

**WHO WILL TALK TO ME? AN EXPLORATORY CASE STUDY
ON DEATH AND DYING IN A TALKING CIRCLE**

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This thesis is dedicated to my mother, Lorraine Crockett
and to all the people who have died horrible deaths

ABSTRACT

The aim of this exploratory study was to analyze, from the perspectives of the researcher, a conceptual model of communicative exchanges on death and dying and the conditions under which people talk about this salient subject. The researcher designed and implemented an interactive website on death and dying and conducted F2F interviews with 8 participants so as to identify major death and dying thematic elements in informal conversations. Using a mixed methods approach to decipher and assess potential visitor behaviors and themes online and an offline, results indicated substantial visitors to the website over a period of time but limited and almost non-existent visitor feedback or comments. In F2F conversations on death and dying seven major themes were identified: Best practices for living; what is a good death; what is a bad death; what death means; preparing for death; personal experiences with death; and, death is not the end.

PREFACE

Our time is coming. Why push matters and talk about death, you may ask, when conversational topics should enliven, not depress and when daily urgencies trample on everyday agendas, leaving scarce moments to ponder our inevitability? Death matters. With aging, death thoughts bubble to the surface, parents and friends pay heed to the final bell and our own pesky health issues give rise to mortal doses of a harsh reality: this life will end someday.

The threat of death has followed me into war zones, narrow escapes from abuse, and illness. It has been an unwelcome friend in moments of profound depression where, surrounded by cruelty and evil, I considered its eternal promise. Evading grief was a survival tactic, which failed me when my mother and best friend died within a short time of each other. I was so bereft some days I could barely fathom life outside my hollowed bed. My howl of a thousand wolves and the unbearable heaviness of being ignited a depth of philosophical ponderings previously submerged in my unconsciousness. The fragility of my humanity lay bare and I had no tools to share the complexity and depth of my most intimate feelings.

I was lonely and finding comfort in everyday conversations eluded me. Friends had families and when death happened in those circles, members danced metaphorically around the grieving individual, providing solace and care. I had no family. My mother was my compass, my savior from the orphanage and my light on my darkest days. When my best friend died, I was stung with a reality so terrifying and yet so mysterious, my silence became my defense in a world where casual conversations became a cacophonous symphony of meaninglessness. I was then

struck with an illness that would kill me sooner than I would like. I turned to the Internet as an unlikely ally.

I was an orphan without a best friend but with a new non-human friend – the Internet. I needed to talk and to listen to what others had to say about death and dying, mortality, illness and loss. This solemn adventure evolved into a verdant landscape of inquiry, transforming my loneliness into a personal quest towards understanding the process of death, how we communicate on death and its effects on the choices we make while we are alive.

This thesis was given birth as a way to release inner turmoil, to transcend grief into the realm of meaning of what it means to be alive when we know we will die. It is also an inquiry into how we talk about death in cyberspace and to each other. In face-to-face (F2F) conversations, it is rare to talk about death openly and enthusiastically but the Internet, as a communication tool, is awash in death related websites, support networks, faith based perspectives on death and dying and, even, how to plan a class act funeral. Stories on the Internet inspired me to have a celebration for mom at a swanky four-star restaurant, not a depressing funeral. I invited a catholic priest, a Buddhist monk and a Hawaiian healer to send her off, congratulating myself on being a good daughter who covered all afterlife bases.

This project is unconventional. I need to face facts here. I have struggled through various methodologies and research strategies, trying to be accepted into the halls of academia. I finally understood that if my life is unconventional then it stands to reason my thesis probably will too. Life is good and it will be fine.

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CHAPTER ONE

INTRODUCTION

1.1 Background and Significance

This exploratory case study will investigate the nature and particularities of cyberspace communication and meaningful digital and face-to-face exchanges as it relates to death and dying. As a relevant and vital communication tool, the Internet has evolved into a barrier-free open frontier where mining for essential information and a robust exchange of ideas are commonplace, especially if few people are talking about it offline. The influence of technology appears to be lifting the veil of silence on death and dying as the private becomes public in online ceremonials, streaming funerals and blogs written by people who are dying. Death and dying related issues have exploded on the Internet, crowding the online interactive universe with global dialogues. Death and dying is being discussed in the cyberspace public square, influencing commentaries on public grieving and end of life care. Death education sites, support groups for grieving families, and sites devoted to the loss of a child welcome new audiences – just Google your need and you shall find.

Communication scholars' scant attention to death related communication reflects our collective hesitation to discuss these matters. Research is falling behind the tremendous online conversations taking place. Semiotics, phenomenological and epistemological perspectives gaze in other directions and even family and interpersonal communication scholars are slow to tread on this delicate landscape

called death. The field of health communication shows promise; bridging the gap between social sciences and the health fields, scholars and practitioners have taken the lead in investigating end-of-life communication, palliative care, cultural sensitivity and other communicative issues in emergency rooms, hospice care and family grieving.

If communication is about the ways in which groups and individuals synthesize their immediate and mediated environments, and attempting to make sense of it, then the online universe is saturated with enough material to enrich the communication research field considerably. Technology has altered how we talk, what we talk about and when we talk about it. Interactivity and interconnectivity enables humans to communicate through email, messaging, chat rooms, streaming video and forums on issues they may or may not feel comfortable talking about offline.

Are people motivated to respond to stories and information on death and dying? Are communicative needs being fulfilled or do people, such as myself, ache to be heard? Do people want to have conversations on death and dying and are they willing to be interviewed on video, which could potentially be viewed by hundreds of people? If so, what are the major themes underlying conversational talk on death and dying?

Holistic and small in scope, the significance of this case study lies in its potentiality to discuss all aspects of a multi-media conversational model of how people talk about death and dying in the everyday, what they talk about and why they talk about it. It seeks to offer potential new areas of inquiry in the field of communication, personal growth, psychology, new media and death and dying studies.

Most significant is how communication on death and dying in the everyday may shape our worldview and alter personal changes as well as re-shaping values and moral decisions. How does our awareness of our death instruct human choice in determining how we live? Does death awareness and death acceptance inspire lifestyle challenges, for instance? Would we become more sensitive to human suffering in the world and would the emphasis on material acquisition as a pathway to happiness be trumped by more ethereal propositions on what is considered to be a good life?

1.2 Purpose and Rationale

The purpose of the thesis is twofold: to create, document, describe and analyze a self-constructed ‘talking circle’ on death and dying, using a case study as a research strategy and to identify key themes unearthed in face-to-face digital informal interviews. The study will examine the conceptual and practical elements of what I have designed as a ‘talking circle’ on death and dying. Symbolically the circle represents a non-hierarchical, non-linear way of communicating delicate issues in which people can talk and listen freely and openly without judgment. Borrowed from traditional and indigenous uses of the talking circle as a means to deepen discussion, the talking circle will consist of the blogger and content developer (myself), cyberspace commenters, and eight participants who will engage in F2F conversations which will be videotaped and shown on my website.

To this date, there appears to be little or no research on how death and dying is being talked about in non-threatening conversational situations. I call this kind of talk, everyday life talk or casual exchanges. I define non-threatening as those conversations occurring in casual spaces (as opposed to hospital or hospice).

The purpose of creating a communication model, which I call a talking circle, is to discover who will talk to me, and what they will talk to me about.

With current communication research focusing on end-of-life care, Information, Communication and Technology (ICT) scholarship on thanatology related issues and technology's stature in fomenting end of life discussions, this study takes a different perspective on death and dying talk. Ideally, the study might influence and extend scholarship into the various facets of how death communication is perceived and discussed, providing multicultural, contextual and layered communicative perspectives and meanings on what is unarguably a momentous event – our final curtain call.

In summary, this study seeks to analyze how death and dying is talked about in casual conversations and on a blogger's website.

1.3 Research Questions

I have identified three pertinent research questions, which relate to the design, interconnectivity elements, content and communication exchanges.

RQ1: Will people engage in a conversation about death and dying after interacting with online content on death and dying?

Who will talk to me about death and dying? This question is based on several assumptions: a) though not at the end of life, people are curious about death and dying; b) people are motivated to listen and talk about death and dying for various reasons; c) they will talk less about their personal fears and more about personal experiences with family members and their philosophy; and d) Website blogging, as a multi-dimensional communication tool, is a potentially extensive and

anonymous space to share information and to discuss death and dying, more-so perhaps than face to face conversations.

RQ2: What are the major themes people discuss when they talk about death and dying?

This inductive approach is based on the assumption there are key areas of importance in general discussions on death and dying including concepts of a good life and a good death.

RQ3: If people experienced death and mortality awareness, would they be motivated to alter their worldview and make positive personal changes?

This question is based on a personal assumption that awareness of an issue leads to different lifestyle changes and that, in fact, may lead us to live more conscious lives. This awareness, if ever reaching a critical tipping point, could potentially alter policy directives as it relates to geriatric care, the social net, anti-violence legislation, personal growth and transformation.

These three questions identify key aspects of if and how we talk about the dying process and death. The intention of this preliminary investigation is to advance understanding and new insights into the phenomena of talking about death and dying.

1.4 Theoretical Guidance

The case study does not seek to directly influence or test a model or theory. A sprinkling of relevant theories in the field informing or capturing aspects of the study inspired the shaping of the conceptual design. The theoretical frameworks outlined briefly below have assisted in guiding my initial research questions, elucidated potential areas of communicative inquiry on death and dying and death

acceptance as underscoring new vital potential areas for organizing death related research questions for future researchers.

Ernest Becker's (1973) scholarship on the denial of death states that humans have an innate fear, anxiety and denial over death which may account for the supposed 'taboo' on talking about death and assertions of western cultures living in a death denying culture as opposed to a death acceptance culture. Becker deconstructs human nature, providing a theory of human motivation and posits that our human motivations including quirks and communication pathways are just a compiled mess on how we deal with and repress our demise. The denial of death lies at the root of diverse forms of social motivation and was originally framed as the Terror Management Theory. Becker (as cited in Pyszczynski, Greenberg, Solomon & Maxfield, 2006, p. 349) argued that 'because people deny death and avoid facing it, they seem unfazed by their mortality and readily conform to cultural expectations and demands regarding who they are and how their lives should be lived.' What about when people accept death?

More recently scholars have re-invigorated the theory and, designing a vital new theory on Meaning Management, have asserted that positive psychological outcomes can be achieved through confrontation or acceptance of death, offering a broad range of behaviors from the negative to the positive and in complex and diverse ways (Pyszczynski et al, 2006, p. 356). An acceptance of our mortality may provide motivational impetus for personal growth, which can have positive effects when new information or experiences are integrated into psychological structures (Wong, 2008). Two motivational systems are at play here – controlling fear and promoting personal growth. The role of communication in how we perceive ourselves in relation to our individual and collective acceptance of death is a rich

landscape for potential multi-disciplinary research. I hope to mine information from the conversations, which may (or may not) increase our understanding of the link between talking about death and acceptance of death, meaning making, and lifestyle changes.

Also helpful in designing my conceptual model was how the uses and gratification theory (U&G) provides a relevant lens in how people use the Internet to fill a need while media offers gratification and opportunities for the user. The theory assumes there is an active audience making decisions, they know media content and are goal oriented (Ruggiero, 2000). While U&G has historically been used as a theoretical approach in both studies of new users and new mediums, computer mediated communication (CMC) offers a new vitality to the mix in that it 'permits researchers to investigate mediated communication situations via single or multiple sets of psychological needs and motives (cited in Ruggiero, 2000, p. 28). In a recent study (Trammell, Tarkowski, Hofmohl & Sapp, 2006) examining Polish bloggers through content analysis, the researchers used the U&G theoretical perspective to ask why people blog and their motivations for creating and maintaining a blog. The researchers found that the majority of bloggers needed to talk more than they needed to listen.

While the U&G has been traditionally used to understand uses and gratifications on larger population sizes and mediums, I use these two motivational theoretical frameworks as guides to understand the motivations of the blogger, the digital storytellers and the audience users in my study, attempting to deconstruct and interpret death and dying talk.

Lastly, I am guided by a category of interpersonal communication which begs to be explored, if only briefly, in this study. Some theorists have found that

CMC, as an interpersonal medium, does not lend itself towards sharing emotional content. Hyperpersonal communication constructed and developed by Walther (Bubas, 2001) posits that this type of interpersonal communication is one that appears more desirable in computer-mediated communication than in face-to-face (F2F) communication. It would follow that relational intimacy around a difficult issue or theme – such as the conversation on death and dying – can be developed more fully on-line where the boundaries of ‘talk’ are more expansive, more anonymous and more permissible. Some scholars argue that self-disclosure is a communication phenomenon in cyberspace and that in the absence of nonverbal cues, increased intimacy can occur (Jiang et al, 2010).

1.5 Final Thoughts

The findings from my case study elucidate the need for further investigation into how we communicate on death and dying. Meaning management theory may hold the most promise for future communication inquiries and endeavors. This theory turns Becker’s scholarship on its heels by assessing acceptance of death and the ramifications of that acceptance. I cannot express deeply or passionately enough the wealth of research potential into this arena.

CHAPTER TWO

LITERATURE REVIEW

The thematic literature review relevant to this case study is as follows:

Communication Studies on Death and Dying, death attitudes, death and dying and baby boomers; death and dying on the Internet, social support on the Internet, blogging, talking circles and digital story telling. All topic areas bear witness to the plethora or paucity of death communication, providing a holistic framework of how death and dying is being discussed online and offline.

