed them to establish communities with social beliefs, values, rituals and traditions. This capacity is what Becker referred to as the 'capacity for culture' (Liechty, 2013).

The basic human drive for survival and the intellectual capacity of humans counteract one another. Liechty (2000) writes that Becker suggested that this basic contradiction in our

nature is the root of human anxiety; further writing that Becker believed to have 'normal mental health.'

Humans must spend an enormous amount of their psychological and emotional energy in the creation and maintenance of a basic lie about their mortal condition; they must strive to keep from immediate awareness this potentially immobilizing recognition that death is coming... (p. 126).

Liechty (2000) further writes that "this mortality anxiety and the concurrent desire for immortality...is the very energy cooking in the unconscious" (p. 249).

The Role of Culture

Becker's theory of generative death anxiety theorized that culture was another factor in denying mortality. The human species became a 'culture-creating species' because, as Liechty (2013) writes that culture, in its basic purpose, "essentially works to assure them [humans] in narrative and symbolic form that they are *more-than-mere-mortals/animals*" (p. 126).

Becker introduced the concept of 'immortality striving' describing it as a way in which humans disquiet their own death awareness by "immersing oneself imaginatively in images of strength, power, and more life" (Liechty, 2013, p.126). This concept can be considered today, in the context of our present culture, whereas the characteristics of strength and power are romanticized and idealized through various mediums of popular media.

Thanatology

Fonseca and Testoni (2012) note the word thanatology is of Greek origin, outlining that "in mythology, *Thanatos* (death) was the son of *Nyx* (night) and *Chronos* (time) and the twin brother of *Hypnos* (sleep)" (p. 158). In the early 1900's two emerging areas of investigation, both words of Greek origin were proposed: *gerontos* and *thanatos* to represent gerontology and thanatology, respectively (Fonseca & Testoni, 2012).

Thanatology (known as the study of death) is an interdisciplinary approach that encompasses various areas of study with the aim being “to construct a scientific comprehension of death, its rites, and its meanings” (Fonseca & Testoni, 2012, p. 157). Thanatology emerged as an accepted discipline of science in the 1950's and thanatology, or the study of death, had developed into a legitimate academic area of study for purposes of research, teaching, and writing, and as a clinical specialty (Doka, Heflin-Wells, Martin, Redmond & Schachter, 2011).

Increased Interest and the Emerging Study of Death

Doka, et al (2011) identified four factors underwriting an increased interest and awareness of death-related subjects including: *changing demographic conditions, historical aspects, sociological and social psychological components and cultural considerations*. They contend that with the increase of the gerontologic population in the developed world, there has been a concurrent increase in the field of aging with expanding examination and study of dying, death, and bereavement. “Life was not only extended-death was as well” (Doka, et al., 2011, p. 120). They further purport:

The prolongation of dying has created new strains for medical staff, new ethical issues, and new forms of care, which have all served to increase both public awareness and interest in the discussion and organization of dying, death, and bereavement (p. 121)

Doka, et al (2011) refer to Lifton and Olson's (1974) assertion that the 20th century was defined by the introduction of the nuclear bomb. The nuclear anxiety compounded with various other forces created a heightened awareness of the fragility of life. “Faced with the possibility of the nuclear death of civilization, new diseases, environmental holocaust, or random terrorism, death has emerged as a critical social concern” (Doka et al., 2011, p. 121).

The sociological and psychological consideration contributing to the increased awareness of death was reinforced by social movements like The Death Awareness Movement and trends of

the 1960's. During this time, society began to "assert the rights and dignity of the dying" (Doka et al., 2011) including the belief that death is a natural process and the dying should be acknowledged and accepted with openness (p. 121). Life-prolonging technologies were criticized and considered degrading. It was also a time where cultural beliefs accentuated personal autonomy with the popular demand of the legalization of physician-assisted suicide. This trend is gaining traction with today's culture, resonating and embracing "the rights of autonomous individuals to control their own destinies" (p. 121).

Doka, et al (2011) outline the final factor contributing to the study of death and death awareness: culture. The authors suggest that religious and secular beliefs, that once owed to the significance and understanding of death, no longer filled that role in society. "In a society that is materialistic, death was avoided or denied" (Doka, et al., 2011, p. 121).

Similarly, in an article written by Fonseca & Testoni (2012), authors point out that various shifts in cultural standards have contributed to the heightened awareness of death and dying. The authors assert that in recent decades, there has been a considerable increase in life-expectancy because of progressive technology; a shift in scientific impulses to explain and measure phenomena replacing what once was satisfied by secular or religious beliefs, and a preoccupation with physical perfection. Life was not only extended, but death was as well (Doka, et al, 2011). These cultural shifts contributed to an impaired ability to cope with death and served to need to postpone death with the thought that "people want to live longer but want to remain youthful" (p. 158). The authors assert "Death began to be considered a failure, and the weakening of the body, a natural consequence of aging, has been interpreted as imperfection" (Fonseca & Testoni, 2012, p. 158).

Contemporary Culture of Death Denial

In the article, *Emergence of Thanatology in Death Education*, Fonseca & Testoni (2012) explore the evolution of human-kind's relationship to death and the resulting shift of attitudes toward death; the authors reflect upon Aries' take on the evolution of Western attitudes towards death. In his book, *Western Attitudes towards Death: From the Middle Ages to the Present*, (1974) Aries contends that attitudes regarding death have substantially transformed (from the Middle Ages to present) including customs and rituals that once supported a healthy knowledge and familiarity of death. Death has gradually morphed into a concept that is avoided, denied and considered fearful.

Fonseca & Testoni (2012) offer an example of a considerable paradigm shift in the event of death, writing "In earlier times...death was an event that occurred at home, shared by the family and the community" (p. 159). The authors assert that by sharing the dying experience with family, the dying were comforted and the experience of dying was not lonely. Currently, the event of dying generally takes place in a facility or hospital and no longer in homes, with family and friends surrounding the loved one. The article identified religion as a substantial factor in shaping the way humans have approached and coped with death referring to Darwin's work in the 19th century. The cultural acceptance of Darwin's biological approach to evolution proved a significant shift from that of a largely accepted theological perspective of evolution (Fonseca & Testoni, 2012).

"In the contemporary age, all religions are suffering, because scientific and technological advances have demonstrated that the world can be explained without reference to a god or gods... ("God is dead" Nietzsche, 1896)" (Fonseca & Testoni, 2012, p. 160). The authors suggest that near the end of the 19th century, death was being displaced from homes to hospitals. Hospitals which traditionally functioned as places of health and healing began to assume another

role of receiving the dying. No longer were the care for the dying and the rites and rituals of death familial in nature; they were dispensed and carried out by professionals in institutions (Fonseca & Testoni, 2012). Moreover, the authors suggest another chief transformation of death ceremonies supporting the separation of death from society was the placement of commentaries on the outside or outskirts of town from interurban areas; the former explicated by matters of public health (Fonseca & Testoni, 2012). The authors cite Kovacs (2003) assertion:

Advances in science, technology, and medicine have extended life spans by many years, not only postponing the event of death but also allowing individuals to ignore the very idea of it. (p. 160)

Goer (1995) writes that by the middle of the 20th century, death and its concept, was being overlooked with the threat of disappearing from culture altogether. The use of science supported this reality as “science began to be employed as a weapon in the battle of death” (Fonseca & Testoni, 2012, p. 160). Cultural views shifted and notions of health and death were dichotomous in nature.

While the 20th century's perspective of death and dying works to deny, avoid and separate from it, existing research regarding individuals facing death reveal that acknowledgment and dialogue surrounding death and dying is preferred. Clarke, Korotchenko, & Bundon (2012) note research confirms that individuals facing mortality who express a desire to dialogue about death or explore end-of-life plans are “often silenced and dismissed as being overly morbid” (p. 1400). They further point out numerous research studies reveal that those facing death and dying approach their final transition with a positive disposition and are open to conversations addressing aspects of death and dying.

Research further suggests that confronting death, rather than fearing it or denying it, results in greater well-being and a healthier sense of the self (Cozzolino, Blackie & Meyers,

2014). Findings in a study conducted by Cozzolino, Blackie & Meyers (2014) reveal that reduced levels of death avoidance and death fear predict a stronger, healthier sense of self. This data further contributes to the body of literature addressing the potential psychological growth and enhanced meaning of life that individuals, and ultimately societies can discover as a result of confronting death rather than avoiding or denying it.

Social Constructs of Death

Many of the assumptions and conceptual formulations humans view about death and dying are socially and culturally constructed (Berger & Luckman, 1996; Nakashima, 2003).

Nakashima (2003) suggests the following:

Our collective construction of death and dying continues to convince both the general public and social workers that dying from terminal illnesses involves only intolerable suffering, and it can be, at best, only a struggle that is coped with masterfully (p. 367).

In his article, *Beyond Coping and Adaptation: Promoting a Holistic Perspective on Dying*, Nakashima (2003) encourages the transformation and new vision of death, promoting a holistic perspective on death and dying; a perspective that is ever-evolving and rises to meet the needs of patients in an advanced and complex, technologically centered health care system. The author examines how deconstructing discourse in the realm of terminal social work will only work to bolster this progressive, holistic vision of death and dying. He urges social workers to discover areas and examples that highlight various magnitudes and accounts of living while dying. In efforts to adjust our social construct of dying, he suggests “stories that present ‘unique outcomes’ that do not conform to the expectations proposed by the dominant knowledge on death and dying...” are “exceptional ways of perceiving the time of dying” (p. 372).

Villar & Serrat (2017) examine the framework of narrative care in relation to the evolving culture of long-term care for aging adults asserting the narrative framework also works

to support an evolving, progressive cultural perception of dying. Within the social sciences, the authors contend there has been a surge in interest in the narrative approach. The foundation to this approach is that humans need to make sense of ourselves and the world around us and this is achieved “through constructing, telling and sharing stories that provide continuity, coherence, and purpose to personal experience” (Villar & Serrat, 2017, p. 44).

In another study, Nakashima and Canda (2005) interviewed 16 terminally ill older adults and their findings suggest that the participants used life narrative to construct meaning and resiliency in the face of mortality. Awareness of narrative has impacted our current understanding of the experience of aging and the end-stages-of life in that narrative care offers the opportunity for the aged and dying to maintain and support their identity further encouraging the ability to discover or continue to formulate meaning in life (Villar & Serrat, 2017).

American Cultural Attitude Toward Death and Dying

For many Americans, death remains an uncomfortable matter for both contemplation and conversation, and the topic of such, is taboo and distasteful. (Hobart, 2002). Fox (1981) explores the American attitudes towards death in her article *The Sting of Death in American Society*. She writes “Americans are so extraordinarily frightened of death, it is a ‘taboo topic’...and ‘denial’ is the predominant cultural mechanism they use to deal with it” (Fox, 1981, p. 43). Corr (2015) suggests that as far back as the 1960s, Americans were told death was a taboo topic in society, “a subject that was somehow not acceptable for scholarly research, education or public discussion” (p. 16). He further calls attention to Dumont and Foss’s (1972) description of how American society denies death:

American society and its culture seem quite congenial to an attitude of death denial fostered by the nuclear age, the characteristic faith in science and technology, the relinquishing of the care for the dead and dying by the family and demographic features of American death... (Corr, 2015, p. 47).