2.1 Communication Studies on Death and Dying

What has been the role of communication as it relates to death and dying? When asked by a dissertation committee about what death has to do with communication, McIlwain (2012), a PhD candidate, argued for its relevance because life is through the prism of death and cultural and communicative actions as well as decisions are based upon this realization. According to Mcilwain, culture and communication are essential human actions, which provide meaning; the reality of death is the necessary condition for such meaning. The very nature of life and death relate to everyday life, which is a communicative experience. If we can communicate our understanding of death, how will this awareness of our mortality in the everyday affect how we communicate? Mortality forms a key aspect of our sense of self, however submerged in our consciousness and that it can play a key role for authentic self-understanding and the understanding of others (Onof, 2009). Mcilwain is a prophet with a small audience as communication scholars in his field struggled to understand any significance as it relates to death and dying.

In recent years, communicative experiences have been explored, further breaking down the silence barrier on death and dying at least in peer reviewed journals and books. Sense making at the end of life is tantamount to accepting or denying death. A recent study found that the topic of death is avoided in hospice and hospital settings (Planalp & Trost, 2008). Physicians have difficulty providing a balance between sensitivity, news and timing, as the underlying value in hospital settings is that life should be prolonged. The authors asked what the role of communication was in coming to terms with death. Exploring three theories which address this challenge, they found that problematic integration theory, terror management theory and trauma management theory can be a communicative route to finding meaning in death and deepening connections with the living. The authors argued for further exploration of theoretical and applicable communication findings are needed as they may be able to lay the groundwork for effective communication strategies for the over 400,000 volunteers who care for the dying (Planalp & Trost, 2008). Increasingly, principal investigators have been questioning death and dying related communication or lack of at the end of life as well as initiating discussions of death acceptance and death avoidance.

Lack of communication about death and dying is a huge challenge in hospital and end of life care settings. Scholars have found that storytelling eases fear and promotes communication. One of the challenges in palliative care is how to optimize care and assess end of life needs for patients with a terminal illness, as there are often communicative disconnects and vocabulary convergence. Sharing stories and patient narratives often reveal end of life needs which can help caregivers and professionals deliver compassionate end of life care (Arnold, 2011).

Using narrative research methodology, Weinstein (2009) found that

storytelling is important for caregivers and relatives of the dying person. The author was interested in competing and sometimes contradictory stories that people tell as they struggle to understand the death process of themselves or loved ones. People are critical of the dominant medical narrative of dying as opposed to the reality of death and of hospice. Research into the effectiveness of narratives is underdeveloped but some of it has been chronicled including therapeutic writing by hospice patients, which invariably leads to an increased understanding of their death. Weinstein notes that some research has looked at people who are grieving and how their stories can bring out the healing power of narration. The healing process allows the narrators to become the lead characters. People need to appreciate the forces that exist in a persons' experience. As Weinstein points out that there is a range of narratives for the same story and that consistent themes emerge – anger at the medical establishment and appreciation toward the hospice. The analysis of narratives has implications for future communication research, an area of inquiry which I hope to contribute to.

Storytelling as a communicative device plays a powerful role in the family grieving system. How do families navigate on a communicative level? There is little if anything being researched or tested on how families communicate and make sense out of loss. Communication theorists have a long way to go in this area. Potential ethnographic research on families would yield important information as well as auto ethnographic approaches in grieving processes might yield some interesting data. A key premise in communication studies on death and dying is that because humans are social beings and learn through interaction, communication is central and serves a unique function in the grieving process in

terms of how we navigate loss in family situations and how humans cope, renegotiate roles and keep the deceased one alive through communication.

Communication scholars provided an in-depth review of the grief literature (Bosticco, & Thompson, 2005). Organizing a concise and detailed review, the authors suggested general avenues for future communication research including family communication studies on grieving. The senior author of the study recently lost a child to cancer and her work in this field reflected her own response to grief. She suggested auto ethnographic approaches in which 'scholars may use the grieving contexts in which all families naturally find themselves at some point.' Such work is likely to prove personally productive for scholars as it helps them cope and grieve themselves while enabling them to learn something about family communication and grieving for the benefit of other scholars and those in need. (p. 274).

Scholars have also investigated communication challenges in end of life care, which bring to light the formidable obstacles in achieving open communication about death and dying issues. A recent study investigated strength of associations between fear of death, mortality communication and psychological distress. The role of communication was used to identify the complex relationship between fear or acceptance of death and psychological distress to see if there were any distinguishable differences in communicative moments. While there was a fear of death and depressive symptoms, it was unclear if mortality communication could enhance their wellbeing (Bachner, Y.G., O'Rourke N, & Carmel S., 2011).

In summary, this brief overview in communication studies bears commenting on. For the most part communication studies are focusing on end of life care, grieving processes, and family and personal communication as it relates to the

end of a life. As Thompson states in her death and dying bibliography (2014), there are very few articles on death and dying from a communication perspective.

Lamenting aside, research in the communication field on death and dying holds much promise. Thomas states the conceptualization of ‘more is better’ does little to expand our collective understanding on the processes of communication during terminal stages. We are only at the beginning of a rich field of study. The proposed study seeks to look at the dynamics of talking about death and dying in everyday life (not at the end of life) – an area not even being explored.

2.2 Death Attitudes and A Good Death

When and if people talk about death and dying, they may talk about their attitudes and what they consider a good death. This section provides an overview of scholarship in this area, highlighting cultural considerations on death acceptance or death avoidance.

Death and dying are universal expressions for all cultures and groups, made complex and profound with issues of body, mind and spirit (Warren, 2005). Ancient texts such as the *Tibetan Book of the Dead*, *The Egyptian Book of the Dead*, and the *Celtic Books of the Dead*, attest to the historical importance of death and dying and the care in supporting the dying person (Institute of Energy Medicine, N.D.). Holistic approaches and palliative care modalities were, and continue to be part of the cultural norm. Concerns, fears of the unknown, reluctance to leave behind family and friends, desires to live were universal issues which continue today (Groves & Klauser, 2009).

Numerous cultures throughout the world continue to accept and communicate about death and dying as a natural part of life. For example, older

Koreans view a good death as being surrounded by their children, not being a burden, dying after all parental duties are performed and completing a natural disease. (Lee & Ho, 2009). A good death is dying while sleeping, surrounded by family and dying with no pain. For young Koreans who think about death, a good death was being able to say they had beautiful lives and they wanted gratitude and peace and all ages stated they wanted to say that life was beautiful, without regret (Lee & Ho, 2009).

Historically while death and dying had strong communal and spiritual components assigned to the philosophy, process and actual death, western societies in the post industrialized era individualized death and dying, segregating death into a silent dark closet. In America, the First World War was the dividing point between acceptance of death and denial of death. The numbers of dead were overwhelming, a retreat from death and a descent into silence resulted. American culture in the 20th century has been a century of death avoidance partly due to increased secularization and medical advances (Kansas State University, 2012).

If the First World War marked the beginning of denial of death, the death of Princess Dianna in 1997 marked the beginning of increased public acceptance of death, a return from the tribal communal mourning to public mourning. 'When Dianna died, there was no place to hide' (Berridge, 2001, p. 58).

Measuring death attitudes as well as a universal construct on a 'good death' proves elusive and challenging. How cultures define a good death, or a good life for that matter is a difficult endeavor as there is great plasticity of how humans view circumstances of life and death and the relativism of the terminology 'good' and 'bad' (Hanks et al, 2009) between cultures and communities. The conceptual framework of a good death has been given some attention with strong agreement

that the concept was highly individual, based on perspective and experience and changeable over time (Kehl, 2006). Given the multitude of descriptions and discussions on the subject, an overall general description, sufficient for the purposes of this discussion is that a good death is ‘one that is free from avoidable death and suffering for patients, reflecting individual preferences for how a person wants to die.’¹ It is also useful to include that a good death is a death that self and others view as a comforting and ‘smooth’ transition from a living to a nonliving state.²

Walter (2003) argues a good death depends on three things: the extent of secularization, the extent of individualism and, lastly how long a typical death takes. He argues that a return to the communal in contemporary western societies might be occurring because death is becoming a shared experience. (I will argue this shared experience is being strengthened by ICT’s). Shared experience and a return to death with dignity re-emerged with the hospice movement in the sixties. Local communities, driven by the mantra that every human being has an inherent right to live as fully and completely as possible until the moment of death, initiated this movement which enables patient-centered care that is empowering, unconditional and non-judgmental (Leming, 2003). Movement leaders sounded the clarion call for getting professionals, non-professionals, family members and the patient to talk about death. Kubler-Ross and other pioneers provided a stark reality – that the unwillingness to talk about death and pretending that patients could recover made the death process terrible (Maranz Henig, 2005).

¹

² The definition of a good death was utilized various definitions from dictionaries including Segen’s Medical Dictionary and McGraw-Hill Concise Dictionary of Modern Medicine. After reading several definitions, the composite I created integrates most secular descriptions.

The concept of a good death has changed over time and continues to change within and between cultures and societies. Attitudes about death are shifting and yet conversations continue to be segregated to end-of life care in hospital or hospice settings and in grieving contexts. In a *New York Times* article, Robin Marantz Henig (2005) anguished whether or not humans will ever arrive at a good death. Haunted by memories of his father dropping dead on the toilet, he fears the unknown, bemoaning that people are still not talking about death and that silence and our unwillingness to 'look it straight in the face even as we make noises about accepting it' has ramifications for end of life care and the denial of death.

We may be witnessing the disintegration of a western death taboo but silence still reigns. While there is a proliferation of death and dying graduate programs, academic mortality research, and entertaining books on the afterlife, bringing greater awareness to death in public spaces, the topic of death is still considered an inappropriate discussion at the dinner table or with parents who resist acceptance. Death for some means the re-enchantment of death as part of our spiritual evolution as it is no longer the taboo it once was (Lee, 2008). For some writers, death is a defining aspect of human existence, a key to our commonality and that once a person starts thinking about death, maybe more loving can occur, years not wasted, bringing us closer to our purpose in life (Pugh, 2012).

Our society needs to approach death and dying as part of life and there needs to be a more expansive conversation so that humans will be sensitive to life in all its complexities (Uhlmann, 2008). Communication has a big role to play in supporting a death acknowledging culture rather than a death denying culture. Van Dyck (2011) asks how do we become familiar with the topic because while fear is a big reason why people don't think or talk about death and dying, the bigger

reason is people do not have the words, the familiarity with the topic that helps to find a natural segue to start. Telling stories, starting the conversation not at the end of life but in the everyday may slowly move us to a death accepting culture. Don Schumacher, CEO of National Hospice and Palliative Care Organization, states that society is more of a death-denying society that it ever has been in the past because everyone is participating in a myth that we can just keep on going (Pettypiece, 2013). With suffering and death everywhere, very few people want to talk about it and will utilize all means to delay the inevitable. Not talking about it, will not make it go away – death is part of our life journey (Fanning, 2011).

It may be so that we will deny and delay the last curtain call but columnists are taking the charge in discussing death, sharing sentiments similar to myself. Carol Smaldino (2013) says that baby boomers like her will bring the topic to a new level of accessibility as they have done on other issues. She states that she needs to find ways to talk about it that ‘don’t end in smiley faces or slogans like everyone fears death, something that isn’t even true on its own’ (para. 8).

2.3 Death, Dying and the Baby Boomer Generation

We do not have a framework for how to enhance conversations on death awareness and death preparation and lack conversational cues on how to talk about death as part of everyday life. Things are slowly changing, possibly due to the baby boomer generation who are known to be leaders in social change, dominating the cultural, political and economic landscape for six decades (Kadlec, 2013). Kadlec outlines the major death related concerns of baby boomers including encouraging broad support and open communication from medical staff; desires to minimize suffering and find closure; controlling the dying process and emphasizing

spirituality and deeper meaning. The boomer generation is not only likely to dominate the conversation in health care advances but in health care approaches and decision-making because these 75 million people have dominated American life for decades (Barr, 2014). Canadian baby boomer desires including wanting to live forever, die in their sleep and pain free and, most importantly, die with dignity with both caregivers and recipients of care having positive attitudes (Pullman, 2004).

Baby boomers may be leading the charge because, as cultural historical evidence shows, they like to take charge but they are also caring for their parents who are dead or who will die in the coming years. Added to that, by the year 2030, approximately 5.3 million baby boomers will be reaching the end of life (Kaplan, 2005).

In a humorous article, a news writer stated that historically baby boomers turned every personal experience into a national trend. (Ohman, 2013). The boomers had this propensity to be leaders in everything from saving the environment to growing hair long and having multiple sex partners. Ohman suggests they are leading the conversation about death in ways once thought unimaginable. By having death dinners, which he describes as having a tasty group meal and 'having a solid rap session where meaningful, beautiful feelings are shared' like the Big Dessert. He then goes on to share about a baby boomer Death Dinner participant who wanted his children to scatter the ashes around a favorite mountain in Tibet, which the writer considers to be the ultimate baby boomer conceit.

Indulgent or not in their wishes, baby boomers are taking the lead as they have in other areas of contemporary culture. Current predictions on baby boomers and health care include salient ideas on how baby boomers will shape the near

future as it relates to death and dying. Among these are that baby boomers will live longer and seek out technologies to do so and that they will be in charge and will seek more control over the dying process, allowing time for spiritual closure and reconciliation and choosing comfort focused care which allows one to die with dignity. Like founders of the natural birth movement, baby boomers will start an end of life movement with more humanization and intimacy in the death process. Death will become de-musicalized and be viewed as a natural event that should be managed in natural settings. (Williams-Murphy, 2012).