Fox (1981) identifies two major developments in the twentieth-century American society: the advances in medical science and technology and the increasing elderly population. She examines the shifting views of medical professionals (physicians, nurses, and social workers) who find themselves dealing with death “more firsthand than anyone else in our society” writing that these professionals are communicating more openly about ethical issues and moral dilemmas. Fox (1981) further points out factors to consider in the evolution of death and dying in America include quality of life dilemmas, autonomy issues, and acute conflicts with institutionalized values of the medical care system and professionals.

Conversely, existing literature suggests America is not a death-denying society. Corr (2015;2014;) writes “it is preposterous to assert that America is a death-denying society when there are so many activities and components within society that are in whole or in part related to death” (p.23). Corr (2015;2014;) writes the definition of Robert Kastembaum's (2012) death system in America as “the interpersonal, sociophysical, and symbolic network through which an individual's relationship to mortality is mediated by society (p. 18). Robert Kastembaum's death system offers a framework outlining functions of the death system and elements and components within the American society. Corr (2015;2014) and colleagues (2012) suggest that while many aspects of the American culture appear to remove death from mainstream life, it is incorrect to label America as a society that wholly denies death. Conversely, Dumont and Foss (1972) submit that America's culture and the individuals within both accept and deny death, concurrently.

Subjective Experience of Dying

The concept of a 'good' death is evident, particularly, within hospice literature; however, definitions of a 'good' death vary across disciplines. The Institute of Medicine (1997) define a good death as one that is "free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patient's families' wishes; and reasonably consistent with clinical, cultural and ethical standards" (p. 23). Leading Thanatologist, Robert Kastenbaum, identified *preparing for death with clear decision-making and affirmations of the whole person prior to dying* is a critical component of a good death (Black & Csikai ,2015). Clarke, Korotchenko, & Bundon (2012) assert that literature suggests many individuals define a good death as one that is "free of prolonged suffering, pain and/or breathlessness" (p.1401). Research indicates that North Americans tend to appeal to the preparation for death and retaining a sense of control (Clarke, Korotchenko, & Bundon, 2012). Pihlström (2015) asserts that individual self-control is a "widely-shared and a powerful cultural value" (namely in Western societies) and believes that the dying "should have the opportunity to continue self-controlling as long as they feel they are capable of doing it...and the opportunity to give up that control in a way that still preserves their human dignity" (p.63). Black and Csikai (2015) list four themes outlining some challenges the dying face affecting end-of-life quality including *physical* (pain, impaired bodily function); *psychological* (depression, loss of dignity, anxiety); *spiritual* (meaningless/hopelessness of life); and *psychosocial concerns* (burden to others, loss of social role) (p.31).

Euthanasia (a word deriving from the Greek meaning "good death") is gaining more traction in the United States, recently. Black and Csikai (2015) note various stories of hastened deaths have gained the attention of mainstream media, citing three separate cases of individuals

suffering from chronic or terminal illnesses. While circumstances were different, the desire for death because of their physical circumstances was the same. "Death is, above all, an individual experience" (Corr, 2015, p.17). While there are many ideas of a 'good' death, Shneidman (2007) contends "a good death is one that is appropriate for that person" (p. 245).

Experts in the Field of Death and Dying

Herman Feifel and Elisabeth Kubler-Ross are widely recognized as pioneers in the field of death education and the death awareness movement. *The Meaning of Death* published in 1959 (edited by Feifel) was what many authors consider the work of the death awareness movement, which at that time, was synonymous with death education (Fonseca & Testoni, 2012). In 1969, psychiatrist Elizabeth Kubler-Ross offered an intimate glimpse into the world of dying patients with the publication of her book *On Death and Dying* by focusing society's attention to the terminally ill patient (Wright, 2003). Kubler-Ross interviewed 200 dying patients about their experience of near death and what she concluded is that the fear of death in humans is universal and our need to deny and distance ourselves from death has conversely, caused more emotional damage and morphed into a topic that is suppressed in our society (Doka, et al, 2003). Fox (1981) asserts that Kubler-Ross's work illuminated the contemplation of death and the acceptance of mortality are life-enhancing and the dying can be our "teachers" further declaring Kubler-Ross as a "pioneering catalyst, increasing public awareness of death, mortality, and the needs and experiences of the dying and their caretakers..." (p.51).

Contemporary author Atul Gawande calls for a change in the philosophy of health care in his book *Being Mortal* (2014). Writing from the perspective of a surgeon, he asserts that medical professionals have been trained to ensure health and survival all the while overlooking a paramount issue which is *enabling the well-being* of patients by focusing on the *quality and*

purpose of their lives (Gawande, 2014). In a corresponding PBS Frontline News Investigation of *Being Mortal* (2015) Atul Gawande interviews several dying patients and their loved ones and explores how medical professionals are often ill-suited and uncomfortable talking to patients and families about death and dying.

Atul had a discussion with his former patient's husband as his patient died from stage four lung cancer at age 34 in her ninth month of pregnancy. During the interview, the husband lamented about the cost of constantly pursuing life-extending treatment after treatment which made his wife sicker and sicker asking "what did we miss out on?" He later stated "we should have started earlier with the effort to have quality time together. The chemo had made her so weak that she couldn't hold Vivian [baby]. It was exhausting. And, that was not...that was not a good outcome for...for the final months. It's not where we wanted to be."

In his book, Gawande (2014) refers to "medicalized" deaths because of advances in medicine and technology in the past decade. "Compared to natural deaths, people dying often experience multiple medical treatments that can prolong the dying process and render them incapacitated to participate in their own decision-making" (Black & Csikai, 2015, p. 33). Similarly, neurologist and author Paul Kalanithi explores, in his memoir *When Breath Becomes Air* (2016) what it is to face mortality, the challenges one experiences and questions that face the dying: "What makes human life meaningful?"; and "What makes life meaningful enough to go on living?"

Evolving contemporary views regarding death, dying and the patient's purpose and quality of-end-of life intersect the medical professional's ethical responsibilities. The ever-changing climate of death, dying, and living calls for the re-examination of the Western medical model of care. In addition, the evolving nature of death and dying calls for professionals

working with the chronically ill and dying to start asking these arduous questions to begin to harvest progressive results for the chronically ill and terminal patient.

Summary

The literature review examines death anxiety in humans and how humans use the role of culture to masquerade mortality and mortality awareness. The literature review listed four factors contributing to an increased awareness and interest in death and dying including changing demographic conditions, historical aspects, sociological and social psychological components and cultural considerations. The literature review continues to explore development of the contemporary culture, using the term death denial to classify the attitude and tendency to avoid, deny and perceive death as fearful. It then shifts focus to examine how advances in science and technology have served as vehicles to further distance and silence death and dying in Western society, specifically focusing on the American cultural attitude toward death and dying. It further investigates the subjective experience of death including ideals of 'a good death.' The final focus of the review of literature highlights experts in the field of death and dying and their respective outlooks.

Conceptual Framework

Self-determination theory (SDT) is a macro-theory of human motivation and well-being with the focus being on volitional or self-determined behavior and the conditions that promote it, and a set of basic and universal psychological needs, namely those for *autonomy*, *competence*, and *relatedness*. The fulfillment of the psychological needs is considered essential to vital, healthy human functioning (Self-Determination Theory, 2008).

The three basic psychological needs fundamental to SDT include *autonomy*, *relatedness* and *competence*. Self-determination theory operates on the notion that when these three basic psychological needs are met and supported within a social context, individuals thrive and experience more vitality and self-motivation which can work to underwrite an enhanced state of health and well-being (Self-Determination Theory, 2008). Forms of maladaptive behaviors and psychopathology are congruent with the neglect of the basic psychological needs. (Ryan, Deci, Grolnick, and LaGuardia 2006).

The application of the self-determination theory was advantageous in helping to frame and develop the interview questions. With this theory in mind, I wanted to gain a comprehensive understanding of the participant's basic psychological needs, how they were being met and challenged, and his personal development throughout his final stages of life. The design and development of the interview questions were critical in supporting a thorough, multi-dimensional examination of the participant's experience of actively dying.

With the self-determination approach in mind, and drawing from social work practices with terminally ill patients, interview questions were developed using five conceptual categories. The categories include: planning for living during the terminal process, exploration

of feelings about impending death, living with the prospect of death, planning for death and planning for the family after death (Pilsecker, 1975).

The first set of interview questions pertain to his experience of his illness. Questions in the second interview primarily focus on his positive use of awareness of mortality. The third, and last set of interview questions focus on spirituality as a resource, his vision of a "good death" and advice for those living.

The three basic psychological needs in the self-determination theory, *autonomy*, *relatedness* and *competence*, are three important needs to highlight when exploring the participant's life with a terminal illness. These factors directly impact the quality of life and more importantly, the vitality of his life.

Vitality, as defined by Oxford Living Dictionaries (2016) is "the state of being strong and active; energy" and "the power giving continuance of life, present in all living things." This word is paradoxical when considering it in the context of death and the process of dying. However, the self-determination theory suggests that this approach works to strengthen and reinforce the quality of being and the enhancement of life, ultimately channeling vitality. This framework is relevant and appropriate to apply while conducting research regarding death and dying being that it promotes life and the quality of, even when facing the end-stages-of life.

It was important to the researcher to consider and explore the ways in which the participant experienced limitations and potential restrictions due to his illness and how he faced the challenge to adapt to life with a terminal diagnosis. It was also critical to examine the nature of motivations and internal resources that he drew from to inform his experience of the final transition.

He is an active individual and has been so his entire life. He has remained single, relying solely on his autonomy and independence. This is an important factor in considering two basic psychological needs: *autonomy* and *competence*. The aforementioned psychological needs drastically, and abruptly, digressed as a result of his terminal illness. The participant stopped driving which considerably impacted his ability to be autonomous. This conceptual framework provides a lens and clarification for how the experience of death and dying can potentially derive and illuminate the vitality of life.

Methodology

This is a qualitative, exploratory case study using a case study method, interviewing one person about his personal experience as the “case” in a series of three interviews. Monette, Sullivan, Dejong & Hilton (2014) assert “qualitative and contextual approaches offer access to a valuable type of data-namely, a deeper and richer understanding of people’s lives and behavior, including some knowledge of their subjective experiences” (p. 220). The goal of qualitative research is to “gain understanding through depth and richness of detail” (Monette, et al., 2014, p. 241). Monette, et al (2014) further assert “descriptions in case studies and life histories is detailed and sometimes is called a ‘thick’ description-that is a complete and literal accounting of the person and setting under study” (Monette, et al., 2014, p. 241). The case study was formed with three interviews taking place at the participant’s home. The participant’s words will be indicated using italics.

Sample and Recruitment

This research used a purposive or judgmental sampling. One 74-year-old male was selected for this case study because of his experience of actively dying of stage four lung cancer. The researcher and the participant were acquaintances prior to the research study. The researcher approached the prospective participant and explained the purpose of the research was to explore his personal experience of dying. Once consent was received, a meeting was set up with the participant where the consent form was presented and explicated. A consent form was also submitted and signed by the participant’s brother who currently serves as power of attorney for the participant. The criteria for the sample were one adult with stage four lung cancer, living

out the end-stages-of his life and who possessed the fortitude to complete a study of such delicate nature.

Measures to Assure Confidentiality

The participant was informed that the interviews would be recorded on a locked portable recording device owned solely by the researcher. The data from the interviews were transcribed by the researcher and deleted from the recording device upon transcription completion.