These concerns translate into increased personal conversations and potential policy changes in the health care system. Hundreds of people are partaking in ‘death talk’ dinners hosted by baby boomers. Communicating about end of life choices seems to be a major concern. A new initiative, called “Let’s Have Dinner and Talk about Death’ was launched and on August 24, 2013, hundreds of death dinners were held in 15 countries. To help launch the conversation, the founder Michael Hebb, a fellow at the University of Washington offered readings and videos on death as well as talking points on his web site. These death dinners are breaking the taboo on death conversations as well as initiating conversations on end of life directives and death desires (O’hara, 2013). Death cafes are sprouting up. Birthed by baby boomers, most of the attendees worldwide are baby boomers born between 1946-1964. Many of the participants are experiencing the death of their own parents, shaping their own end of life days has become a priority concern.

As we talk about death and dying more, communication scholars will be more likely to take on a once forbidden and under-researched communication area. Will this have ramifications for the choices we make in life? And in that regard, what will constitute a good life? As a baby boomer and a lifelong social justice

activist, my interest in these matters, has moved from passive interest to aggressively being part of the conversation as well as part of finding solutions to the many death related challenges baby boomers face.

2.4 Death Acceptance and a Good Life

Ernest Becker's theory that our basic motivation for human behavior is the need to control our most basic anxiety – the fear of death – has proven to be both resilient in terms of evolving theoretical power as well as inspiring a new generation of terror management theorists who have considered other possibilities. If our refusal to acknowledge our mortality leads us to such morbid actions, violence and denial, what does death acceptance look like? Would there be a clarion call to live a fuller, more meaningful life?

What is not a universal given is what the 'good life' constitutes. Like a 'good death', 'the good life' evolves throughout an individual's life span. For some it is the American dream, a high standard of living, and for Kanye West, a good life means living life drama and worry free. If you stack religious values into the equation, the 'good life' becomes a rich tapestry of cultural, religious, societal and individual values. Most recently, *Psychology Today* (Howell, 2013) highlighted a study that showed that self-development increases happiness, which is often equated to the good life. The researchers asked users of Beyondthepurchase.org, how they defined the 'good life.' It was found that the majority of users defined it as developing personal strengths and contribution to others and that well-being and the 'good life' was synonymous to a certain degree.

According to a recent scientific study, thinking about death can be good for the soul and the well-being of an individual (Society for Personality and Social

Psychology, 2012). Researchers admit that there has been very little understanding in how death awareness in everyday life is capable of positive motivating attitudes and behaviors (Vail et al., 2012). He cited numerous examples of experiments that suggested a positive side to reminders about mortality including promoting better health, sustainable positive behaviors and empathy.

On September 11, 2001 a tragedy of horrific proportions took place at the World Trade Center, a mile away from my own residence. The responses varied from a fear of death being played out on political talk shows to increased aggression towards hostile nation states to torture to outbreaks of violence and discrimination against marginalized peoples. As part of this unfolding drama and experiencing a loss of personal possessions and watching people jump from the top floors, I also witnessed an empathy and endurance of the human spirit of New Yorkers and citizens around the world. As a psychologist points out, there were altruistic responses as people talked about personal growth, a need to understand human diversity and a desire for non-violence and peaceful communication not only in their personal lives but on a global scale (Neimeyer, Wittkowski, & Moser, 2004). Death inspires fear but it also inspires positive reflection and desires for themselves and humanity. While there are correlates to death and anxiety, pioneering research and emergent conversations are taking place on the relationship between death acceptance and positive behavioral responses and actions. Part of death acceptance is an ability to talk about it (even if it is to yourself!).

In a seminal study designed in 1994, a model of death acceptance was formulated which had three components: neutral acceptance which sees death as a part of life; approach acceptance which suggests a belief in an afterlife and is focused on a future perspective; and escape acceptance which comes into being

because of unhappy and unrelenting life experiences which make death look like a welcome alternative. The model focuses on the prospect of death and, while limiting, offers a beginning of a conceptual relationship between life choices and reality and acceptance of death as it incorporates mortality into a contextual web of meaning (Neimeyer, Wittkowski, & Moser, 2004; Wong, 1994). These and other models as well as findings point to inconsistent data and moderate correlations between an accepting attitude and life satisfaction. Some scholars have found no correlation between acceptance of death and positive behavioral outcomes including increased self-esteem. As Neimeyer points out, much research still has to be done in terms of refining statistical techniques, creating incisive designs and more systematic engagement with the ‘problem of death in human life’ (2004).

Our capacity for meaning making and social construction as it relates to acceptance of death and life success is great. How we find meaning in death has important implications for our well being and the well being of others. As Wong and Tomer (2011) point out, death defines personal meaning and determines how we live and clearly articulate that now is the time to focus on the process of death acceptance. The authors stress that it is time to talk about death that is humanizing, life enhancing and liberating and that research is needed on a good death which could prove to be fruitful for the positive psychology movement. The authors state that humans may be more respectful and more compassionate. Wong’s (2008) experimental model of approach and avoidance systems in dealing with death has two complimentary tendencies resulting in two different motivations and life orientations.

Our current cultural tendency to seek security and avoid pain and suffering is defensive and protective. Conscious and unconscious defense mechanisms

safeguard us but do they help us to live a full, productive and meaningful life?

Wong (2008) cites that the other motivation is an approach system to dealing with death and anxiety and is concerned with worthwhile life goals and dealing with negative roadblocks. Wong reworks the terror of death into these diverse systems and states that the terror of death can teach us what really matters and how to live authentically. The human quest for meaning and spirituality takes a front row while the anxiety and defense system take a quiet seat in the back.

Humans can most likely never be free from death anxiety. Scholars are now saying that it is possible that death acceptance can set us free from anxiety and live with purpose and vitality and that this acceptance can be a cornerstone for a good life (Tomer, Eliason, & Wong, 2012, p.69).

It is the positive orientation that I, as researcher, am interested in. The Meaning Management theory as opposed to the Terror Management Theory is concerned with essential questions of how a human should live and how they can live a fulfilling life. (Wong, 2008). The positive life orientation focuses on transformative confrontation with the human condition in its totality and seeks to maximize meaning, joy and fulfillment. According to this perspective, we can either face death with either hope or fear and we can be concerned with death or we can be concerned with life. The choice is ours. The crucial aspect of this bold new direction in reframing terror and denial of death, is that if we review death as a reminder of our mortality, death anxiety can not only be mitigated by the potential for self transcendence and self-actualization can increase substantially.

Death awareness and mortality researchers have stated that scholars should "turn attention and research efforts toward better understanding of how the motivations triggered by death awareness can actually improve people's lives,

rather than how it can cause malady and social strife." Write the authors: "The dance with death can be a delicate but potentially elegant stride toward living the good life" (Vail, 2012).

A vital part of understanding death awareness and how it relates to human potentiality and positive human development is to uncover significant themes underlying death related discussions in everyday life. By talking about death, we may be able to uncover the hidden fears and aspirations of people, who through sharing and conversing on this issue, directly or indirectly are aware of their mortality.

2.5 Death and Dying on the Internet

Rapid developments in information and communication technology have had an impact on attitudes and communication about death and dying. There is an expansion of death and grief moving from private to public spaces and a shift has taken place primarily because of communication technologies (Gibson, 2007). Death images are mediated by the visual and communication technologies as well. A growth spurt in communication technologies has emerged, enabling people to share online about intimate and private experiences of self and others.

How people grieve and talk about death has changed considerably over the years. Grieving for the loss of a loved one was once a private experience. The role of how the Internet mediates death can be viewed in the Michael Jackson death. People were empowered to grieve in ways that they could not privately. The online Jackson memorial had an individual stamp. Social media is facilitating traditional grieving states as well as enacting social change in context that are themselves part of a wider reformulation of the relation between the public and the private

(Sanderson & Cehong, 2010). Technological advancements and software have allowed thousands of individuals to share grief online. There are thousands of online memorials and memorial websites, offering empathy and support of bereaved individuals. The bereaved person who organized and set up Web Memorials often reported that on-line friends were considered more supportive than the people in their lives (p. 330).

The Internet can provide a sense of community between people about issues they care about. People blog on their illnesses, which allows families and strangers to keep up with their prognosis and process. There are even online live memorials and funerals so that people who live far away can watch the funeral through the comfort and distance of their devices. The private is becoming public. The web is providing a space for opening up conversations between diverse groups. Socially problematic grief or illness narratives are providing an unprecedented arena for presenting alternative or marginal views and for resisting dominant views on privacy, illness and death (Walter, 2011).

Early articles in studying the effect of the Internet on offline relationships and degrees of isolation painted the darker aspects of Internet culture. More recently the increasing volumes of literature suggest that Internet culture is favorable for social interactions online as well as offline. In a recent study on online memorials (Roberts, 2004), it was found that memorials can aid in shared grief and enhance relationships and communication about the dead. While online communication about death and dying cannot be a substitute for direct communication, studies have found that the blending of interactions provides more support for the bereaved (Roberts, 2004). In what ways does technology provide a forum for rituals otherwise performed in non-mediated environments?

Evidence of contemporary practices of mourning has more virtual connectivity and greater technological access and, from that perspective, people never really die. People are able to visit with the dead and engage through comments and postings. The dead can live in a virtual world. Haskins (2007) suggest these areas of investigation can provide interesting future research on networking sites and their uses. Interactivity has the potential to embody one of the biggest potentials in cyberspace, allowing new discussions, opportunities and online rituals (p. 406). Cyberspace allows for interactivity on issues related to death and dying in ways that traditional media was not able to do. In online obituaries, there is more open space to discuss issues and to express feelings, offering more engagement between users than in traditional media where gaps in coverage, issues of exclusion and limitation of space exist (Hume & Bressers, 2009).

There are many contributing factors as to why conversations on death and dying may seem to be more prevalent on the Internet, a research venture for future scholars. What is known is that these conversations cross inter-generationally, inviting a broad range of audiences, participants and content creators who discuss mortality, the death of loved ones, friends and acquaintances. The question for future generations of scholars – ‘will the increased and open discussion of death and dying on the Internet lead to a culture of death acceptance and, if so, how will this affect the world at large?’ - is a question in which scholarship is in its infancy. Although my proposed case study is small in stature but bold on promise, I hope to contribute to the evolving scholarship on death and dying on the Internet.

2.6 Social Support on the Internet

The literature review on social support provides ample evidence that online support networks thrive especially when it comes to illness including cancer and depression. These issues, difficult to discuss in offline everyday life conversations, find a home with millions of people worldwide who seek help, companionship and advice on thorny issues. Recent studies on the role of cyberspace and social support indicate that computer mediated communication and forums provide social support in all its complexities. 28% of Americans who use the Internet participate in online support groups and about 58% of cancer patients use the Internet for information and support. According to the Beaudoin (2007), Internet use leads to increases in social support and community building, thus alleviating feelings of loneliness, depression, and anxiety.

The Internet offers valued added communication alternatives for people experiencing illness and loss. McLaughlin (2007) conducted a study on social networking and young cancer survivors and found that youth used a social networking and video sharing intervention program as a way to fulfill needs, which were unmet in their 'offline' lives. In another study on bereaved mother's experiences of peer support via the Internet, it was found that there was extensive emotional, community and cognitive support and that the online discussion forum was a viable alternative to face-to-face communication (Aho, Paavilainen, & Kaunonen, 2012).

While it is still undecided if cyberspace can provide social support or have the same value as offline support, it can be shown that technology has impacted human lives. The dynamics of CMC includes a sharing of thoughts, fellowship and interests. (Muncer et al., 2001). As websites have moved from the domain of medical professionals to self help and self-searching sites, the question of whether

cyber networks enhances social support and social support will generate new lines of thinking and scholarship (Drentea & Moren-Cross, 2005).

This short literature review on social support provides ample evidence that online support networks thrive especially when it comes to illness including cancer and depression. These issues, difficult to discuss in offline every day conversations, find a home with millions of people worldwide seeking help, companionship and advice on thorny issues. Technology is neutral, it is what we do with it, and how we take advantage of its neutrality to advance conversations, which are difficult to maneuver in offline environments.

2.7 Computer-Mediated Communication and Blogging

Blogging is a democratic avenue to claim our voices and share with the world our thoughts, ideas, products and services. Our voices and our conversations have been extensively researched in communication hemispheres most notably through the lens of computer-mediated-communication. The dynamics of CMC includes a sharing of thoughts, fellowship and interests. (Muncer et al., 2001). Blogs, as a form of CMC are perceived as tools to further engage with people, offering people new relationships (Singh, Veron-Jackson, & Cullinane, 2008). As previous studies have shown and which have been outlined above, the Internet is a communicative value to reduce isolation, loneliness and to find like-minded people through the various mediums of CMC. Blogging about illness and chronic pain has been shown to increase connections with others and advance a sense of purpose to help others. In a study conducted by Rains et al (2011), it was found that support for health related issues was increased when the number of blog posts made by bloggers was positively associated by proportion of posts and reader comments.

Blogging can be a cathartic experience and is perceived as a form of social support from other community members (Yeshua-Katz & Martins, 2013).

Blogs have historically been used to document intimate revelations, experiences and thoughts as they related to an individual's life (McCosker & Darcy, 2013). Approximately 8 million people have created blogs, which has attracted the research community in huge numbers (Pew Internet & American Life Project, 2004). Blogging traits and reasons for initiating blogs include releasing and mitigating emotional tension, expressing opinions, and seeing others' opinions. A study on gratifications showed that a significant number of blogs were created to serve personal expression, with the end result of experienced gratification and feelings of self-fulfillment (Papacharissi, 2002). In an overview of blogging, Chung and Kim (2007) stated that blogging can be used beneficially for emotional management. Using a case example of cancer patients, it was found that amongst patients and between patients, families and their allies, blogging is an important component to manage life and serves as a positive social and interactive communication tool.

In 1996, Timothy Leary, a baby boomer pro hallucinogenic hero threatened to broadcast his death and dying process on the Internet causing, what I suspect, the world's first global sensation on a public death. In the end he didn't but according to his friends, made good on a promise to 'give death a better name.' Since that time, blogs on death and dying have surfaced. According to the Blog Catalog there are over 200 blogs with death and dying related themes and a cursory look on Google illustrates that individuals and couples are writing about their own process of dying during a terminal illness, a portrait of a dying mom, and scattered thoughts of dying people written as far back as two years ago.

The promise of blogging lies in its ability to claim a personal voice and to share that personal voice with the world. The technology is there but whether or not people are actively communicating and exchanging on life's final frontier, depends on several factors, not the least of which is finding a willing and talkative audience and online friends.

2.8 Claiming our voices: Talking Circles and Digital Storytelling

2.81 *Digital Storytelling*

Storytelling is the sharing of events and accounts and have been used in all cultures to educate, to preserve culture and instill ethical and moral values. Digital storytelling is the bridging of this great oral tradition of sharing with new digital technologies. The practice of digital storytelling is the sharing of personal narratives through photography and video, composted collages and recorded voice-overs (Airutz, 2013). The rise in digital storytelling and participatory media offers many opportunities to share stories whether it is from marginalized communities or salient issues, those ripe for discussion. It is the authentication of voice, which is integral to individual and collective flourishing and social inclusion (Dreher, 2012).

Digital stories can be offered as a forum for individual narratives. It has been shown that creating personal stories offered enhanced understanding of a health issue, which provides a tool to share messages in the communities (Cueva et al, 2013). The healing power of digital storytelling has been showcased in Native communities where individuals have shared profound stories of their lives while learning how do create digital stories (Intergenerational Native Storytelling Project, 2011).

2.8.2 Talking circles

A talking circle is an indigenous method for conducting a group process and making decisions. A talking circle comprised of Comanche women and health workers were utilized to understand the barriers and beliefs as it related to breast health (Haozous et al., 2010). Circles are considered a traditional instrument of communication for dealing with conflicts as well as a place to harness wisdom, to feel secure or seek comfort. The circle usually consists of a number of people to share ideas, cares and energies in ‘total unity and a sacred connection to one another’ (Paul, n.d., para. 1)

The talking circle is a method that provides a respectful, orderly and meaningful social context for sharing views. Modifications of the circle include a facilitator who guides discussion and selected topics (Kholghi et al., 2012). Talking circles are employed as a traditional method of group communication in native communities and these approaches allow people to allay fears, build collaboration and trust. By allowing people free expression, those in the circle are empowered to find their voice. The underlying value of a talking circle is the awareness of the interconnectedness of the ‘sacred’ that binds people together and that what we do to the web of life, we also do to ourselves (Voices Compassionate Education, n.d.). Talking circles empower people to be full participants in the discussion and can lead to discussions that further elucidate issues as well as be self-reflective. There are guidelines, which are not unlike computer mediated communication except that the foundation lies in respect and honoring of another voices, rather than to the limits of computer technologies. The guidelines include that when a person talks, they are not interrupted and that people listen to the speaker. In traditional talking

circles, there is no hierarchy and people do not have to worry about social structure or class ("wiseGEEK", 2003-2014).

In one recent talking circle, native elders felt comfortable in talking about a difficult conversation – their use and misuse of a drug (Momper, Delva, & Glover Reed, 2011). It differs in the western traditional forms of communicating in that there is a sense of communication and interconnectedness that is not found in some F2F communication. The talking circle can become a rich source of identity, interaction and information (Kaminski, 2006).

In recent years, the talking circle concept has been discussed within a context of the 'digital age.' A mediated talking circle is an experiential digital, media environment, which provides a ritualistic approach to community interactions and discourse. The goal is to provide a safe environment and allow participants to concentrate on a particular topic. In one particular situation, the mediated talking circle allowed students to express their thoughts about a special topic and were encouraged to build community with each other through the uploading of media elements, camera usage and video projectors. This mediated talking circle was designed using a mixed reality system called the Situated Multimedia Arts Learning Lab, which allowed a relationship between digitally mediated components and a physical F2F learning context (Martinez, Kep, Birchfied, Campana & Ingalls, n.d.).

Websites are starting to utilize the foundations of the talking circle. In a 6th grade class webpage, the teacher writes to the class that they are becoming responsible digital citizens and this is where the class will have their online talking circle to reflect on topics and deepen an understanding of those topics (Voisin, Mrs. & Rossi, Mme.). White Bison, a non-profit American Indian charitable organization

based in Colorado Springs, has been offering healing resources to Native Americans. In 2011, the organization started an on-line, voice based virtual talking circle each evening on the net where people can talk about sobriety and recovering ("White bison speaks," 2014). A Teen Talking Circles Blog has been initiated online to provide young people with a safe space to reveal their dreams through video and discussion blogs (Wolf, n.d).

It is important to remember that the talking circle construct for this case study is, in actuality, a communication model I designed which reflects the values and priorities of Native talking circles.

2.9 Conclusion

The literature review provides a kaleidoscope into the ways death and dying is being viewed and talked about in popular culture, communications and cyberspace. While it is considered a hot topic in some circles, most notably the baby boomer generation, a paucity of communication research studies exists which would shed light on how death and dying is talked about amongst those of us who are alive. No conceptual models exist as to where one might look at communication exchanges on this essential topic thus giving credence to creating an exploratory and inventive model of communication on death and dying in everyday life.

CHAPTER THREE

MATERIALS AND METHODS

3.1 Introduction

This chapter describes and explains the quantitative and qualitative research process that informs this study. ‘Who will talk to me’ is a case study utilizing surveys, web analytics, conversations and exchanges to assess if people will talk about death, and if they do, how they talk about it. I developed a multi-method research strategy that supported the descriptive, exploratory and thematic nature of the research. This chapter discusses the preliminary processes, the overall design and multiple data collection and analysis activities used to answer the three research questions.

The entire process was a dynamic experience, involving multiple data sources and participants. Figure 3.1 illustrates the conceptual model of the project.

Figure 3.1 Case Study Design



3.2 Research Design

In order to explore who and what people talk about as it relates to death and dying, this study utilized a multi-method case study approach. Utilizing an inductive research approach, and moving from specific observations to broader generalizations, my intent was to identify common themes in talking about death and dying in everyday life and to formulate an initial hypothesis. Concepts employed are open-ended and process oriented. I sought to understand meaning, form and content as it relates to talking about death and dying in everyday life, which meant that subjectivity and bias were inherent in the study.

The study was primarily undertaken to investigate who will talk to me about this subject. I created a conceptual model of death and dying communication – a online and offline communication model that reflects the ambience and the objectives of indigenous talking circles. I also identified communication themes when talking about death and dying in the everyday. I constructed a virtual and face-to-face ‘talking circle’ because an existing communication model, which incorporated F2F and online discussions, did not exist.

While the case study as a research approach has generated debate as to authenticity, veracity and usefulness, especially in obtaining results which can generate theory, I chose this design as I wanted to utilize my creative artistic skills and develop this conceptual model of talking about death and dying in everyday life. It was to be my primary source for yielding results in the case study. Yin (2003) states that the case study is beneficial when a researcher seeks to answer the “why” and “how” questions and when you cannot manipulate behaviors of participants.

This study is a holistic investigation into previously uncharted territory, comprising of different actors, layers and parts. Not to convolute matters, the case study is unique in that it utilizes a multi-prong approach in how we talk about death and dying and it does so by analyzing a constructed model of communication exchanges. The study looks at sub-units separately which are situated within the case analysis. Single case with embedded units has the possibility of illuminating the case because of the rich, diverse analysis (Baxter & Jack, 2008). Exploratory and descriptive in nature, the case study is appropriate, as the focus – talking about death and dying in everyday life– is an underdeveloped research path in communication studies.

In summary, the needs for flexibility, to utilize multiple techniques and sources of inquiry and to assess a broad spectrum of conversational exchanges lend itself towards open and fluid methods of inquiry, thus potentially yielding a robust area of exploration for future research endeavors. As I mentioned earlier, the case study is marginally guided by theoretical considerations, which I do not prove or disprove. Rather, I am inspired to enter into uncharted territory and understand, if only minimally, how people talk about death in dying and if they will talk to me in cyberspace.

3.3 The Talking Circle Model

Because this research study does not have an implicit or explicit theory that predicts a phenomenon under study, my constructed model was used to guide the design and methodological choices of the study. Figure 3.2 represents a visual representation of the communication model (talking circle), which can potentially be applied to conversation deemed difficult to talk about. It is not a hypothesis -

building model as much as a way to categorize the diverse elements of a discussion. The overlaps of circles represent the communication flow and relationships between the variables of interest, or what could be called a unit of analysis.

In the sections below, I will describe the initial processes of the project and then explicate data collection methods.

Figure 3.2 Model of a Death and Dying Communicative Talking Circle

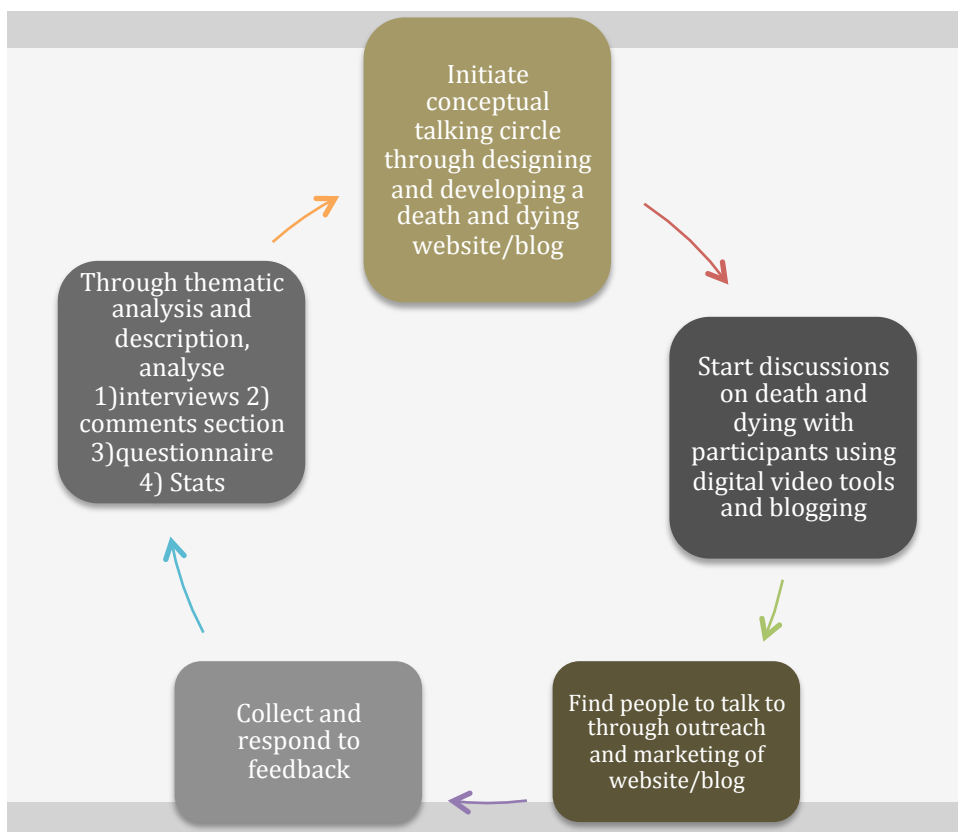


3.3. Initial Processes

This study was conducted from a primary source base - a multi-media interactive project whose purpose was to develop a website that could embed the multimedia elements and support different communicative formats and lines of inquiry. Before designing the multimedia project, I assessed the most efficient avenues to reach the final destination: crisp and concise answers to my exploratory research questions. It required creativity so as to capture death and dying related themes and it required a linear data driven approach.

Initial interest was generated from a graduate class I took in multimedia; at the time I was experiencing the beginning stages of grief, which would continue unabated as more members of my community circle died. For this specific study I created a new website in which the interactivity would support the cyberspace talking circle model. As part of my initial design, I also felt that digital stories should be added, giving another layer to my study. I wanted F2F interactions, which would be recorded and edited into a digital story, then posted as a video online. Figure 3.3. illustrate the general processes undertaken for the case study.

Figure 3.3 Who will talk to me?



Website

The process of building a website from scratch seemed daunting. I wanted to communicate with people but had to be willing to learn the technology, which up to

that point had eluded me. I found a webhosting provider after reviewing what hosting services were the best and were reasonably priced. I then created a domain name www.journeytotheunknown.net, which reflected both my personal sentiments on death and dying, and the conversation I wanted to have with other people. I also felt that the URL was easy to find and remember.

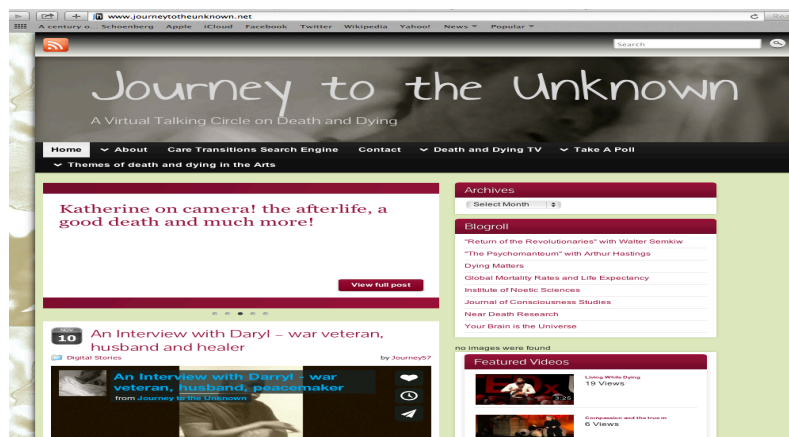
I taught myself design basics, web layout, learned basic HTML language and chose a template on Word Press. My online goals included creating navigable high quality material that was diverse enough to tweak the heart and mind strings of new users. After experimenting with different designs I decided on the various components of the website which would potentially solicit and elicit responses. The following were processes I utilized to enhance interactivity on the website.