Transcribed documents were stored in a locked file cabinet owned by the researcher.

Transcribed information will be destroyed by no later than May 15, 2017. Consent forms will be retained for three years as required by federal law, but not later than May 15, 2020.

Protocol for Ensuring Informed Consent

Prior to each of the three interviews, the participant was asked to read the consent forms outlining the purpose of the study, why the participant was selected, how his response will be kept anonymous and confidential, and what resources to utilize should psychological issues arise.

The researcher asked the participant if there were questions for the researcher regarding the consent form. As a precaution of the participant's privacy, the researcher provided alternate locations for the interviews to be held. The researcher explored with the participant what it would look like to hold the interviews in the participant's home. As a safeguard for the participant's emotional well-being, mental fatigue or embarrassment, and to safeguard potential coercion the participant may feel, the participant had the right to stop participation in the research study at any point without disclosing a reason, the right to waive interviews as the participant saw fit and the option to decline answering any question in the interview. The researcher also checked in with the participant throughout the interviews to evaluate his mental, emotional and physical comfort and well-being. The researcher indicated to the participant that

protection of the participant's physical, emotional and mental well-being was top priority and if the researcher and participant found the interviews to be too rigorous, the interviews would conclude immediately. The researcher consistently checked in with the participant's brother, who acts as his brother's power of attorney, as an additional precaution to gauge the participant's physical, emotional and mental well-being.

Data Collection

Three semistandardized interviews were used as the primary tool for data collection for this qualitative research study (Bergh, 2009). The interviews were conducted at the participant's home. Each interview was completed in approximately one hour with the length of each interview, contingent upon the participant's energy and well-being during each interview. The interview questions consisted of thirty-two primary, open-ended questions. The questions were categorized into three domains exploring the participant's *experience of the terminal process*, *living with an awareness of death*, and *spirituality as a resource/advice for living* (See Appendix A for a complete list of the interview questions).

Data Analysis Plan

“Qualitative researchers stress the importance of context and of viewing and analyzing data with an appreciation for the complete context in which the data were produced” (Monette, et al., 2014, p. 436). Moreover, case study designs are considered contextualizing strategies in qualitative research. Monette, et al., (2014) assert “data analysis in case studies focuses on description and narrative rather than on categorizing strategies” and further assert “The researcher describes people's lives and experiences in detail” (Monette, et al., 2014, p. 437). The Publication Manual of the American Psychological Association (2009) assert “case studies illustrate a problem; indicate a means for solving a problem; and/or shed light on needed

research, clinical applications, or theoretical matters” (p. 11). A second researcher was commissioned to analyze findings to increase rigor of the study.

Researcher Bias

There is a bias in the research study as the participant and the researcher had a pre-existing relationship prior to the study, having been acquaintances for approximately seven years. The participant and the interviewer has had numerous discussions about various aspects and topics of the participant's experience of dying for approximately eight months prior to the research study. As a response to the bias, the researcher submitted the interview schedule to colleagues for reactions and input.

Findings

Introduction to Case Subject

The participant is a 75-year-old man, residing in St. Louis Park, Minnesota. He was born and raised in Minneapolis. He was drawn to music (specifically the piano) and at age four, he was playing the piano with two hands. At age 18, he toured Europe, playing the piano. The participant, a pianist by trade, spent ten years touring across Europe. He is an adept traveler, approximately traveling to Italy twenty-nine times across his life span. His identity is closely shaped by his affinity for creating and performing music and his experience as a worldly traveler.

The participant is no stranger to illnesses and physical health challenges. As a young boy, he regularly suffered from petit mal seizures and identified as experiencing physical challenges as a child growing up. When the participant was 21 years old, he was assaulted by two assailants. The sustained injuries caused him to suffer a stroke and bleeding of the brain. Eventually, the injury brought about three separate, life-threatening craniotomies throughout his life span. In addition, during his late 20's and early 30's, the participant was diagnosed with colon cancer. He underwent radiation and chemotherapy which was considered successful as the colon cancer remained in remission for the entirety of his life.

His experience with physical illness and physical challenges and facing mortality numerous times in his life is integral in shaping his perception of death and dying at this stage of his life. He talked about how he felt when he was faced with his mortality for the first time in his life when he was younger.

I wouldn't think about it. My way of dealing with it was not to...The only reason I am able to deal with things, I'm not afraid to think about it [death] anymore, and this goes to that thing that I've been talking about just lately: I'm not afraid to listen.

He approached the diagnosis of stage four lung cancer at age 74 in a different manner in that he felt he had lived a good life up to this point. He had previously undergone aggressive medical treatment with success in his younger years; however, he was not driven as he once was, to seek aggressive treatment. He discussed his frame of mind when he was first diagnosed and the role hope plays regarding the individual facing terminal illness and their family and friends, alike.

I know that I will get through it somehow. I have never forgotten that. The thing with this thing [cancer] is that people say that I'm going to live longer, and the reason for them doing it is because they can't really take it [death] on. And they're hopeful which I like. They're hopeful people. They are hopeful that I will get better and it doesn't hurt to say that to someone who has a terminal illness-that they will feel good and feel better and I may live a long time. And I may, who knows how long I will live?

He described his approach to his terminal illness saying, *I don't think dying is about death, that I really don't believe. It's about living and some days I don't feel like living so well, but I really do...I really do feel it's about life.* Furthermore, he touched upon the process of growing old stating that he doesn't feel that it's something one can prepare for, but rather a process *that you just have to be a part of and not be afraid to be a part of.*

Narrative Themes

Both myself and a second reviewer examined transcripts separately and then, together, identified common themes and sub-themes. Five emerging themes were identified from the data using content analyses of the three interviews with the participant: *physical states, mental behaviors, spirituality and time.* Three of the five emerging themes have sub-themes to further articulate the meaning of the participant's experience of dying.

Physical States. The theme, physical states, as it relates to the participant's experience of dying, is subcategorized by *states of being*, *felt senses*, and *physical things*. The components of physical states are more abstract in nature.

States of Being. Examples that illuminate states of being allude to the participant's experience of being grateful, hopeful, present, open and loving.

He made mention of gratitude or feeling grateful a substantial number of times throughout the interviews. He discussed various ways he feels grateful: living as long as he has, for change, the choice to be positive and peaceful, purpose throughout his life, for love (both people that love him and whom he's had the opportunity to love), love from God, the opportunities to be generous with people throughout his life, openness and understanding. He described gratitude as a type of sustenance for our soul suggesting, *gratitude is the most important food*.

He discussed the role of hope, or being hopeful within the process of dying. He described the role of hope in his life now, saying:

It's hope, not just for the future but for the moment. I can't control the future, but I can control the moment and a hopeful spirit does a lot for me right now. Just the feeling of hope.

He further stated, *hope is love, strength, and openness. You can't have hope without openness; when you're shut down. He feels that during the end-stages-of our life, we all have hope of some kind for what's ahead of us; however, he doesn't think about it too much or venture too far into the future because I have enough to keep me here, right now. And I'm not concerned with that.* He has a feeling there is peace beyond life, in some way; but said he doesn't dream a lot about what's beyond.

A robust sub-theme throughout the interviews is the notion of being present or living in the now. He considered the act of being present as one of his great life lessons; a lesson that he continues to live with hope and daily intention. He continually emphasized the importance of being present throughout the interviews as he feels it is critical to living a balanced and peaceful existence; one of connection to one's self, other people and a higher power.

The participant discussed social trends, contending that technology averts people from being present in their lives. He expounded on technology, communication via text message and the social effects it has on people as it relates to the act of being present:

It's separating us because you can't possibly have a thought, a long fulfilling thought of your own without constant interruption. And the thing is, most of this stuff...the back and forth [texting] is just trite. It really is. Think of all the energy used and spent every day on the words: and, but, hi, love, love...love. SO much I love you...and in case I didn't say it, I love you. You know, and all of this triteness takes away sincerity. Anything repeated too much loses meaning. And young people do not have an elastic vocabulary.

He also feels that it isn't easy for people to be present due to society's desire for excessive medications and pills. He believed societies' propensity for popping pills and medications is unfortunate and viewed it as a *mental exercise to zone out of life*. He strongly believed that while there are significant barriers to being present, it is still one of the most meaningful ways of living and dying and it can be achieved with mindfulness and *some work on our part*.

The participant felt that being open or openness is also a paramount state of being throughout the dying process. When asked if he felt more open because of his terminal illness, he responded:

Yep. More real. It is a gift. When I say more real, I mean more honest. And, it's...you know that kind of thought softens what you see in the people around you, too. There's a quieter kind of understanding of the people around you. Something I don't need to change with them, or affect particularly. But, maybe augment just a little with a little love and kindness.

He attributed his openness, or ability to be open as a major factor in his ability to be understanding and accepting of all things around him and within him. He purported that one cannot have peace without being open and felt that being closed off or shut down from possibilities thwart the ability to experience peace and an acquired sense of spirituality.

The final sub-theme is the participant's experience is love, or being love and loving. During the interview, he articulated *the only thing I want to be now, is loving*. He offered different adjectives throughout the interviews that describe his character or his state of being when he was younger: energetic, controlling, frenzied, and even fussy at times. He shared that it's his intention to be only loving at this stage in life. His definition of love is *being in the moment, with the spirit of love*. When asked where he finds love at this time in his life, he said, *Everywhere. Everywhere. People. Certainly, not things. But, there are wonderful people everywhere we go. Everywhere*. After some time exploring the role of love in his experience, he declared *there are only two things that really are the most important things about life and living: and one is to love and the second is to be loved*.

Felt senses. Examples of this sub-theme illuminate his experience of understanding for the world around him, forgiveness, tiredness/weariness/lack of energy and success.

I asked the participant what he felt his best attribute is and how it has served him throughout his experience; he replied his *understanding*. I further teased out his definition of understanding by using clarifying words like people, love or the universe. He responded, *Everything. To everything that is energy of any kind. And to have that understanding with no prejudice. But, you can't have understanding with prejudice*. He correlated his understanding to openness or being open. He is certain his spirit is completely and freely open, and further described the final stage of his life as liberating.

The participant spoke about forgiveness and explored the role of it as it relates to his experience. He felt forgiveness is a critical aspect in having/feeling a sense of peace throughout the process of dying. He contended *we cannot live in a place of hope when we can't forgive. It will impede our hope in one way or another* further stating it is *something that you may have to do and you may have to repeat in your heart...you may have to repeat it to make it actual*. He found that during this final stage of his life, forgiveness and the act of forgiving is tied into the idea of 'unfinished business.' Unfinished business or ambiguous loss, is a reoccurring topic across the literature on death and dying in which those facing mortality or the end-stages-of life examine issues they may consider unfinished and/or requiring some closure before the final transition. Pauline Boss (2016) first coined the term *ambiguous loss* in the 1970s, defining it as "a situation of unclear loss that remains unverified and thus without resolution" further declaring "people must construct their own meaning of the situation within a paradox of absence and presence" (p. 270). He felt forgiveness and the act of forgiving is interrelated with the concept of ambiguous loss.

...A lot of forgiveness goes into that [unfinished business]. A lot of the things that I consider unfinished business are the things that I really can't do anything about. And there again, I have to forgive either the person or myself. Or both. And we all have to remember that we are human. And we aren't...we don't have to be completely frail or completely strong. We're human.

He raised the feeling of regret as part of his experience in his final stage of life and supposed that the act of forgiveness is interwoven with feelings of regret. He shared, *One of the things that I think is important to talk about is regret. And, I think there are, honestly, a few things I do regret...that I could've but didn't do; I didn't make time for and I do regret that*. He talked about regret in relation to both people and situations in his past. Looking back, he believed he could have been more in the moment and "less busy with life and work." He talked about feeling sad

as he examined his moments of regret and circled around to the concept of forgiveness reminding me:

Again, it goes to forgiving ourselves for being human. And that doesn't mean that being human is an excuse...for anything, because it isn't-it doesn't hold up as an excuse. But what is...is and what was...was... and we do need to remember we're human and...forgiveness is so important. There is no hope, absolutely no hope without forgiveness. There just isn't.

He further associated accountability and responsibility, maintaining *when you don't take responsibility as much as you could have, something's got to give. And that's where forgiveness is so important.*

A prominent and overarching sub-theme that illuminates the participant's experience (which is particularly noticeable in relation to his physical being and forms in which his cancer presents) is a combination of feelings comprising *tiredness/weariness/lack of energy*. The participant categorized the lack of energy or the inability to summon energy as one of his primary frustrations throughout his process of dying (which he's found energy to be periodic and appear in spurts).

The one thing I'm noticing and the appearances of it [cancer] to me, the feelings, the whatever, were once in a while, I felt like...ugh, tired, terrible weariness; terrific, heavy weariness that would just wash over me, I felt like something was going to happen. And it really felt that way, it wasn't physical pain but it was the absence of any energy.

When asked if he's ready to die he replied yes, alluding both his body and mind are tired. He described it as an *exhausting tired; the solo energy, when I think I must getting closer, ugh! And then the next day, I am up*. The participant revered energy as he finds it to be a limited resource with periodic, restricted access.

You know, it [energy] goes up and down; not way up-my energy doesn't really go way up, but it does go up temporarily...and, I can't really say that I go out of my way to protect it when I do have it because I use it when I can. When I don't have it, I don't have it and then I'm quiet and I rest.

He spoke of moments when he is especially tired and he experiences *a kind of garble of thoughts*. During those moments, he purposely calms his mind and *doesn't try to figure anything out*. At this stage in his life, he is learning how to pace himself to efficiently utilize the energy he has.

If I'm going somewhere...I used to be able to wait until the last moment and hop in the shower-I did just that...hop into the shower and hop out and shave. Now, I make it a pleasure because I do it more slowly...and it really is kind of fun.

He doesn't fight the lack of energy, but rather reframes a potentially stressful reality (absence or lack of energy) into a mindful, pleasant event in which he finds enjoyment. He is very conscious of the energy he has now; though. He is wary of the energy he acquires because it can leave just as fast as it comes.

The final sub-theme that is significant to the participant's experience is success. The participant correlated success and peace defining success as something that takes effort to attain and something that cannot be taken. He qualified success as a way of knowing or being rather than material items such as money. He believes people confuse success with having physical things or money; his understanding of success is very different.

I think success is like peace. I think it...success is not just a word, it's something that takes effort. And if it hasn't taken effort and just handed to you, too much money...people think of success as money-it isn't. Success is knowing or realizing that you've done something well. Success is having people in your life whose lives, or life you can actually see you're making a difference in or that their making a difference in yours. Success, is not by any means, having a lot of things. It isn't. Because any of those things...success is something that cannot be destroyed. It's not a thing. It's a feeling-a good feeling. Even if it's a small accomplishment. But, nobody can hand success to us. It's up to us to do something, be something that earns it.

He further purported that while success, as it were, cannot be taken, it can be destroyed. He suggested that we can do it to ourselves by external forces *that get into us or around us, but it can destroy success and it can take away our very lives*. He talked about the former statement

sounding nebulous in nature, but warned that external forces can be powerful and if overlooked, can consume or steal away elements vital to our happiness and peacefulness. He linked gratitude as a specific way to thwart the threat of external forces.

Physical things. This sub-theme illuminates examples of more concrete, physical things which have been, and continue to be, an integral part of the participant's experience including energy, death and dying, people and technology.

The concept of energy, is a principal, overarching force in the participant's experience and is an emerging theme throughout the research. The participant further delineated the concept of energy as it pertains to the energy or aura of people and himself and the energy or aura of the physical world around him. The former categories can intersect and crossover as he further posited that people can have positive or negative energy, just as the physical world (i.e. cultural attitudes and beliefs) can hold positive or negative energy.

Vitality, as discussed previously, is "the state of being strong and active; energy" and "the power giving continuance of life, present in all living things." Vitality adequately frames the participant's idea of energy. He feels all living things are made of energy, including but not limited to people, animals, and mother nature.

He feels energy is fundamental to the experience of living and dying. He also maintained the importance of protecting his personal energy, and awareness of his personal energy. During this stage in his life, when he has restricted access to a depleted level of energy, he guards his personal energy by being selective of the people with whom he chooses to spend time and the way he expends his energy. He chooses to devote his energy to people who have a positive, uplifting energy about them and actively stays away from those people who may deplete or exhaust his energy with energy that is negative or aggressive in nature. He feels that negative

energy, the feeling of anger as such, is one of the most consuming emotions we can feel and impose on others. Conversely, he described positive energy, such as the feeling of joy, as a healing force. He talked about how his experience of living and dying are interrelated with energy.

It all goes back to this thing called energy. Everything keeps going back to it. And it does in life with all of the things that have a potential to make us frightened, make us sick, make us sad and make us angry. We have to protect our energy; nobody else can protect our energy.

The participant believed protecting and nourishing our energy is vital to selfcare. He warned that it is also challenging in many ways to preserve our personal energy reserve. He holds true that our energy is our own and we are responsible for our personal energy, further asserting that it is the fault of our own if we allow other people to take our energy or misuse it. He strongly feels that it is detrimental and irresponsible of that individual.

There are vultures who will take it without even knowing they are taking it. But, I...I don't think the world is full of vultures. I don't think the world is a horrible place, it still isn't as frenetic as its getting. I think there are still really good people and there is a lot of good energy all around us.

He said he receives energy from other citing people, meaning and purpose in his life (music and playing the piano) and nature, as examples. He talked about his interest in genealogy going on to say that he's researched genealogy for twenty years and how it, too, has given him purpose and meaning. During his final stage, he finds working on genealogy invigorating and described how he's loved collecting all the data over the years and the memories of it. He's talked about feeling grateful that he's had the opportunity this past year to finish it so that when he passes, those surviving him will be able use the data in some way.

The second, prominent physical aspect of the participant's experience is people. He discussed the dynamic role of people in his life, presently. One of the great lessons the

participant has learned throughout life and continues to learn through the process of death and dying is that the people in our lives are vital. He feels that humans have needs and many of those needs are met by people. He talked about his needs today.

My needs are simple now, really they are. You know, I love it when someone I love says "well, I don't really need much of anything," and we (just as humans) we do have needs. Maybe not as much needs for some rather than others, but we all do have needs and other people are important-much more important than I think we care to realize. I feel really sorry for people who have no awareness or refuse awareness about the value of other people in their lives. Maybe if it's fear, or umm, who knows what, but, that's unfortunate. But, I do need other people. I don't need them, desperately; I don't want to have to need anything desperately, but I do need other people.

He touched upon self-sufficiency, saying that it is wonderful to be self-sufficient as we feature we are, but that most humans (remaining especially true for him) still need people. He maintained, *even if it's their needing me that's important-because that is important in life.*

He talked about the importance of having a loving attitude toward others and now, how his is grateful for the people in his life, those who've passed on and those still living. He explored the grief that comes along with losing people he's loved in life and the importance of discerning unhealthy or sick people in his life, and accordingly, keeping a distance. He felt many kinds of people have been teachers in his life remarking, *even the vilest person can still be a teacher.* He continues to perceive people as gifts and sources of love asserting that he finds love everywhere because *there are wonderful people everywhere.*

The final physical aspect of his experience is death and dying. The participant reflected on death and dying, responding *I don't think death is a dreadful time at all.* He further explained that he has no expectations of it that are specific.

I really think, (and what I do think what would be wonderful to see) once again, in some form, are the people that I love. But, they are with me in life...just in thought, some constantly.

The participant noted his general attitude toward death and dying *isn't just something that's come upon me. I think it's based on what I've seen and heard, and how I've watched other people close to me handle it as they've gone.* He's learned that it doesn't have to be a fearful time and individuals he's witnessed who were afraid to die, had anxiety about the fear of the unknown; a fear that the participant confirmed he doesn't possess. The participant shared that he isn't reminded of his mortality daily, explaining that he hasn't labored over this [terminal illness] and for that he feels very fortunate. He expressed that he has no anxiety about the process of dying and finds that he feels more peaceful than he has ever been in his life.

The participant talked about the final stage in his life has been a time when he chose to simplify his life. He felt *being in this place [aura] as it is today, is far less complicated.* He described his disposition now as *freer...freer of a lot of 'what was.'* He talked about letting go of things that he never allowed himself to process. He stated he *feels confident and has confidence that everything is alright and will be alright.*

He shared about his affairs and preparations he's made for his impending death. He indicated that his final will and testament is very simple because he no longer owns very much. The participant explained that he has given his money away while still living and he considers the ability to do so a blessing. When asked about his standing healthcare directive he responded: *No heroics. None. No recitation, no tubes, no anything.* Moreover, he asserted that when his time comes to travel to another incantation, *"I'm going...not to the hospital, I'm just going."*

The final sub-theme of physical things is technology. The participant discussed how technology and social media adversely impact our communication with one another as well as our sense of personal peace or spirituality. He explored the principles of social platforms

including Facebook, Twitter and Instagram. He felt that they encourage us *to do too much in a short amount of time*. He also felt technology is a drain on our energy, daily.

It takes so much of our energy though the day, constantly, all this technology...Listen, you can't really have a spiritual person-you can't be that spiritual of a person with phones ringing constantly, and constantly texting.

He used the adjective 'seductive' to describe the appeal of technology, saying *it [technology] is easy and it's constantly there*, further noting that *when you're not getting a text message, you're waiting for one*. He declared technology to impede our ability to be present, and all the while, our lifetime clock is ticking away.

He feels *nothing is more healthy than good old conversation, person to person; regular vocal interaction*. He talked about our technology-driven lifestyle, making mention that perhaps one day it will *short-circuit* and we'll be forced to talk to each other. He followed that sentiment up, asserting we will all have a tough time talking with one another with a vocabulary of ten words. The participant addressed the topic of our limited vernacular multiple times.

Do you know what's bothersome? We don't use our words anymore. We don't know how to speak anymore. I hear these words all the time: awesome, amazing, cool... awesome, amazing, cool...ok, awesome, amazing, cool....no, yes, cool, awesome, amazing...dude.

He concluded discussion around the topic of technology with the following sentiment: *time goes fast enough without all of this crap [referring to texting and social media] and then waiting for an answer*.

Mental. The emerging theme describing the mental component of the participant's experience is subcategorized by *emotions* and *cognitions*.

Emotions. Examples of emotions illuminated and expressed by the participant throughout his experience include sadness and joy.