1. **Content planning and implementation** My goal was to provide a content rich website and though I was limited by a lack of professional web development training, I wanted to cover a wide range of topics related to death and dying which would ultimately include art galleries, interviews, interactive features, stories, and a blog, which included announcements of new digital stories. I created original content as well as resources. My home page included the recent blog which was usually a new digital story, featured articles, recent comments and a Blogroll which was a combination of resources, websites and additional articles. My headers included 'Death and Dying' TV which were archives of all digital stories, 'Take a Poll' and a search engine, 'Care Transitions'. The later two will be discussed in the widget section.
2. **Plugins** Plugins are a type of software application, which offer browsers additional functionality and interactivity. These plugs enable

participants to view files, movies, add comments and feedback and to post videos. For my website, I added a video plugin, a comments plug in and a stats plugin which was used to assess user vitality.

3. **Widgets** A web widget is a downloadable application embedded into a website for specific functionality. I added a widget downloaded from PollDaddy, which is a service that creates surveys and polls. I added the widget to the website and designed three polls and followed the step-by-step instructions to design the content of the widget. With Polldaddy I could customize how my polls look from font to color. I did not want to ask multiple questions across a wide range of question types but rather ask a multiple choice question in which ‘voters’ could select one answer or have the option of entering their own answer in the Other field. I selected another widget, The Care Transitions Search Engine which was designed to support quality improvement efforts in healthcare and helps healthcare organizers quickly find reliable and actionable content on how to reduce hospital readmissions, improve care for frail elders, and improve the way care transitions are made. (growthhouse.org).

Figure 3.4 Cover webpage



Marketing and public relations

My initial strategy was to design a complex communication plan for blog outreach which would entail a very expansive marketing research endeavor and included gathering data from analysis of current blogs, effectiveness of blogs and taking into consideration blog competition. After designing the website which was a long and tedious process, I decided I would simplify matters and only include nurse and hospice associations, death and dying organizations, thanatology degree programs, relevant scholars, Facebook friends and 50 hospices listed on Facebook. I did not design any press releases, nor did I spend any money advertising my website or linking in with other websites.

The initial processes were aggravated by numerous mistakes in web development but as an essential part of my 'talking circle' design, it was essential to keep to my ad hoc project title – a creative choreographer of the dance of death and dying.

3.4 Methodology

As mentioned earlier, 'Who will talk to me' is an exploratory multi-method single case research undertaking designed to discover and glean themes underlying conversations with a small group of participants as well as quantifying communicative moments and exchanges on the website and relevant social media such as Facebook. My data analysis was assessed through three different venues: (1) analysis of transcriptions based on 8 F2F interviews; (2) analysis of the comments and feedback sections of the website and Facebook posts; and (3) analysis of answers to the question, "Why did you participate in this study". I have segregated the primary qualitative and quantitative research methods, each with

subfields of sampling procedure, selection of participants; procedure, data methods and finally data analysis.

3.4.1 Quantitative Research Methods

To measure who and how many people could ‘potentially’ talk to me, I used quantitative measurement tools and a basic adding system to describe the status of the phenomenon of online visitors, who they were, and how often people visited my site.

Sampling Methods

The online participants were unique and repeat users who visited my website and who communicated with me or liked my Facebook posts. The potential population of these users were confined to 1) people who accidentally may have stumbled upon my website, and respondents from my limited marketing and outreach. The later was an example of cluster sampling in which groups were randomly selected based on similar characteristics – in this case, organizations whose mission was related to death and dying or who were friends of mine.

To measure how many people communicated to me through the website or Facebook, I assessed who were online commenters, visitors and users on Facebook and website blogging posts.

Procedures

After building my website, journeytotheunknown.net, I installed a real time plugin - StatPress - which manages statistics about blog visits. Immediately upon being installed it starts to collect stats about visitors and pages read. I made sure to delete all incoming spam.

With regards to measuring how many people talked to me, I followed the following procedures. After completing the website, I sent out an initial email to Facebook friends saying that I had a death and dying website. I then created a marketing database of over 100 organizations and compiled a list of 69 Facebook pages that were directly related to death and dying. These included hospice sites and death and dying organizations. I would periodically send out emails to organizations and posted a listing of my website on Facebook pages. On several occasions, I posted to my Facebook page. I kept an accurate record of the dates of my Facebook postings but not with email outreach initiatives.

Data Collection

My data collection plan involved culling data from multiple sources so as to potentially extract rich resources of information of website popularity, number of hits, response rates and comments. This simply constructed plan depended upon strong stats and accurate recordkeeping of Facebook postings but were found to be the most reliant to answer design considerations which were not overly cumbersome or would require an extensive learning curve. At the end of February, 2014, I collected all the data and organized it according to specific variables, which would tell me how many people visited, the origin of their visit, and the most popular website pages. I collected user comments and feedback from the following online locations 1) Polldaddy; 2) my Facebook page; 3) blog comments; 4) website comments; and feedback

Methods of Data Analysis

At the conclusion of data collection for Statpress and the number of user comments, the responses were saved in an excel file. I did not use a data analysis

program but used a simple number count. I recorded naturally available data in an excel spreadsheet.

Validity

Validity measures whether a statistical test is valid enough so that the results can be interpreted or applied in current research or future research. Face validity, a simple, common-sense form of validity, was used to test the effectiveness of the website analytics. Known as the weakest form of validity, it is useful for researchers such as myself who, for numerous reasons, were unable to apply content validity to these website analytics.

Word Press does not offer a lot in the way of site analytics and so it was difficult to determine the best instruments and measurements to guarantee precise numbers of online visitors. I did not test the most popular plug-ins, which include Google Analytics, All in One Webmaster, WordPress Stats and Statpress for accuracy. Because I was a beginning website developer and taught myself the basics for this project, I chose the plugin which was the easiest to install and the least expensive and seemed to get good reviews.

3.4.2 Qualitative Research Methods

Questionnaire

Sampling Procedure and Selection of participants

I decided to interview a small number of participants for my informal conversations on death and dying. My sample frame were people I knew. I used convenience sampling as an approach, which is a type of nonprobability sampling technique. I recruited my participants through phone calls, emails and F2F conversation. Every person I asked to be part of the study answered in the

affirmative. The individuals who I selected for my case study answered both the questionnaire and participated in the informal interviews. A total of eight participants were involved in the study. After choosing the participants and settling in to videotape the interviews, I realized that the majority of my interviewees were baby boomers and female.

Table 3.1 Participants

<u>Participant</u>	<u>Gender</u>	<u>Generation</u>	<u>Type of Work</u>
Nancy A.	Female	Baby Boomer (1946-1963)	Non profit executive director
Meleanna M.	Female	Baby Boomer (1946-1963)	Artist, writer, filmmaker, teacher
Katherine L.	Female	Baby Boomer (1946-1963)	University Lecturer
Daryl	Male	Millennial (early 1980s –early2000s)	Undergraduate Student, Ex military
Susan S.	Female	Baby Boomer (1946-1963)	Professor, writer and poet
Leslie	Female	Baby Boomer (1946-1963)	Professor and educator
Sally F.	Female	Baby Boomer (1946-1963)	Non-profit leader and trainer
Shelly	Female	Millennial (early 1980s –early2000s)	Unemployed social worker

Procedures

All 8 participants did not answer the question, 'why did you participate in this study' on their consent forms. I called them up after the interviews, and recorded the answers verbatim on a sheet of paper.

The recruiting for the participants began in January 2013 and was completed by February, 2013. The participants signed the consent forms and I set up interview dates either in their homes or in my office at the University of Hawaii. While the informal conversations were F2F, I set up a small video camera to record the interview, ensuring there no ambient or distracting noises were present. I set the video recording either on a tripod or my desk and put my head above the camera so the participant would look directly at me.

I taught myself the basics of video editing and created the videos in Imovie. I did not do substantial editing of the interviews as I did not want to take away from any pauses, deliberations or repetitive statements. The beginning of each video opens with either a short piece of opera and a montage of collected images that were relevant to the discussion and did not use breaks to punctuate different conversational threads. The final clip was a piece of music from either a musical digital interface from Apple's Garage band, a piece I composed myself or a slice of an aria and, finally, a loop for the credits and contact information. I then uploaded the final video on Vimeo and had each participant approve their video before uploading it on to the death and dying website.

Data Collection Method

The method for the questionnaire was to answer one question: Why did you choose to participate in this study? I entered the answers into the computer and grouped them according to subject matter.

For the digital stories, I conducted in depth one-on-one informal interviews with 8 participants over a period of 3 months. These qualitative in-depth conversations were not predetermined responses to preconceived questions; instead they were structured as informal conversational interviews. I did not design an interview protocol nor did I do pilot testing on any of the questions. I either opened up the initial interview with ‘What is a good death?’ or ‘What comes to mind when you think about death and dying?’ The informal interview process was the most parsimonious way I could receive a wealth of information in a non-threatening way, respond to their non-verbal and facial cues, and understand their impressions on death and dying. I also wanted to have the interviewee to have control over the interview and wanted to explore his or her feelings about the multifaceted issues involved in death and dying.

Data Analysis

Answers to the question, ‘Why did you participate in this study?’ were assembled onto a word document. I reviewed the text repeatedly and asked myself what the answers were really about. I used topic coding because answers to the question were my first step in interpretive work that I would undertake in the interviews and gave me a glimpse into potential themes without the complexity of a lot of data. In Excel I created a small table, coded and grouped the phrases. Four themes emerged: 1) Importance of topic; 2) Lessen Fear;; 3) Personal Experience; and 4) Comfortable with Interviewer.

The data analysis for the informal interviews was more complex and based on the procedures and philosophy of thematic analysis. As mentioned previously, the analytic purpose of the case study was exploratory and content driven, analyzed

from raw data. Codes were not pre-determined and were not generated from previous hypotheses or theories.

Thematic analysis is a process of encoding qualitative information (Boyatzis, 1998) and can take a variety of approaches with a lot of flexibility depending on the goals of the researcher. It is a layered interactive and iterative approach that suited me because my overall goal was to unearth themes as they related to talking about death and dying in everyday life. I used a hybrid approach, gleaned methods of thematic analysis. I created a code rich template, created from extensive and repeated readings of the transcriptions.

I collected the data (informal interviews/conversations), capturing it on video. After spending approximately 40 hours transcribing, the final transcripts for each individual was entered into the QSR NVivo data management program where a process of data coding and initial identification of themes was undertaken. Themes capture data, which is important to the research question and represents a meaning or patterned response within the individual data set (1 interview) or the collective data sets of all interviews (Braun & Clarke, 2006). I did not develop a code manual nor did I test the reliability of codes but instead familiarized myself with all the transcripts and wrote down ideas and notes as I went along asking myself what codes I might want to use, specific interesting tidbits.

The process of coding data and creating nodes was a purposeful endeavor and after making several mistakes in coding, I started working on thematic maps, exploring the relationship between codes, the left-overs, and how initial themes may be related to one another. I developed parent child relationships, merged nodes (i.e. spirituality and religion) and, in some cases, deleted nodes because they were either not useful or were covered in another node. I grouped nodes into trees

and from that exercise, I was in a better position to do theme building and analysis of the defining issues. I then created 10 tree nodes from the 30-plus codes and reviewed the material again. I created a word result on three words to identify how often they were used.

After reviewing the coded tree node extracts, I saw definable patterns and decided to reframe my codes from the tree nodes into an excel spreadsheet. Culled and refined from the initial coding, I identified 23 codes and created a table in which the column titles were the following: *Name of Participant; Codes or Proto-themes; Issues Discussed; Themes Identified; and Major Themes*. I went back to NVivo and organized the issues discussed under each code. I copied phrases from the transcripts and put under *themes identified* in the Excel spreadsheet. At this phase I had identified the themes' essences, related how each specific theme affected the entire picture and organized through cutting and pasting relatable issues discussed under one of seven major themes I had identified.

In essence, I had re-examined the text carefully once again aligning phrases, issues discussed and themes so that I could go beyond surface meanings of the data and be able to tell a fairly accurate story of what the data meant within the context of talking about death and dying.