On occasion throughout this process, the participant described feeling periods of overwhelming melancholy and would find himself weeping for hours. He posited he's not depressed; but rather, open to the feelings that come. During the interviews, we explored his feelings of sadness or grief related to his death and the process of dying; he referenced his mother.

My mother used to say about the bad or about the sad, all of us are going to have a little sorrow, or a lot of sorrow-but we owe it to ourselves to try to put a time limit on it. And I think that's so true. And, try not to catch yourself in a place where you're thinking 'Oh, life is such a drag.'

Throughout this process, he stated he has been open to an array of emotions including fear and grief, and he would allow himself to feel those emotions; however, he explained that he's always able to lift himself up. He is intentional to put a time limit on emotions that would eventually, if lingered upon too long, suppress various states of being like gratitude, peace, positivity and determination.

He discussed various ways he experiences joy during the process of dying. He has learned to find joy in simplicity and in simplifying his life. As mentioned previously, he felt his aura (energy) is far less complicated during this stage which he treasures. He described astonishment as he disclosed that this is the first time in his life that he is purely listening. He felt the ability to listen was a result of expanding his mind which he determined was motivated by his terminal illness. He talked about his living space and how it is the smallest space he's lived in, and that he's never enjoyed living in a space as much as he does now.

In simplifying his life, he has also worked to minimize the efforts of his brother in dealing with his final arrangements and affairs. The participant has been concerned throughout this process to not be a burden to his loved ones; thus, the action taken to uncomplicate and simplify his affairs accordingly. He's created a 3rd drawer, as it were, as a way lighten the load

for his family; he views it as a drawer of help and some instruction, carefully pointing out that it is not his purpose to control what his family does once he's passed.

Cognitions. Examples of cognitions illuminated and expressed by the participant throughout his experience include positive thoughts/thinking and recollection of memories.

The participant felt he met his terminal diagnosis with a positive outlook and a certain acceptance. He further described how his mindset and approach to his diagnosis have been precast by his former experiences.

See I had a history of...I don't like to say I've always been sick, but I've had so much illness in my life that I feel that I'm fortunate that I have because it has helped me learn a little bit about illness, and about survival. Do you choose to survive with a negative attitude? 'Oh, I'm not this...I don't have that...I won't be able to do this or that.' It's nuts. That is just...and you know, if that isn't caught and checked early on, that [negative attitude] can last right through old age. And, people don't want...the world is not interested in your complaint. I think most people have things of their own today-challenges that we don't even know-never will know....

He commented on the importance of controlling thoughts and feels that it is a primary way to take care of our general well-being. He asserted that lingering on thoughts and emotions that obstruct personal progression and adversely diminish our sense of well-being is fruitless and unproductive; results in which we don't have time to spare. He instructed ways to take care of myself.

Take care...and when I say take care, don't be afraid to use your brain constructively. Don't let yourself think about things that are hurting you. When I say hurting you, so that you're hurting yourself. But, try to do what you can to keep your own aura of peace protected. Nobody else has a right to that. They don't, unless you give them-entitle them-to that right.

The participant commented on the role of his memories and how they fulfill him at this stage in life. He discussed how his terminal illness has altered his lifestyle in that he was an avid traveler. He recalled he would fly back and forth to Los Angeles at least one time per week for a period of ten years and how it was a large part of his identity. Rather than longing for that part

of his life again, the participant described how fondly thinking of those moments in time is satisfying.

Yeah, but the beauty of it is...This is the beauty of it is: these things that I may miss, as you say, and think about. I don't have to redo them; I don't have to go back to that place; go back to that situation. I can have this glow and this surge, kind of...of goosebumps just thinking about how it felt; how wonderful it was. I don't have to be there. I don't have to get on a plane anymore to be there. That's the wonderful thing about it. And it's a shocker-roo to me, too. It is. I loved LA. I loved the few people that I had contact with there; the places I frequented. The wonderful, beautiful places, good food, lovely atmosphere. Just wonderful going to movies and going to art exhibits and theater. I saw wonderful theater in New York over the years; just unforgettable; ugh, yeah. But, I can have those moments again. I can have them right now; everything that was wonderful about them.

He suggested that memories can be employed as coping mechanisms and described how he utilizes his memories in a therapeutic or healing manner.

When you lose most of the people that have been dear to you, that causes something; and we as human beings, I think we try to fill up those holes with something and umm, and it's not always easy to fill those things with worthwhile things-with food, or alcohol, or drugs or whatever. But, if we let ourselves, memories can be very healing. And...and there are, even though we've lost people who had become dear to us, other people who are in their own way, dear. So, life goes on; as long as there is life around us.

Behavior. The theme of behavior is a critical element of the participant's experience.

The theme is subcategorized into *communication* and *actions*.

Communication. The participant found that communication with others addressing the process of dying and his terminal illness don't come up very often. He commented about communicating with others about his circumstances.

It [cancer and dying] does not come up with the people with I am close to and um...I think that's kind of interesting that it doesn't; not that I am expecting to be, but I find when I've known someone that was dying or very, very ill, I've been interested in knowing how they were feeling at the time, mostly so that I would have some idea whether or not I was going to make them too tired, or whatever.

He noted that people are inhibited when speaking about his cancer and his experience of dying and is unable to definitively contribute a particular reason why people don't broach it. He supposed that, perhaps, there isn't much to say about it; however, in the same breath, goes on to shared he feels better to talk about it when he's physically uncomfortable or experiencing pain.

In the first place, I haven't really had lengthy conversations in my mind about it since I found out it's happened. And it isn't because I am ignoring it or denying it or anything, I just don't really find the need to [talk about it] when I don't have comfort; (which is not all that often) but, when I am uncomfortable because of something related to or distantly related to this thing, [cancer] then I talk about it for some reason. Just the idea of saying that 'it hurts' or 'it aches;' it feels better, even if it just temporarily...it feels better. I don't know what that's about...but, I've noticed people are restrained when it comes to speaking about it especially when they are not familiar with it or haven't lost a loved one to it or known a loved one that went through some sort of cancer.

Actions. Fundamental aspects of participant's experience of dying include actions or steps that enhance his experience, examples including choice and responsibility. The participant discussed the impact of choices as it relates to both living and dying.

Everything is a choice. Everything in our lives is a choice. I believe in a certain amount of predestination. But, I do think most things in our lives are choices. And, the idea that you could live your life being afraid to make any kind of choice, is just scary.

On multiple instances, the participant correlated choice with various subjects including spirituality, peacefulness, calmness, and being present. He underscored the critical element of choice and talked about how it can enhance and elevate the ways in which we live our lives and the process of death and dying or work to diminish and fracture our experience of both.

Our choices are important and once we start getting away from being part...mentally part of our choices, making stupid decisions for whatever reason, we really can't expect a great outcome; a peaceful outcome. And then there are those unfortunate people who really never have been able to really make choices for themselves; they do in a way in that their choice is to have somebody else make their decisions and choices for them.

The participant firmly believed taking responsibility for choices, states of being and ways of living and dying directly influence our general quality of living and dying. Throughout the

interviews, he demonstrated ways in which he takes responsibility during his final stage of life including feeling sadness and melancholia for only a limited amount of time and taking responsibility of his mental health by choosing positive attitudes, beliefs and ways to augment and protect his energy.

...we are responsible for the good and bad in our lives. We're also responsible for dealing with the good and bad in our lives. It isn't up to other people.

He correlated the role of responsibility in his life to happiness. While he hasn't been perfect throughout his life, he stated he's been more involved with the role of responsibility and further associated his availability to the capacity of being present. He stoutly maintained we are responsible for our own aura and energy.

Spirituality. Spirituality is an emerging theme and component of the participant's experience of dying. The participant defines spirituality as *peace in your soul*. He discussed the role of spirituality in his experience, throughout this past year and through his lifespan. He understands spirituality to be a choice that takes work to develop. He indicated that he was inspired by others when developing his own sense of spirituality (namely his parents) and felt that spirituality can be obsolete at points in our life, owing to our humanness. Because spirituality is a choice, he felt that there are times in our life that we move away from spirituality, albeit conscious or unconscious, and there are other times in our life we move closer to spirituality and spiritual growth. He described frustration about our societies' disingenuous perspective regarding spirituality; he stated *spirituality is just a word that people continually pick up and put down and then pick up, again*.

The participant perceived his understanding of God to have qualities of love, mercy, kindness, and peace. He expressed weariness of secular religion in that he feels it operates with fear and control. He mentioned *obedience to a spirit* to revere one's higher power, moreover, he

asserts that it's been his practice to cultivate and grow his spirituality. He attributed God as the reason he is having an easeful, peaceful experience of dying.

I think it's a gift from God, through other people. I really do. And, one of the wonderful things is-and that's a gift, is that people would have an expectation of finding something of spiritual value from you. And that is the supreme gift. Really, because there isn't anything else. It's all window dressing. Just...there just isn't anything else, but human connection.

He referred to *the expectation of people finding spiritual value* as the opportunity to share, explore and document his process of dying through this research. He expressed gratitude for the role and purpose we have served in each other's respective world.

Time. The final emerging theme highlighting the participant's experience of dying is the component of time. Being granted extra time is something the participant felt grateful for in that when he first received this diagnosis in October, 2015, the participant was given an expiration date of January, 2016. He shared his thoughts on this projection.

I didn't believe it. And maybe that was stupid on my part; maybe I should have. I didn't really accept it...In fact, what I did was forget about it. What good would it do for me to really know and think this is your deadline. Boom. That's why they call it a deadline.

The projection of his limited time did incite some action and preparation on the participant's behalf as he started gathering the contents of the 3rd drawer.

Throughout the interviews, the participant circled back to thoughts that his life *happened so quickly* and *time goes fast*. He talked about *racing against time* to complete his family history project. He feels gratitude for living as long as he has.

I'm grateful that I've lived...I didn't ever...I've been talking about this a lot just lately-how I didn't expect to live to be almost 75. No, I never lived that way thinking I would live that long. Maybe I was living more in the moment than I thought. But, it came awfully fast; that I will say, especially the last few years. One of the things that I think is important to talk about is regret. And, I think there are, honestly, a few things I do regret...that I could've but didn't do; I didn't make time for and I do regret that.

The participant referenced the exercise of futile actions relative to the element of time and feels technology, social networking and texting (as a form of communication) encourage us as a society to *do too much in too short amount of time because we're racing against time*. He linked feelings of regret to his choice to not make or take time, albeit a person or a situation. Upon reflection, he said he would have been *more in the moment and less busy*.

Discussion

The purpose of this research is to explore a personal account of a man's experience of actively dying. Specifically, the proposed research explored and examined a 74 year-old-man's experience of dying with stage four lung cancer. In this section, I will examine the ways the research findings intersect existing published literature regarding this topic.

Research findings of this study revealed minimal relation to the literature review as there is a gap in the literature regarding case examples exploring the subjective experience of dying. While there is a growing body of literature regarding death, and dying, very little literature exists detailing the experience of subjectively dying and the valuable insight and information those dying can bear to professionals to enhance quality of care for the dying and the quality of living for the dying. In addition, virtually no published literature exists exploring various life lessons imparted by the dying and how their insight can positively augment the quality of the ways in which we live our lives.