CHAPTER FOUR

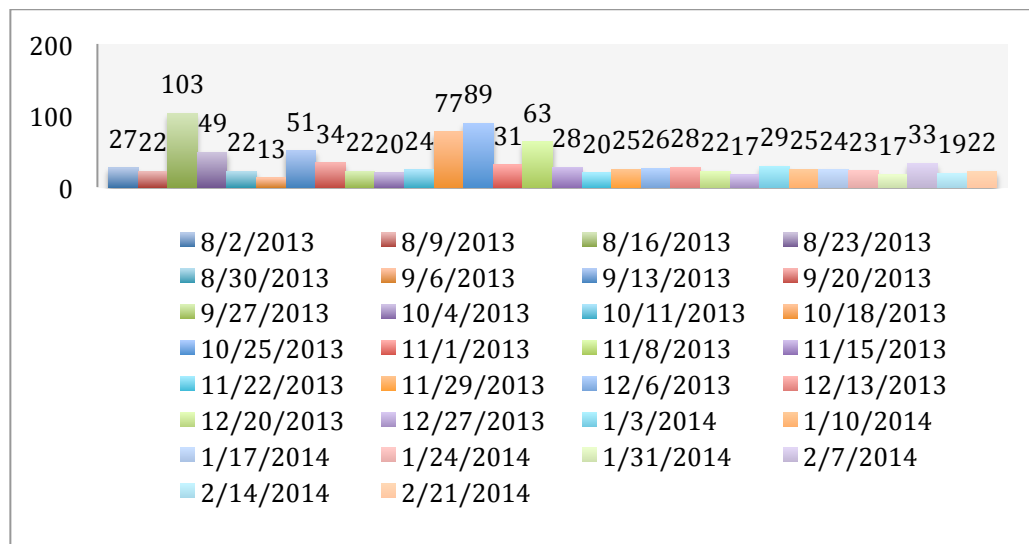
RESULTS

This chapter presents the findings of the present multi-method case study in two sections. Section one identifies the quantifiable results gathered through stats on website unique visitors, website visitors by geographical region, popular page views and traffic sources to the websites. Section one also describes Facebook outreach and comments and results for the online polls. Section two describes the interpretive and qualitative results of the brief questionnaire and the major themes uncovered in the unstructured interviews with 8 participants.

4.1 Who might want to talk to me?

Research Question One sought to find out who will talk to me in cyberspace. Before anyone will talk to me, they have to visit the webpage and indicate an interest in the subject matter. Figure 4.1 illustrates the number of unique visitors to my website.

Figure 4.1 Weekly website unique visitors * Unique visitors refers to the number of distinct individuals requesting pages from the website during a given period, regardless of how often they visit.



A unique visit will tell me what visits are viewing my site from the first time and can track them as unique by the IP address of the computer. The number of unique visits will be far less than visits. From August 2, 2013 to February 21, 2014, I had a total of 1005 unique visitors. The highest number of visitors occurred on August 16, 2014, which is the date I sent out a mass email to death and dying related organizations. The increase or decrease in number of unique visitors did not reflect the dates I sent out Facebook postings.

The table below analyzes the geographical location of my visitors. Most of the visitors originated in the United States, followed by Canada. A visit is one individual visitor who arrives at a web site and proceeds to browse. A visit counts all visitors, no matter how many times the same visitor may have been to the website.

Table 4.1 Web page visitors by geographical region

Cyberspace Country of Origin	# of Visits*
United States	2637
Canada	696
Great Britain	65
Australia	53
Brazil	21
Russian Federation	14
Germany	12
LAN	7
New Zealand	5
India	4
Mexico	4
Chile	3
Israel	2
Poland	2
Lithuania	2
Ecuador	2
Belgium	2
Turkey	2
Spain	2

I did not target audiences in terms of geographical region, however most of my outreach was confined to the United States. I do have many Facebook friends all over the world but can't account for higher number of visitors in Canada, Great Britain and Australia except to say anecdotally that these countries are very active in death and dying related research and advocacy.

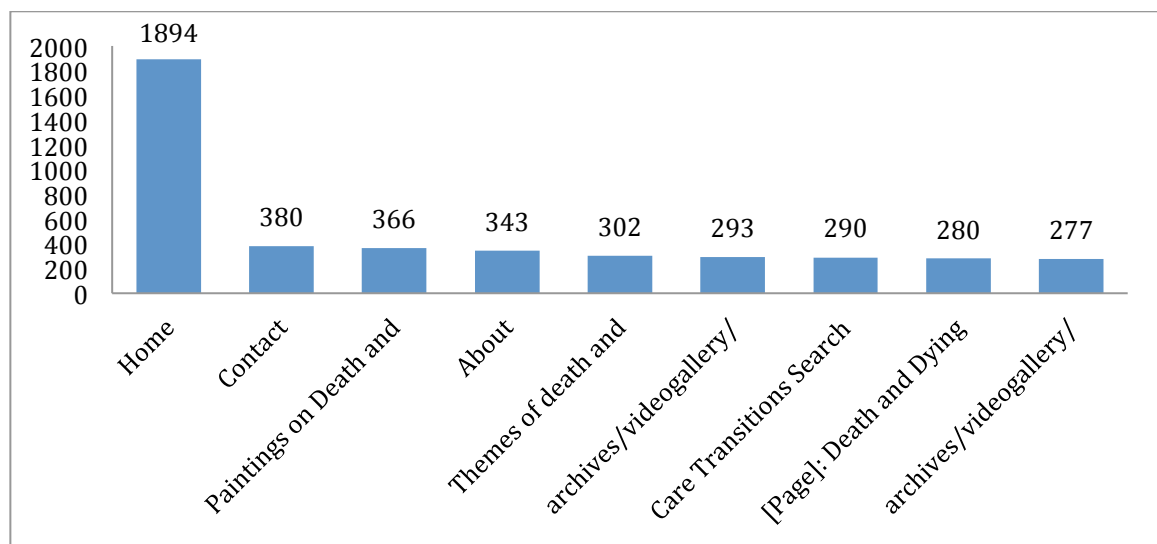
Page views are also called impressions and are requests from a user to load a particular HTML file on the Internet. A visitor can reach a page more than once and it is counted as an additional page view. Below in Figure 4.2 is an assessment of popular page views. The highest number of page views were my homepage which is similar to a storefront window and should be appealing, at the very least. It appears that a lot of users 'moved on' for various reasons. I provided visual and verbal cues to reveal the site's underlying content and encouraged deeper browsing in terms of featured posts, recent articles, and resources, supplying return and new users with new content as it became available. Results indicated a lot of people visited the page and potentially read the daily post or video on the front page.

Popular page views included contact information and the about page to find out more about the project as well as how to contact me. Unfortunately, only about 3 of the 380 visitors to the contact page, reached out. Themes of death and dying had three categories of which to choose from: Poems on death and dying, paintings on death and dying, and, themes of death in dying in short stories. These were also popular and could have been a result from indirect traffic whereby a person was researching an art related topic on death and dying.

People may not have wanted to talk to me but they wanted to have more information on how death and dying is being perceived and discussed in the arts. A

few hundred people visited death and dying TV where I archived digital stories, as well as the video gallery signaling users who were interested in the digital stories and videos about death and dying. The website stats did not include viewers to each video or digital story. People also came to the website to undertake the Care Transitions search which could be translated as my website being also a place to find health care services as well as questioning what care transitions is all about.

Figure 4.2 Most popular page views



People can locate my website through different streams. They can find it through direct navigation and type the URL in traffic, email links and bookmarks. There is also referral traffic, which is traced from links across the web, social media, and email. Lastly, there are organic searches to my website which are from queries that send traffic from any major or minor web search engines. I wanted to find out why they wanted might want to talk to me.

Table 4.2 illustrates how visitors arrived at my website. Did they just click on to a link provided by my limited marketing and outreach activities or were they

searching for terms and accidentally stumbled upon my website through an unrelated search. Table 4.2 analyzes the top traffic sources to journeytotheunknown.net.

Direct navigation seemed to be the most prominent way, people found my website or remembered my website from previous views. Meleanna Meyer, a F2F participant, is a minor celebrity in the arts and many people search for her on the web. That may account for that search term. Most of the traffic was organic searches.

Table 4.2 Traffic Sources to Journeytotheunknown.net*

Top Search Terms	Times
Journeytotheunknown	2551
a+dead+woman%27s+secret+theme	9
meleanna+meyer	5
journeytotheunknown.net	4
death+as+theme+short+stories	3
short+story+about+death+and+dying	3
short+story+with+theme+of+death	3
guy+de+maupassant+a+dead+woman%27s+secret	3
death+and+dying+blog+susan+Schultz	2
guy+de+maupassant+on+the+journey	2
www.journey+in+to+the+unknown	2
story+about+death+themes	2
short+stories+about+journeys+to+death	2

How many people actually talked to me on the website? Three people responded positively to the digital stories. The comments were one sentence and to the point: loved the video; interesting; and, really nice. I was hoping for reflective responses or comments on what the participant may have said in the digital story that moved the user. My talking circle was not working out so well! Thinking that heartfelt stories would be considered, especially in light of the subject matter, I had hoped for the promises of CMC and hyperpersonal communication research, which allowed for intimate conversations in the online world.

Outreach on Social Media

Disappointed in not receiving comments on my website, I utilized marketing strategies and social media to get out the message on death and dying. I sent the following message to 69 Facebook sites, which were related to death and dying.

Aloha! My name is Charmaine Crockett and I live in Hawaii - I designed an interactive website on death and dying - would love to hear your stories or comments on some of the posts and digital stories. Thank you for taking the time to look at the new adventure and thank you for your work and love! www.journeytotheunknown.net .

Many of these sites were hospice pages as well as death and dying online cafes. I received zero replies. The findings surprised me as I thought that, if anyone were to respond it would be death and dying organizations.

I then decided to send out a Facebook message to all of my 503 Facebook friends, letting them know I started a website on death and dying. Initially, I was hesitant to share my project with Facebook friends, whom I knew personally. They would ask too many questions. This was in stark contradiction to my initial purpose in starting the project: to reach out to the world, sharing my views on death and dying and hoping for some solidarity.

As you can see from Table 4.3 which highlights dates and responses of personal messages to friends, I did not receive a lot of likes, not nearly as much as when I send a picture of myself or share a video on kitties, which can garner about 50 hits. The most likes were on November 10, 2013 when I released a digital story on Daryl whom I said was a war veteran and had experienced violence his entire life.

Results indicate that on Facebook, death and dying are not a popular topic to discuss and comment on. Unless someone or a pet actually dies like a Facebook friend's dog who died and who received at least 200 likes and 50 comments, we may be out of luck when sharing an intimate and potentially vulnerable area of discussion. The one notable exception was a long comment from a friend in Amsterdam who shared an extensive story of a death in his wife's family. Please see Appendix C for Facebook comments.

Table 4.3 Facebook Personal Messages to Friends

Facebook	Date	Likes	Commenters
New Blog on Death and Dying	September 15, 2013	11	10
Interview with Sally Fisher Released	October 22, 2013	6	3
Interview with Meleanna Meyer	October 25, 2013	4	2
Interview with Daryl Released	November 10, 2013	19	9

Polls

Online polls are useful for generating a potential discussion or to get a pulse on visitor thoughts – in this case on death and dying. I designed three polls in an effort to grasp what people were thinking about, if their thoughts were similar to mine and I also wanted to give them an alternative to posting comments on the webpage. They could add their voices to the discussion anonymously without spending a lot of time giving feedback on comments or sharing intimate stories. Below are the findings from the three polls.

Table 4.4 Polldaddy #1 What frightens you most about your final departure (11 respondents)

Answer	Votes	Percent
Dying Alone	2	18%

Being in Pain	2	18%
Not feeling like I accomplished enough in life	2	18%
A laundry list of regrets	1	9%
Not resolving anger issues	1	9%
Having a long dying process	1	9%
That I wasted too much time on small stuff	1	9%
Other – Sad children	1	9%

Table 4.5 Polldaddy #2 Have you ever experienced the following? (7 respondents)

Answer	Votes	Percent
A feeling that death may be a continuation, not an end	4	57%
A presence of a loved on who has passed	3	43%
A near death experience	0	0%
Communication with a loved one who has passed on	0	0%

Table 4.6 Polldaddy #3 How often do you think about death and dying matters? (8 respondents)

Answer	Votes	Percent
Regularly	5	63%
Occasionally	1	13%
Not often	1	13%
Rarely	1	13%

The polling results were insignificant because of the minimal number of participants who participated in polling. In the first poll, ‘What frightens you most about your final departure?’ an equal amount of people said that dying alone, being in pain and not feeling like I accomplished enough were given equal weight. Findings from the second poll suggest, like the interviewees for the digital stories, that death is a continuation and people have experienced the presence of a departed loved one. The third poll in which 5 out of 8 people think about death and dying on a regular basis is telling because it suggests that while people are thinking about death and dying, they are not necessarily talking about it – or at least to me.

4.2 What will people talk to me about?

The results in the qualitative section of the case study were paramount to answering the last two research questions:

RQ2: What are the major themes people discuss when they talk about death and dying?

RQ3: If people experienced death and mortality awareness, would they be motivated to alter their worldview and make positive personal changes?

After providing the results to themes in both the questionnaire and the informal interviews/conversations, I will finally turn my attention to RQ3.

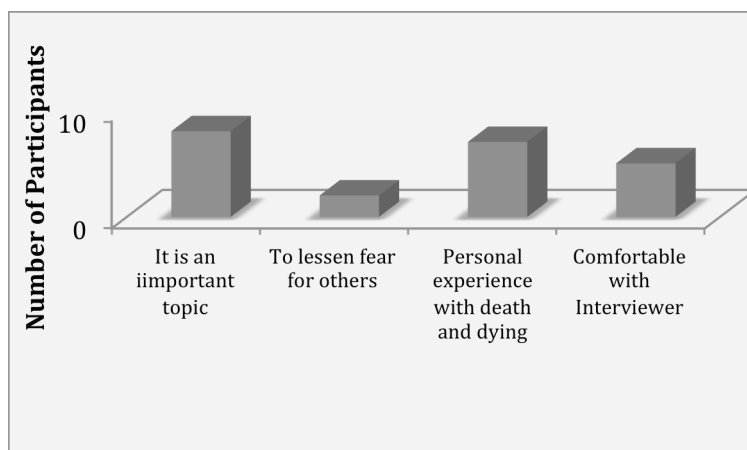
Why did you participate in this study?

At the bottom of the consent form, a question on why the participant agreed to the informal interview and to be videotaped, was left unanswered by all participants.

After calling them, I realized it was difficult for them to write down the answer.