A considerable factor regarding the participant's experience is that the participant declined pursuing medical treatment of any kind throughout his process of dying. The participant's relationship with professionals throughout this research is nearly non-existent; therefore, no data was gathered and analyzed to provide suggestions or recommendations how professionals in the medical and social work fields can improve care practices for the dying. The data did provide an in-depth, subjective account of a dying man which offered an intimate glimpse into the internal world of an individual who is mentally, emotionally and physically preparing for the final transition.

The participant's experience illuminated noteworthy aspects in the experience of dying to consider for future research regarding death and the subjective experience of dying. A major

element to examine in the participant's experience is the general lack of fear and anxiety toward his approaching mortality. The participant's absence of fear cannot be definitively attributed to any one reason or specific ability of the participant. Perhaps, a culmination of significant elements totaling the participant's experience contribute to a greater experience of living while dying; void of fear, anxiety, depression and isolation at the end-stages-of life.

Additional elements illuminating the participant's experience of dying include: peaceful acceptance of his terminal diagnosis; willingness to explore and discuss his experience of death and dying with others; availability and openness to the feelings accompanied with death and dying e.g. fear, joy, sadness, happiness, peace, love, gratitude; an overall positive attitude; minimal pain with no medical interventions e.g. chemotherapy or radiation; and personal growth during his final stage in life. The participant defined spirituality as *peace in your soul*. It would be helpful to further study his personal sense of spirituality and the role it played in his experience of dying.

Living Space at the End of Life

Some findings relative to the participant's experience of dying and existing literature highlighted the importance of living space for those facing end-of-life stages. The participant emphasized that his living space is vital to his experience of dying, describing his space as *sacred* and *calming*. This finding can be correlated to the quality of living at the end-of-life in institutions like hospitals and nursing homes. Black and Csikai (2015) suggest that most deaths in the United States occur in institutional settings, reporting 46% died in medical facilities and 21% died in nursing homes. They further write that the increase in institutionalized deaths directly contrast individuals' preferences and desires to die in their own home (Black & Csikai, 2015). The participant indicated living in a place that was *sterile* and *cold* would adversely

impact his experience of dying. We examined the ritual cultural shift of death occurring at home versus death occurring in the hospitals and institutions beginning in the 19th century in the literature review, suggesting that the living space is associated with a higher end-of-life quality.

Extension of Life and Death and Quality of end-of-life

Another finding common to both the experience of the participant and the literature is the extension of life expectancy due to advancements in medicine and technology. The protraction of the dying process often lead to “medicalized deaths,” which signifies multiple medical treatments that can prolong the process of dying (Black & Csikai, 2015). The extension of life doesn't necessarily translate into a positive or healthy quality-of-life. Black and Csikai (2015) assert that chronic illness largely defines the experience at the end-stages-of life for most elderly Americans. The participant commented on the topic of extended life expectancy and being elderly in the context of Western medicine:

Every creation that comes into play starts off as something good and ends up being a chore. I think to give people a little longer chance at life was a neat thought. And, now we have a lot of people living too long and the quality of life isn't there. And people will say “oh, well they're breathing, and smiling once and a while...well, it might be gas...who knows?”

Application of Self-Determination Theory

Energy, the protection of energy, and the awareness of personal energy, is a fundamental subject for the participant throughout his experience and sub-theme throughout the interviews. A potential association can be established regarding the participant's concept of energy and the aspect of vitality within the self-determination theory (SDT). Ryan and Deci (2008) assert that a pertinent aspect within the self-determination theory concerns “the energization of people's psychological processes and behaviors” or the concept of *vitality* (p. 182). The authors define vitality as “the energy that is available to the self—that is, the energy that is exhilarating and

empowering, that allows people to act more autonomously and persist more at important activities” (p. 182). Deci and Ryan (2008) and colleagues (2006) posit that autonomous regulation is not depleting but rather the opposite in that it can be vitalizing and energy boosting. Autonomous regulation is the experience of “volition, or a self-endorsement of their actions” as opposed to controlled regulation which is the experience of “pressure to think, feel, or behave in particular ways” (p. 182). The participant has maintained a relative sense of autonomy and self-reliance throughout his experience of dying. Furthermore, the participant's three psychological needs central to SDT (*autonomy, relatedness and competence*) have been continually fulfilled and satisfied throughout his experience. He highlights and emphasizes the integral role of people in his life and experiences competence by working on his genealogy project from which he acquires purpose and meaning. He discussed the topic of autonomy at this stage in life and he described feeling more autonomous regulation at this stage in his life than ever before. He is no longer caught up by what others think and say, describing his mind as freer and limitless.

Another potential connection can be made regarding the participant's lack of anxiety, fear and avoidance of his mortality. The lack of fear could be related to his younger years when he first found himself faced with mortality. Three separate craniotomies are three separate instances when the participant was unsure if he would come out alive. As noted previously, the participant had also undergone chemotherapy and radiation in his 30's due to colon cancer. This is yet, another instance when the participant was faced with the very real fact that he may not live. The participant had a robust relationship with his mortality prior to his final process of dying and notable factor to consider regarding the lack of death anxiety, fear or avoidance.

A causal relationship could possibly be made between maintaining a sense of self control/choice during the end-stages-of life and a sense of vitality or bolstered energy levels. An

aspect to consider is that the interviews were conducted inside the participant's home. Going to the participant's home helped him to retain a sense of control within his own surroundings. It also was a very intimate space where he could talk to me about pictures, books and movies he had collected throughout his life. We talked about his life and his death. Research with him was personal in nature; and there is cause for that because dying is a delicate event and the topic of one's experience of dying is sensitive and complex. Future research should approach a dying person and their situation with full contemplation and care for the individual's overall health and well-being. Additional research would be helpful in determining if there is a causal relationship between a sense of self control/choice and vitality or increased energy levels and how this relationship could potentially contribute to an improved end-of-life quality.

Limitations

There are several limitations of this research study. One limitation is that the findings are not generalizable beyond this case and this man's experience does not represent the entire populations' experience of the dying. Another limitation of the case study method is that it is entirely subjective, depending on the account of one man. The end-stages-of life are delicate and the intimate experience of the dying also pose challenges to gathering research as there may be a limited number of people willing *and* able to allow someone to research and investigate their experience. Also, having a pre-existing relationship with the participant prior to research can be considered a limitation due to maintaining an objective perspective. However, in my experience I believe it was a strength. I was better equipped to endorse *his* voice throughout the research and minimize my interpretations or assumptions regarding the participant's intended meaning. The research would have been less authentic and more reliant on my interpretation of the participant's words, experiences, thoughts and feelings.

Implication for Future Research

The topic of death and dying is a burgeoning topic. The increase in the elderly population and the evolving process of death and dying in the United States warrants future, in depth research. The action research methodology may be an effective method of research. Action research aims to both increase knowledge, experience and understanding of a current situation and engage in a process of change (Paul, 2015). Action research methodology may be a used to increase understanding about current practices and care at the end stages of life throughout facilities including hospices/palliative care facilities, nursing homes, home health care and hospitals. This methodology allows researchers to explore, implement and evaluate different models of care. In the similar spirit of action research, focus groups collaborating with community organizations could also be an effective method for investigating end-of-life care practices and ultimately, developing steps for a process of change. Engaging focus groups help researchers give voices to the participants in the development process. Another consideration for future research is to build upon a multitude of case studies regarding subjective death and dying. Creating a foundation of case studies could offer an initial framework with which to explore, investigate and research the personal experience of dying. Data may then be used to establish improved, progressive care practices for professionals in the medical and social work fields.

The field of social work has a unique partnership in the process of death and dying; social work as a discipline would undoubtedly benefit from a renewed, holistic perspective of death and dying. Nakishima (2003) suggests utilizing narrative accounts of the dying, identifying them as a “fertile source for learning how a dying person’s strengths and resources can be mobilized to form an alternative meaning of dying that does not conform to prevailing beliefs of death and dying” (p. 375). Through narrative analysis, social work research can illuminate the intimate

experience of the dying person thereby gaining psychosocial insight and awareness surrounding mortality, death and dying.

Implications for Social Work Practice

As previously discussed, the protraction of death and dying in America and the increased number of people dying in institutions today, the need for an expanding social work role with death and dying issues is clear (Hobart, 2002). Social workers need to explore existing social supports for elderly and terminal clients as the social engagement piece of the participant's experience appeared to largely account for satisfaction and positive experience during the end-stages-of life. Death and dying can be lonely and potentially isolating, so it would behoove social workers on behalf of the client's health and well-being to focus on strengthening and/or developing social interactions and engagements.

The participant was grateful for the opportunity to talk about his experience of death and dying. Research indicates that eliciting conversation regarding individuals' facing mortality or the end-stages-of life positively impacts their experience. Satisfaction and meaning is gained by creating a narrative of one's life and past experiences. The impact of narrative care and the experience of the dying should be considered and explored; further research needs to be gathered regarding narrative care and the potential implications on end-of-life quality. Research reveals there are barriers to engaging in hospice/palliative care services earlier in the dying process and it is an underutilized benefit. It is incumbent for social workers to strive to provide more education and care options regarding the earlier engagement of hospice and palliative care services.

The field of social work needs to continue to develop professional trainings, conferences and academic courses related to end-of-life care practices and challenges that face both

individual and families faced with death and dying. Dialogue across disciplines regarding end-of-life care would be beneficial to professionals working with the elderly and dying as well. Physicians, nurses, attorneys, and religious leaders are all integral roles in the process death and dying in today's culture.

Moreover, it is imperative that social workers, particularly those who work with terminally ill patients and families, continue an ongoing, introspective dialogue exploring personal attitudes and beliefs associated with death and dying. Death and the process of dying is a multidimensional subject that can stimulate a host of emotions. Black and Csikai (2015) assert "One's own mortality is evoked in discussions about death and dying and practitioner's abilities to discuss dying should be examined closely" (p. 43). Exploration of the emotions attached to mortality, death and dying require time and attention; through our own personal reflection, we can better meet clients and families.

Researcher's Reaction

Death is the last chapter in everyone's book and I was granted the privilege and honor to accompany the participant in authoring his last chapter. In my research, I have discovered death is not for the faint of heart and neither is living and in many respects, both experiences comprise similar tenets. Crossing into the unknown with the participant has been uplifting and exhausting, trying but wildly worthwhile; the grandest lesson I have been fortunate to learn. Because I had a unique relationship with the participant and was so closely connected to him, I feel that I experienced many of the ups and downs just as a family member may have. The nature of our relationship steadily evolved and the depth of the relationship increased the further along we were in the research process. I have been honored to accompany him, only partly, in his final transition, as dying is a very intimate experience.

My voyage with him began in January of 2016; the very month he was told by his doctor would be his last. I have known the participant for years, and have always been moved by the ways in which he lived his life. I was first inspired to develop this research study by observing how he was processing and handling his terminal diagnosis. He was displaying such acts of grace on both fronts. He was balanced and calm; he seemed almost peaceful! I asked myself, what permits him to be so available to his impending death? Do the methods in which he lives life somehow translate into the methods in which he dies? If so, how are they connected or interrelated? If my suspicions were even partly true, I understood there was much to learn and explore concerning his experience of death, dying and living.

Through our years of friendship and observing his perspective and approach to life, I determined that he is an exceptional human in a very distinct way: the way in which he makes himself available to the experiences of people and life with relatively minimal fear and an abundance of loving acceptance. In my perspective, he embodies love in an unrestricted and open manner toward people and his person. I think his experience of living while dying is exceptional in fashion which I deemed valuable and meaningful to explore. Thus, my research study was born.