After reviewing the brief transcripts written verbatim from telephone conversations, I extracted five major themes. Below is a graphic summary of those themes

Figure 4. 3 ‘Why did you participate in this study?’



Eight participants (100%) participants thought that death and dying was an important topic to talk about. Meleanna stated that:

It is the other end of the chapter of living that I have to face and explore intimately. I am intrigued by the complexity of where the conversation, where we join – all of us. It was a privilege to do the interview.

Five individuals stated that they had personal experience with death and dying and wanted to share their story with others. Susan S. happily noted that because she witnessed her mother's life leading to her death, the subject of death and dying was important to how she looked at the world. Two individuals wanted to mitigate fear for others who may be watching their videos online. Katherine stated that "I am hopeful that by sharing my story with others that they will feel less fearful about death and dying." Two individuals stated they wanted to lessen fear for others. Leslie L. said the following:

It is not something I fear, death and feel I have grappled with the mysteries of it. I am comfortable with it and feel connected and spiritual about it. I am just okay with death and a lot of people have a tough time with it. I wonder if some of it is my ego and feel strongly there is an afterlife and because I feel so positive about, I can talk about it. Maybe I feel cocky about it. Here is what I know.

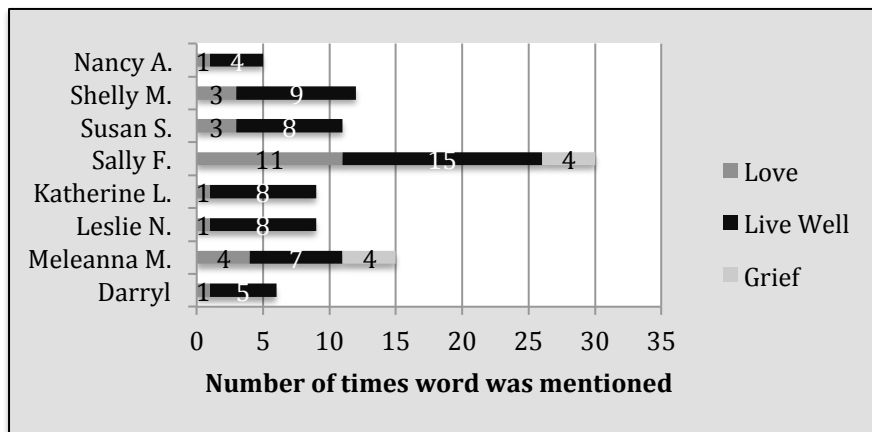
Five people of the 8 participants disclosed they felt comfortable with me and considered me a friend. Says Nancy, "It is an important topic that too many shy away from. If a stranger asked to interview me, I would not have. Relationships count for a lot." The research directives in this case study did not ask why people may talk to me but this small questionnaire illustrated the possibility that under certain conditions, people will talk to me.

Informal interviews

The following section addresses summaries of key findings as they related to the last two research questions. The research problem underpinning the purpose of my study was to ask what people talked about when they talked about death and dying. As explained in the methods section, this aspect of the research involved numerous layers of inquiry.

In the first phase of the coding and analysis, I utilized a text search query in NVivo and coded for three words, which I felt to be important when talking about death and dying. My purpose was to identify if an idea or topic would be prevalent in my sources and to decide to pursue a line of inquiry in the text.

Figure 4.4 Word frequency count in conversations



The inference made from this basic content analysis of word frequency count does not imply that these coded words reflect the greatest concerns on the part of the participant but it does suggest that love and living well were areas of interest to all individuals and on more than one occasion within approximately 30 minute conversations. Sally, a leader in the AIDS movement knew that living well was important to people who were dying. All participants were interested in living well

or facets, thereof. Two individuals mentioned grief. Love was a concern to all participants, an important element in living well.

After reviewing the data within textual contexts, I coded, merged and recoded in the software program, highlighting and extracting essential texts that could be assigned in a meaningful way. The following is a summation of key areas of discussion (not words) or collection of nodes, organized under a data structure, the tree node. Discussion focused in three key areas: Personal experiences with death, life philosophies and the actual experience of death. How one lives and what is considered a good death were the most prominent areas of discussion. Six people had personal death related experiences with family members and five people made a connection to spirituality and life as well as death.

Tree Nodes with sub-categories	Sources	References
Personal Experiences with Death		
Family	6	8
Self	4	5
Violence	3	6
Life Philosophy		
Being in community	4	5
How one lives	7	32
Spiritual matters	5	7
What is Death		
A good death	6	12
Bad death	3	5
Death as a cultural experience	2	5
Death as an experience of life	3	6
Death as part of spiritual experience	4	6
Death is not the end	2	5

**Figure 4.5 –
Summation
of key areas
of discussion**

The next phase of my findings involved re-creating a long list of the codes I initially identified across my data set because I wanted to re-focus on broader themes and combine further different coded extracts. I regrouped codes and phrases, aligning thoughts and patterns together. I then created final thematic groupings, dissected into smaller themes. The following graph illustrates the seven major themes that people talk about when people talk about death and dying in the everyday.

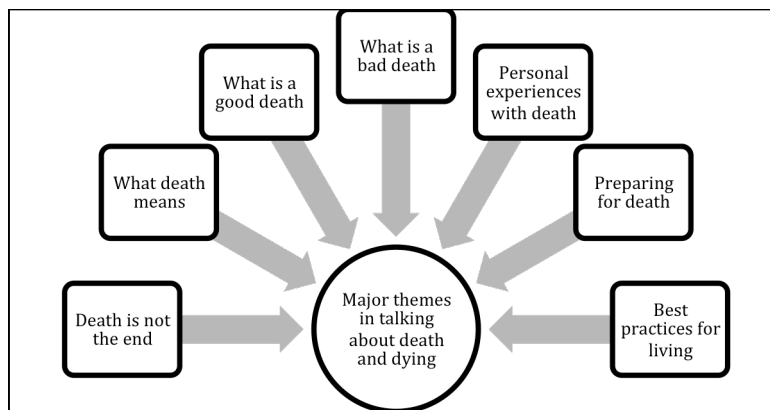


Figure 4.6
Major themes in talking about death and dying

This paper considers how death is talked about in casual conversations between people who are very much alive. Conversations were fluid interactions between myself and the participant involving stories, experiences, and perspectives on life and death. In two cases, people spoke eloquently and in great detail about a death, which occurred in their family. Even amongst those participants who focused on a particular subject area such as war or the dying process of a mother, these emergent themes arose.

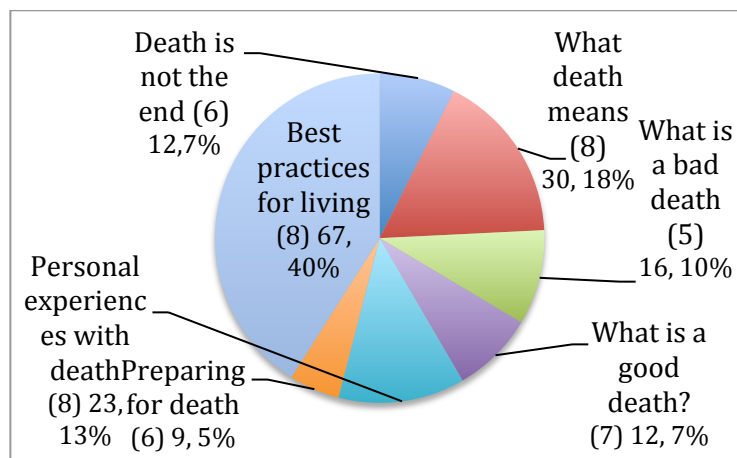
For clarity, I have defined the following themes as such:

1. Death is not the end – ‘Something’ or experiences happens after your heart stops beating.
2. What death means - Perceptions on how death is defined and perceived by participants.
3. What is a good death - How to die well and comfortably.
4. What is a bad death - How not to die

5. Personal experiences with death – Participant personal experiences with themselves, family members or through experience.
6. Preparing for death – How participants prepare for the final experience.
7. Best practices for living – how to live when you know you will die.

In this final phase of analyzing my data, I reviewed each participant transcript, all phases of coding in NVivo and by hand, ensuring that phrases or sentences captured were not my own thoughts during the interview process. Figure 4.7 illustrates the phrase or sentence count as it relates to each theme, followed by a percentage of that grouping within the totality of the seven major themes. The number of participants engaged in conversation under a particular theme is listed in the parenthesis. Phrases or sentences were captured from statements, or the essential thoughts of a participant. I left out supporting statements as it related to that thought and did not count duplication of the essential thoughts (some participants repeated themselves). The percentage refers to the percentage a theme was prominent relative to all seven themes. Please see Appendix D for final thematic map, structured and organized into three columns (codes, keywords/issue, phrase or sentence) and thematic headings.

Figure 4.7 Sentence or phrase counts



For the most part, I did not steer the conversation in certain directions. Five of the 8 participants were asked in the beginning of the conversation, ‘What comes to mind when you think about death and dying?’ or something to that effect. Two of the participants were asked in the opening what they thought a good death was. As an opener to one participant, I asked if she thought about death and dying. I did not control or sway the conversations but instead asked questions and commented based on what a participant shared or did not share.

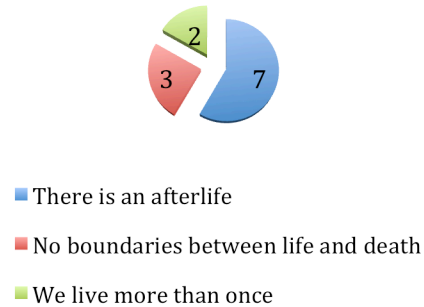
All 8 participants discussed three themes – best practices for living, what death means and personal experiences of death. Mostly everyone wanted to discuss life and at great length. Assigning percentages to each theme gave me an indication as to the duration of time within the cumulative discussions of 8 participants. When talking about death and dying, forty percent of the time was spent talking about life. I did not screen out for length of text or phrase that was coded which may have skewed the findings. This will be discussed more in the following chapter.

The next section will survey the categorical results under each theme. Each theme was rich with anecdotal materials, and heartfelt sentiments on death and dying but there were specific categories that could be culled. Categories are defined as sub-themes under a larger umbrella.

Figure 4.8 illustrates the major categories under the umbrella of ‘Death is not the end.’ This thematic area does not indicate a religious affiliation such as Buddhism, which believes in reincarnation or the heaven/hell concept in Christian religions but it does signify a unified response that once you die, then you are dead is not a popular sentiment amongst the participants. I did not screen for religious affiliation but I do know that six participants engaging in this discussion bear no strong religious affiliation.

Figure 4.8. Phase counts under categories in ‘Death is not the end

Death is not the end



Discussions on the afterlife took many forms in this area from one participant saying we go back to the ‘source’ to another participant saying that she had a near death experience and there was life after death. Katherine L. said the following:

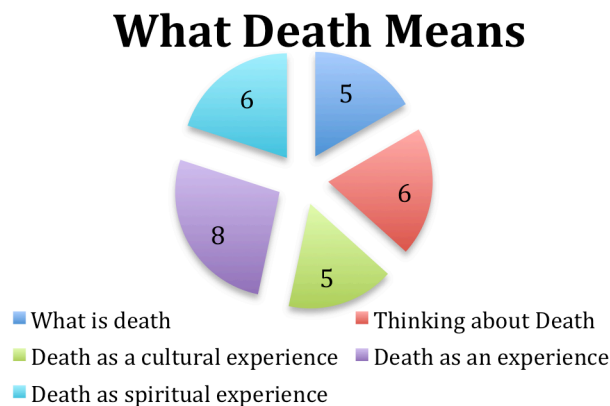
“...it confirmed my own near death and out of body experiences. When we are broken free from this 3 dimensional form, we come to the understanding we are connected. How do I verify that? I cannot scientifically because I cannot. It is something I feel and something I intuit and gives me a fearlessness about death. I will go on and I am in an earth suit. I may come back or go on to something else.”

Katherine L. alluded to the idea on three separate occasions that there are no clear boundaries between life and death. Daryl, a war veteran, discussed the fact that in a war zone when soldiers die, there are no memorials or services for them because of the potential to get fired up. One time, a soldier had died and Daryl had seen his ghost. He knew there was an afterlife but he wondered if there was a relationship between ghosts in the room and having no time to mourn or celebrate a person’s passing.

There were not a lot of responses in this area of inquiry though there was significant discussion around the phrases being extracted. It was an area of interest for six of the eight participants with most comments from Katherine L. who is an academic but also a spiritual seeker.

‘What death means’ thematic area embraces conversations and statements that relate to participant perceptions on, not what the existential or religious connotations are, but on personal feelings of what they think death may be about. Figure 4.9 illustrates this topic may have been more popular to talk about than considerations of the afterlife. After careful consideration of merging ‘Death is not the end’ and ‘What death means’ I decided to treat them as different themes because of the context in which the phrase was being discussed. Figure 4.9 measures the phrase counts under the umbrella of ‘What death means.’

Figure 4.9 Phase counts under categories in ‘What death means’



As a category or sub-theme, ‘Death as an experience’ received the most diverse thinking. Shellie, a no-nonsense social worker said, ‘some of us are on the clock and death is being off the clock.’ Two participants felt death was a process and one quipped that we won’t really know until it happens. Spiritual perceptions

on death were described as ‘we are butterflies going back’, and that death is energy, freedom, and a transition similar to the experience of birth. Similarly, Katherine L. pointed out that ‘death is not the end, there is a point of entry and a point of departure.’ Two participants, when asked what death was, replied that death was a cultural experience and that it meant different things to different people. Five people, upon thinking about death were short on words and described death as ‘something that just happens and it terrifies us’, and that is was powerful to think about. Leslie L. said that when she thinks about death, she wants to be a better person. This last statement will be discussed further when examining the last research question.