Fiscalini (1987) categorizes the parallel process as a chain reaction that can connect “interpersonal situations that are dynamically similar” (p. 29). I believe the parallel process adequately frames my experience with the participant as I found myself connected to the participant in a unique way. It was an emotional rollercoaster for lack of a better term. I think it is important to note that the participant decided against medical treatment and his experience of cancer and dying was different from those who undergo chemotherapy and radiation. In my opinion, his physical self was relatively strong and unaffected. Throughout his experience of

dying, the participant did have some pain associated with the cancer, however, the pain was never consuming nor constituting pain medication. My perspective of the participant's health was one of overall exceptional health and well-being. Mostly during our time together, I shared feelings of health, wellness and vitality with the participant. However, there were times when I also shared feelings of fear, anxiety and doom when he would become weak, confused and have difficulty breathing. Sometimes, he'd experience a tremendous heaviness in his chest and on multiple occasions, he would suffer from headaches that would last three to four days. Not until more recently, did I perceive the participant to be dying or in some form, debilitated by the cancer. Intellectually, I understood that he was dying; experientially, his physical self was deceiving as there was no drastic physical decline nor constraint in his mobility. We were walking together through his death; there were no hospital beds or sickness to render him incapacitated. I realized the participant wasn't dying, conventionally.

At times, I would find myself randomly wondering 'Is today the day I receive a call about his death?' 'How will it happen?' 'Will I be able to prepare myself or will it occur abruptly, with no indication?' These thoughts were consuming, at times. It was challenging to join him, but not fully merge with him into his experience of dying. Maintaining an objective perspective is necessary in research *and* the event of dying is personal; striking a balance was challenging. Maintaining an objective perspective during some parts of the research felt counter-intuitive. Being direct and blunt with him about his dying process was odd, but not uncomfortable because he was never uneasy sharing his experience with me.

Through the examination of the finitude of his life, I began to create a relationship with my mortality. There were times (when I really tuned in to the delicate nature of life and the singular conclusion of it) that feelings of anxiety, fear and grief would wash over me. To cope

with my emotions, I tried to keep the participant's advice in my mind: return to the present moment. Sometimes, it was easy to do so, other times the emotions were almost seared into my mind and soul and sadness radiated throughout my body. It is hard to satisfactorily describe the experience of dying; words almost always fall short.

I believe my reaction and feelings associated with the participant's death and dying were compounded. I was experiencing a parallel process on various planes in that personally, I became estranged with my family and suffering momentous grief and loss. Concurrently, I was experiencing grief and loss associated with the participant, friend and mentor and the separation from my family. The estrangement, was in part, the death of my identity and I resisted acceptance of that reality. At one point in the research study, I felt like the grief and loss of both the participant and my family was crushing my spirit. Any sense I had that all was well and right in the world was absent. I wasn't ok, times two. My life was askew in a surreal way, not uncommon, to individuals facing mortality or the end-stages of life.

Eventually, the participant and I uncovered that our unique partnership served to satisfy one another's need for a different or changed purpose and meaning in our lives. Our relationship, bound by research, evolved into an elevated purpose and served to bridge the gap caused by grief and loss. The participant talked about how the unsuspecting relationship with me satisfied him in a way that he could not anticipate as he never married nor had children of his own. I found support and guidance from the participant when I was in dire need; something I did not foresee. We were healing forces in each other's life and relationship with the participant was a divine intervention

The feelings of grief and loss gradually left even though situations had not changed; the participant was still dying and family relations were still strained. However, I made some

necessary changes and it was the participant who helped guide me during a crucial time in my life. My feelings weren't so raw and I became less emotionally driven. It was then, when I set my emotions aside, I became open to listening and learning. The pivot was vital to my experience. Emotions, when unattended and unexamined, can be the root of maladaptive thinking, feeling and behaving.

Today, I am grateful for the opportunity to continually learn and grow with the participant because he is alive and well. The lessons I have learned with him and from him during this process are lifelong and forever cherished. I didn't expect to research this topic, nor move beside someone while they were dying, but one can't predict some of life's greatest joys and deepest challenges. The parallel process, ushered by the participant, equipped me with infinite tools to help me cope with the inevitable, challenging (sometimes heartbreaking) circumstances we experience throughout our lives. I am grateful for the exposure to the complex nature death, dying and living. The participant's wisdom and experience will sustain me in life and death. Through him, I have come to believe personal development, and evolution of each dimension of our self, (mind, body, soul) can occur through all stages in our lives and by means of every singular experience we choose to be present for.

Conclusion

The purpose of this research is to explore a personal account of a man's experience of actively dying. The participant's experience of dying included a peaceful experience; one without death anxiety and the fear of what's beyond his earthly experience. He was also able to focus on best living practices that supported an enhanced quality of life. Many of his living

practices translated into the lessons for living I learned from him. Being present and living in the now of his life was a major feature of his experience that contributed to a peaceful acceptance of his experience. In addition, protecting his limited energy and utilizing it when it was available was significant to his experience. He was careful whom he spent his on and the ways in which he used his energy e.g. positively versus negatively. He remained focused on gratitude and expanding his personal understanding for the world around him including people. He continued to focus on his openness or being open to everything, experience, emotion and people. He chose to focus on love and being loving, primarily.

Strengths

The qualitative nature of this study allows for a unique and intimate glimpse into one man's fragile experience of dying. A strength of the research study is that a rich, thick description of a personal experience of a dying man offers a unique lens for professionals and caregivers, alike, to explore barriers of care and challenges in meeting the unique needs of the dying. Another strength of the research is the researcher used the participant's own words to understand and explore an in-depth account of his experience. A gap in literature can also be considered a strength of this research as there is nominal research using case studies to investigate the subjective experience of dying. The participant had the opportunity to share his experience of dying and expressed finding great meaning and purpose as a result.

Lessons for Living

The following ideals are the lessons I learned from the participant and his experience regarding living and dying and all that is in between.

- The highest privilege we have as humans is to love and be loved...everything else is window dressing.

- Be present. It is a certain state of being that works to ensure we won't squander the experience of living life and living death, but rather honor both.
- Feed your energy with positive things. Develop a spiritual aura in and around us and keep it blooming. It is our essence.
- Protect our energy. Share it with others, but don't give it or throw it away. Dedicate our finite time and energy to all things deserving.
- People are valuable. Don't underestimate the role of persons and individuals in our lives and throughout the span of life. We aren't entirely self-sufficient and we shouldn't be.
- Control your thoughts. Move towards a sense of peace, calmness and love; chase negativity from your mind, body and soul.
- Take responsibility for your state of being. Look to yourself as no one is responsible for your personal happiness or sadness; and then deal with it.
- Memories are healing; let them be. Hold onto the positive and let the negative drift away.
- Success is a state of being that cannot be taken away from us. Put forth effort to earn it and to protect. Gratitude can both source and protect success.
- Be more open, not because of some drastic happening (like death or dying), but because you make an intentional and concerted effort to attain a liberated state of being.
- The state of openness is a major factor in developing an elevated understanding and acceptance of people, places, things and ideas.
- Being present, in the here and now of our lives, helps us to age at a pace that promotes constant personal development through the stages of life.
- The act of being present is paramount in enhancing of experience of both dying and living.

- Find and develop a sense of meaning and purpose at every stage of development. Invest in something that interests you and helps to keep your mind agile; our minds need exercise, too.

The research explored a personal account of a man's experience of actively dying. From the findings, five major themes emerged describing the participant's experience of dying. Providing a rich, thick description of participant's experience, this research can work to improve end-of-life care practices of professionals and enhance the lives of the dying. The findings also provided some lessons to live by.

The following quote articulates the participant's final thoughts on his experience of dying and mortality:

Our vulnerability becomes more entwined with thoughts concerning our mortality, as the years pass even more rapidly. Despite that speed, our awareness of and gratitude for those important to us seems to slow it all down, and it calms and warms us.

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Appendix A: Interview Questions

What Can We Learn from Death and Dying? One Man's Experience

PERSONAL EXPERIENCE WITH THE TERMINAL PROCESS

1. When were you diagnosed with your lung cancer?
2. What were your initial feelings when you were diagnosed with stage four cancer?
3. Along with the diagnosis, professionals gave you an estimate of your time left on earth. Do you feel that the estimate is helpful to the person facing a terminal illness? Do you feel it could cause undue fear in that person?
4. How did the estimation of your time left influence your perspective on your life and future plans at that point?
5. Are you afraid of death and the process of dying?
6. Do you have any fear surrounding your death? If so, why?
7. How does it feel to talk about your death?
8. Do you struggle with questions of the unknown or your understanding of what lies beyond your earthly experience?
9. In your estimation, what would an ideal way to pass on?
 - a. What would it look like?
 - b. Do you have family and/or loved ones with you or do you imagine your passing happens alone?

LIVING WITH AN AWARENESS OF DEATH

10. How often do you think of or are reminded of your terminal circumstance? Daily? Are you able to forget about it at times?
11. How does your awareness of mortality and the final stages of life affect your living?
 - a. Does it motivate you in positive ways? Negative ways?
 - b. How has it impacted your perspective on life or life philosophy?
 - c. How, if at all, has it impacted your lifestyle? i.e. traveling, exercise, independence
 - d. Influenced your decisions?
12. How have cultural and societal views on death and dying influence your thought process about end of life and decisions regarding your preference of care at the end of life? (Death denial or medical intervention to cure the disease)?
13. Why have you chosen to not partake in any medical interventions i.e. chemo, radiation?
 - a. What informed your choice to forego the medical interventions?
14. Do friends/family/people who are aware of your terminal situation treat you differently? If so, in what ways?
 - a. Do your people have difficulty discussing your terminal illness directly with you? Is denial a part of coping with your situation?
 - b. Have you noticed if your people/family/loved ones treat you as if you're a living man or a dying man?
15. What has been the most challenging in this process of dying/final transition?
16. Prior to your diagnosis, how would you describe your emotional and spiritual state of being? Have you noticed a change from then to now? If so, what are they?

SPIRITUALITY AS A RESOURCE/ADVICE FOR LIVING

17. What is your definition of spirituality?
18. What does spirituality mean to you?
19. What role, if any, has spirituality played in your process of dying?
20. What has helped you cope with your terminal illness/death and dying?
21. Do you feel ready to make the final transition? why or why not?
22. Do you feel that it's coming nearer and nearer? How does it tell you?
23. Have you experienced healing from this diagnosis?
24. What do you find to be comforting to you at this stage of life?
25. What do you feel grateful for?
26. What brings you peace?
27. What have you discovered/uncovered about yourself during this process?
 - a. The human condition?
28. What advice would you give professionals and people alike when treating a dying patient or being close with someone who is dying?
29. What is the role of hope during these stages of life?
30. What do you look forward to now in your life?
31. What concerns do you have for the future?
32. What are the contents of your 3rd drawer?

Appendix B: Interviewee Consent Form

ST CATHERINE UNIVERSITY
Informed Consent for a Research Study**Study Title: What Can We Learn from Death and Dying? One Man's Experience****Researcher(s):** Brooke Benson, MSW graduate student

You are invited to participate in a research study. This study is called What Can We Learn from Death and Dying? One Man's Experience. The study is being done by Brooke Benson, a Masters' student at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Dr. Michael Chovanec, Associate Professor at St. Catherine University.

The purpose of the study is to supplement graduate level research exploring the process of death and dying and how understanding the process can positively inform the ways in which people live their lives, with a greater awareness of what "death can teach the living" by understanding and accepting that death is a universal part of the human experience. Through the exploration of your personal account and experience of actively dying, rich insight will be gained. The importance of this invaluable insight will contribute to and provide recommendations for professionals in the medical and social service field, helping to develop and improve health care models and service for people facing the end stages. In addition, this insight can potentially influence patient's healthcare preferences and decisions during these final stages. You are the only participant in this research. Below, you will find answers to the most commonly asked questions about participating in a research study. Please read this entire document and ask questions you have before you agree to be in the study.

Why have I been asked to be in this study?

You were selected as a possible participant because you have been diagnosed with terminal cancer. You are eligible to participate in this study because of your present experience with the process of death and dying.

If I decide to participate, what will I be asked to do?

If you meet the criteria and agree to be in this study, you will be asked to do these things:

- Participate in the first of three in-person unstructured, audio-taped interviews, lasting approximately 60-90 minutes, answering approximately ten questions pertaining to your experience of your illness
- Participate in the second of three in-person, audio-taped interviews, lasting approximately 60-90 minutes, answering approximately six questions pertaining to your awareness of mortality
- Participate in the final of three in-person, audio-taped interviews, lasting approximately 60-90 minutes, answering approximately fifteen questions pertaining to spirituality, vision of a "good death" and advice for others

This study will involve 3 sessions for a total of 180-270 minutes, contingent upon your level of energy and overall health and well-being during the interviews and/or research project.

What if I decide I don't want to be in this study?

Participation in this study is completely voluntary. If you decide you do not want to participate in this study, please feel free to say so, and do not sign this form. If you decide to participate in this study, but later change your mind and want to withdraw, simply notify me and you will be removed immediately. Your decision of whether or not to participate will have no negative or positive impact on your relationship with St. Catherine University, nor with any of the students or faculty involved in the research.

What are the risks (dangers or harms) to me if I am in this study?

There is a potential for a possible violation of privacy as I will be conducting the interviews in your home (you live alone). There is a potential for possible emotional stress as you will be discussing a very sensitive, and present circumstance topic: your approaching death. There is a potential risk for probing for personal and sensitive information within the interviews as the questions are personal in nature. There is a potential risk for a sense of mental fatigue or embarrassment as the you are in stage four of your lung cancer and have diminished energy. You also experience physical pain due to the cancer. There is a potential risk for coercion in that the you may overlook physical and mental distress in order answer/complete the interviews as an act of goodwill.

As a precaution of your privacy, I have provided alternate locations for the interviews to be held. I have explored with the you what it would look like to hold the interviews in your home and you have indicated that your preference is to hold the interviews in your home. As a safeguard for your emotional well-being, mental fatigue or embarrassment and to safeguard potential coercion the you may feel, you have the right to stop participation in the research project at any point without disclosing a reason, the right to waive interviews as the you see fit and the option to decline answering any question in the interview. I will also check in with the you throughout the interview to ask about your mental, emotional and physical comfort and well-being. I have indicated to the you that protection of your physical, emotional and mental well-being is top priority and if I and/or you find the interviews to be too rigorous, the interviews will be concluded immediately. I will consistently check in with your brother, as additional precaution, to gauge your physical, emotional and mental well-being. I will also seek and would need to obtain your brother's written consent because he has power of attorney for you.

What are the benefits (good things) that may happen if I am in this study?

There are no direct benefits to you for participating in this research.

Will I receive any compensation for participating in this study?

You will not be compensated for participating in this study.

What will you do with the information you get from me and how will you protect my privacy?

The audiotaped information that you provide in this study will be transcribed by myself, and personal identifiers will be redacted from the transcript. Upon completion of the transcripts, I will destroy the audiotapes. I will keep the research results on my personal, password encrypted laptop and only I and the research advisor will have access to the records while I work on this

project. I will finish analyzing the data by May 28, 2017. I will then destroy all original reports and identifying information that can be linked back to you.

Any information that you provide will be kept confidential, which means that you will not be identified or identifiable in the any written reports or publications. If it becomes useful to disclose any of your information, I will seek your permission to disclose information to your brother whom serves as your power of attorney, the nature of the information to be furnished, and the purpose of the disclosure; you will have the right to grant or deny permission for this to happen. If you do not grant permission, the information will remain confidential and will not be released.

Are there possible changes to the study once it gets started?

If during course of this research study I learn about new findings that might influence your willingness to continue participating in the study, I will inform you of these findings

How can I get more information?

If you have any questions, you can ask them before you sign this form. You can also feel free to contact me at 612-310-2173 or at bens7507@stthomas.edu. If you have any additional questions later and would like to talk to the faculty advisor, please contact at Dr. Michael Chovanec at 651-690-8722 or at mgchovanec@stkate.edu. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:

I consent to participate in the study and agree to be audiotaped.

My signature indicates that I have read this information and my questions have been answered. I also know that even after signing this form, I may withdraw from the study by informing the researcher(s).

Signature of Participant	Date
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Signature of Parent, Legal Guardian, or Witness (if applicable, otherwise delete this line)	Date
------------------------------------------------------------------------------------------------	------

Signature of Researcher	Date
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Appendix C: Power of Attorney Consent Form

ST CATHERINE UNIVERSITY
Informed Consent for a Research Study**Study Title: What Can We Learn from Death and Dying? One Man's Experience****Researcher(s):** Brooke Benson, MSW graduate student

Your brother is invited to participate in a research study. This study is called What Can We Learn from Death and Dying? One Man's Experience. The study is being done by Brooke Benson, a Masters' student at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Dr. Michael Chovanec, Associate Professor at St. Catherine University.

The purpose of the study is to supplement graduate level research exploring the process of death and dying and how understanding the process can positively inform the ways in which people live their lives, with a greater awareness of what "death can teach the living" by understanding and accepting that death is a universal part of the human experience. Through the exploration of your brother's personal account and experience of actively dying, rich insight will be gained. The importance of this invaluable insight will contribute to and provide recommendations for professionals in the medical and social service field, helping to develop and improve health care models and service for people facing the end stages of life. In addition, this insight can potentially influence patient's healthcare preferences and decisions during these final stages. Your brother is the only participant in this research. Below, you will find answers to the most commonly asked questions about participating in a research study. Please read this entire document and ask questions you have before you agree to your brother's participation in the study.

Why has your brother been asked to be in this study?

Your brother was selected as a possible participant because your brother has been diagnosed with terminal cancer. Your brother is eligible to participate in this study because of your brother's present experience with the process of death and dying.

If you consent to your brother's participation, what will he be asked to do?

If your brother meets the criteria and agrees to be in this study, your brother will be asked to do these things:

- Participate in the first of three in-person unstructured, audio-taped interviews, lasting approximately 60-90 minutes, answering approximately ten questions pertaining to your brother's experience of his illness
- Participate in the second of three in-person, audio-taped interviews, lasting approximately 60-90 minutes, answering approximately six questions pertaining to your brother's awareness of his mortality
- Participate in the final of three in-person, audio-taped interviews, lasting approximately 60-90 minutes, answering approximately fifteen questions pertaining to spirituality, vision of a "good death" and advice for others

This study will involve 3 sessions for a total of 180-270 minutes, contingent upon your brother's level of energy and overall health and well-being during the interviews and/or research project.

What if you decide you don't want your brother to be in this study?

Your brother's participation in this study is completely voluntary. If you decide you do not want your brother to participate in this study, please feel free to say so, and do not sign this form. If you decide to consent to your brother's participation in this study, but later change your mind and want him to withdraw, simply notify me and your brother will be removed immediately. Your decision of whether or not your brother will participate will have no negative or positive impact on you or your brother's relationship with St. Catherine University, nor with any of the students or faculty involved in the research.

What are the risks (dangers or harms) to your brother if he participates in this study?

There is a potential for a possible violation of privacy as I will be conducting the interviews in your brother's home. There is a potential for possible emotional stress as your brother will be discussing a very sensitive, and present circumstance topic: his approaching death. There is a potential risk for probing for personal and sensitive information within the interviews as the questions are personal in nature. There is a potential risk for a sense of mental fatigue or embarrassment as your brother physical and mental capacity is diminished because of his illness and he also experiences physical pain. There is a potential risk for coercion in that your brother may overlook physical and mental distress in order answer/complete the interviews as an act of goodwill.

As a precaution to protect your brother's privacy, I have provided alternate locations for the interviews to be held. I have explored with your brother what it would look like to hold the interviews in your brother's home and your brother has indicated that his preference is to hold the interviews in his home. As a safeguard for your brother's emotional well-being, mental fatigue or embarrassment and to safeguard potential coercion that your brother may feel, you have the right to withdraw consent for your brother's participation in the research project at any point without disclosing a reason, the right to waive interviews as the you see fit. I will also check in with your brother throughout the interview to ask about his mental, emotional and physical comfort and well-being. I have indicated to your brother that protection of his physical, emotional and mental well-being is my top priority and if myself, you or he find the interviews to be too rigorous, the interviews will be concluded immediately. I will consistently check in with you, as additional precaution, to gauge your brother's physical, emotional and mental well-being. I am seeking to obtain your written consent because you have power of attorney for your brother.

What are the benefits (good things) that may happen if your brother participates in this study?

There are no direct benefits to you or your brother for participating in this research.

Will you or your brother receive any compensation for participating in this study?

You nor your brother will not be compensated for agreeing to participate in this study.

What will I do with the information I get from my brother and how will I protect his privacy?

The audiotaped information that your brother provides in this study will be transcribed by myself, and personal identifiers will be redacted from the transcript. Upon completion of the transcripts, I will destroy the audiotapes. I will keep the research results on my personal, password encrypted laptop and only I and the research advisor will have access to the records while I work on this project. I will finish analyzing the data by May 28, 2017. I will then destroy all original reports and identifying information that can be linked back to your brother.

Any information that your brother provides will be kept confidential, which means that your brother will not be identified or identifiable in the any written reports or publications. If it becomes useful to disclose any of your brother's information, I will seek your brother's permission to disclose information to you (as his power of attorney), the nature of the information to be furnished to you, and the purpose of the disclosure; your brother will have the right to grant or deny permission for this to happen. If he does not grant permission, the information will remain confidential and will not be released.

Are there possible changes to the study once it gets started?

If during course of this research study I learn about new findings that might influence your brother's willingness to continue participating in the study, I will inform you and your brother of these findings

How can you get more information?

If you have any questions, you can ask them before you sign this form. You can also feel free to contact me at 612-310-2173 or at bens7507@stthomas.edu. If you have any additional questions later and would like to talk to the faculty advisor, please contact at Dr. Michael Chovanec at 651-690-8722 or at mgchovanec@stkate.edu. If you have other questions or concerns regarding the study and your brother's well-being and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

You may keep a copy of this form for your records.

Statement of Consent:

I consent my brother's participation in the study and agree to let him be audiotaped.

My signature indicates that I have read this information and my questions have been answered. I also know that even after signing this form, I may withdraw my brother from the study by informing the researcher(s).

Signature of Power of Attorney

Date

Signature of Researcher

Date