‘What is a good death?’ theme had one category as each issue area and thought processes were diverse in their responses. Figure 4.10 illustrates the diversion on what people consider to be a good death and it varies between culture guiding a dying person to being aware and accepting of the process.

Figure 4.10 Phrases stated under ‘What is a good death?’ theme

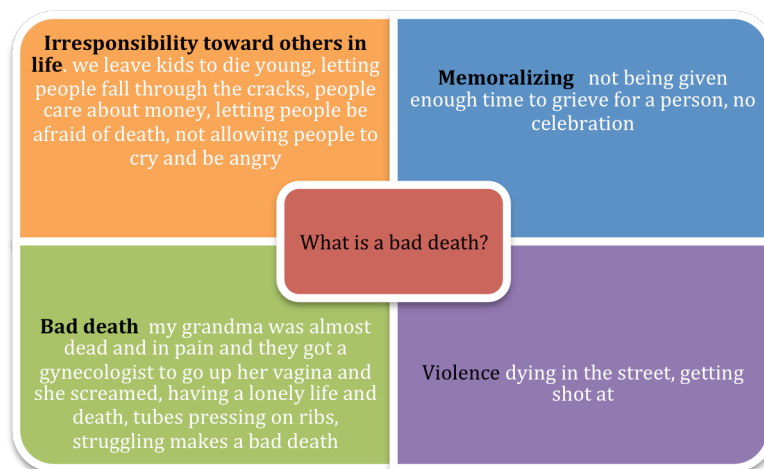


Salient issues such as being in control of the process, thinking of others and living well while alive were dominant ideas on what was considered a good death.

Resolving conflicts was important to a participant – she noted there was nothing worse than having regrets on a deathbed. Most of the participants took a matter of fact approach to the subject except for one participant, Leslie L. who understood what a good death is by being a part of two very bad death experiences. The responses were not dissimilar to those discussed in the literature review in Chapter Two.

What is considered a bad death yielded interesting results. Figure 4.11 illustrates the categories as well as the phrases used when discussing a bad death. Daryl, a war veteran, talked at length about a bad death while others did not because their experiences for the most part were not shaped by a lifetime of violence. I was surprised at the diversity of answers the concept yielded.

Figure 4.11 Phrases stated under ‘What is a bad death?’ theme



Two of the participants had experienced bad deaths in their lifetimes and so they were more apt to discuss it at great length. Daryl had experienced so much bloodshed in his life and knew firsthand what a bad death was. Leslie N. had seen her grandparents die a horrible death, not because of violence but because of the

dominant medical establishment and her father who, at the time, had control over the course of events in his parents dying process and was exposing her grandparents to painful processes in order to stall off the inevitable.

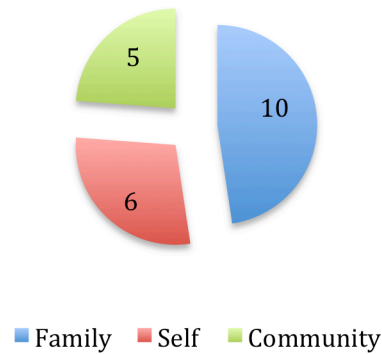
‘Preparing for death’ theme was a significant topic for two participants out of the 6 participants, who discussed it. These phrases and commentary lent themselves towards giving advice to others on death preparation and they fell into one major category or code – preparation. Katherine L. was adamant that preparing for death in terms of directives, wills and directions yielded the benefit of being able to live in the present. Daryl had a leftover comment, meaning there was no real category to put his thoughts under but when talking about preparing for death, he described that how being in war, he could not prepare the enemy combatant for death, nor could you feel sadness. In another context as it related to preparing for death, he quipped that when life is not worth living, a person is preparing for death. Daryl had been suicidal since his return from the war.

Five participants addressed the need to take care of directives and preparing wills ahead of time so they do not burden others after their death. The baby boomers had the most to say on this issue. Nancy A. mentioned that she has already planned her funeral down to the songs she wants and Katherine L. found that when she got her affairs in order, she could live in the moment. Sally F. who was a leader in the AIDS movement for twenty years and had held the hands of over 300 men who were dying of AIDS said that, in her experience, resolving issues, especially family issues, was the most important task a dying person could undertake.

The older you get, the more people we know die. All eight participants had personal experiences with death. Figure 4.12 illustrates the categories as well as

the number of phrases/sentences that individuals discussed these personal experiences.

Figure 4.12 Phase counts under categories in ‘Personal Experiences with Death’



Family experiences of death generated an extensive and rich conversation, especially for Susan S., a prominent writer and poet, who has published two books on Dementia. Susan said that one of the most important facets of her years long caring for her mother was that she became intimate with the process, had allowed life to happen and that, in the end, she became present and alive in her dying. When Catherine L's grandmother died, she knew the exact minute of her departure. Meleanna M., whose husband died when she was 28, had to explain to her young children what death was and where daddy travelled and why he was not coming back.

For Daryl and Shellie, two young people in their early thirties, personal experiences with death came at a young age and in their communities. Both participants lived in the 'ghetto' and the rule of thumb was that if a teen was still alive when they graduated from high school, they were home free. Both participants

saw community members dying and were accustomed to attending funerals by the time they were in middle school.

Daryl, the war veteran had many personal experiences with death. When he was in Iraq his early twenties, he saw death up close and personal. He says,

My second deployment was in 2004-2005. My experience is that I saw a lot of people die. Our base always got attacked and people died. Some of the things I think about are that young people should not go in the army. I thought after one incident I thought that young people should not be here. Older people should be there. Young people die and they do not get to live a life. In the Army, it makes you grow up fast. You are a man in the army. You are a warrior. I felt like kids got robbed. And that is on our side. In 2003, my first deployment, it was the first time I had been out of the country. The crazy thing about it, people kept talking about soldiers dying like on FOX News, which is a bunch of crap. I felt when it came to death in the military, it was very different from death in the civilian world. You could die today on a convoy mission and five hours later I am taking their spot. You do not get time to celebrate, to think about the person, how it affects you.

Three participants had experienced near death or the fear of death in their lives. Daryl had gotten shot at several times. Leslie N. went into surgery one day and saw herself above her body and realized later she had an out of body experience. Nancy A. was told she had several weeks to live and during that time her senses were powered up, especially her sense of taste. Nancy A. wanted to live each moment to the fullest. It turned out that while she had two weeks to accept that she was going to die within the month, the doctors realized they had misdiagnosed her. She was fine and in good health. She recently was diagnosed with an aggressive cancer and underwent extensive surgery. Because of her 'fake death' experience as a young woman, Nancy now feels at peace with herself and her life.

All participants were eager to talk about their personal experiences with death and no one was hesitant to describe the emotions affiliated with their

personal experiences. I am confident that if interruptions and other lines of inquiry did not sway the conversations, they would have talked longer.

Out of all the seven themes unearthed through coding, the last theme, 'Best Practices for living' surprised me the most. Not one person equated a good life with material possessions, money or having a comfortable life. People had numerous opinions on being alive. Every participant discussed this theme at great length. In the final analysis, there were 67 counts of phrases or sentences in which people talked about life, gave inspirational advice, and shared important values to having a great life. The figure below shows the categories under this section and the counts associated with them.

Figure 4.13 Phase counts under categories in 'Best practices for living' theme

Best practices for living



People wanted to talk about being alive in the context of death. I steered some of the conversations but only after participants had discussed death at great length. Being in community was important for Meleanna, a native practitioner and indigenous artist. Being in community was important to live well and that finding the sacred together was essential for a meaningful life. She also stressed that we need to contribute more to the betterment of humankind. She says:

‘You see it in pictures of people who have lost hope. They have gone beyond the pale of their emotions. I am not kidding about zombies, It is a real thing I have seen in photos of Hawaiians in the early twenties when they had no hope, no aspiration to continue when there is such great loss. One can be living and dying slowly is a very painful thing. That is why the whole notion of 'living into your life' makes sense to me. We have to just claim those things that we love and desire, to make change, to be a part of so that we can become the people, be enlivened. Otherwise, why are we here? Those things are very real to me.’

Some participants noted that we have to live fearlessly, waste less time and that we need a culture of caring. Best practices included being a friend, appreciating all human beings and that we need to go after passion, not money. Leslie N. said we can live with meaning at anytime and that a good death is having a good life. In the category, spiritual matters, Shellie M. brought out her religious side and said that we need to spend time with God so as to feel the vibrancy of life. Katherine L said that it is essential we tune into something larger than ourselves. Nancy A. says that we must determine the road we want to go on, especially when we know how it will end.

Love played a big role in how we should live. Shellie M. exclaimed, “love everything, and I mean everything!” Sally Fisher, friend to hundreds of men who died of AIDS, said that it was important to love as much as you can.

In summary, through a qualitative, inductive approach, I have identified the major themes when talking about death and dying with 8 participants. Significant qualitative findings were found in several of themes, yielding potential richness for future research endeavors. Much more can be written on the themes as the transcripts are extensive, breathtakingly rich and, as one reads them repeatedly, more contextualization surfaces.

4.3 If I know I am going to die, will I change?

Research Question #3 asks, 'If people experienced death and mortality awareness, would they be motivated to alter their worldview and make positive personal changes

This section of the research did not yield formidable results. I did not design the interview process to potentially identify or find variables that led to personal changes upon considering their mortality. I had hoped that by discussing life, statements would surface linking increased awareness with lifestyle and personal development changes.

The most dominant theme in terms of length of discussion and phrase/sentence count was 'Best practices for living'. These conversations took place within 15-20 minutes of the discussion and in two instances I steered the topic because I was interested in the research question and interested in their perspective, both of whom had witnessed a lot of death in their lives.

People had been talking about death and thinking about the interview beforehand and the responses were complex, thoughtful and expansive. Leslie N. remarked that when she thinks about death she wants to be a more present person. She stated that right before her interview with me, her daughter called. She and her daughter have not been getting along; however this time when her daughter called, and because she had been thinking about death and dying, the conversation took a different turn. She became nicer to her daughter and listened, without judgment. For the first time in months, Leslie N's daughter told her mom she was loved. She stated at the end of the conversation:

Having conversations would give people things to think about.
Because of this conversation and knowing I would be having it, I

had an experience with my daughter. Today she had a tragic experience happen and it seems like every time I talk to her, I say the wrong thing. Today I was so supportive because I was thinking, what if I am not here today. How do I want her to remember me? At the end of the conversation she said "Thanks, mom." I cannot tell you how much that meant." She had never said that before.

Daryl, who has spent a lifetime in the throes of violence is now in nursing school and wants to be a nurse so that he can heal people from illness. After attempting suicide, seeing people getting killed and being in several deployments, he has decided he wants to be a peacemaker. He says:

Well, my conversation with you today, I started reflecting my life. I am not doing anything wrong but I am not spending life doing meaningful things. Sometimes I just need to kick back. So like watching a reality TV show that is so meaningless that it helps me zone out. I could have taken a walk. I am spending more time outside, pulling out trees and plants. It feels good. I would like to work on that. We all have room for growth. This conversation has heightened my consciousness.

Below is a snippet of part of a conversation I had with Susan S. who had lost her mother after a long illness.

CC: Being that you seem to be aware of mortality, there is a lot of denial of our mortality. It is the survival mechanism but you have a deep awareness of it, you have accepted it. Has that awareness of your mortality changed your priorities in your life? Has it instructed in how you live, in terms of relationships?

SS: There are real slippages. When it is working well...I think I have a bit of luxury of being in my mid-fifties. I do not necessarily have to worry about dying right now. It offers a freedom to contemplate it. This is important. That is one thing I would say. I think that if you are aware of mortality, then. What does John Ashbury say...in your late thirties, the things in the world acquire a sheen to them? You begin to be aware of how things change, you become more aware because you have to let them go. It is important for people to think about.

There is not strong evidence that people change their lifestyles as a result of being aware of their mortality. The most significant linkage comes from Daryl who is seeking peace and healing in his war torn life. Susan S. said that her mother's dying process has shaped how she views the world but she did not go into detail. There is evidence when people talk about death, they do talk about the potential for change and human values surface as well as feelings of love, peace, solidarity and being a friend. This is in alignment with much of the literature as well as in my study, which identified, 'Best practices for living' as the most dominant theme.

CHAPTER FIVE

DISCUSSION

Death and dying are unique and universal processes that every human being will experience, whether they like it or not. They will view and contemplate death from their own deathbeds whether it be in a war or in a hospice and they will view, its tireless regularity, its promises and horror as people they love go six feet under. This monumental experience has not been sufficiently or rigorously addressed in the communications field.

This study attempted to address gaps in how we communicate on death and dying by designing a talking circle – a multi-media communication circle, if you will - between different individuals in different mediated environments. Inductive in its approach the case study sought to unearth conversations and pluck themes from a plethora of verbal exchanges within limited time frames. Through designing an interactive website on death and dying and reaching out to the limited masses of human beings, I also sought new allies to discuss death and dying. As I face my own limited time on earth, not helped by an aggressive disease plodding through my veins, I was curious to find out if people changed their lives, once they were aware of their mortality. The most radical thing I have done is eating a plant-based diet, being a bit nicer and trying finish off a bucket list including trying to visit 40 more countries. Was anyone else changing his or her personal behaviors, I wondered?

This chapter will discuss my main findings in the case study, consider methods and address shortcomings and weakness. I will also comment on the relative importance of interpretive results within a larger context and how it can

further our knowledge and understanding. Lastly, I will discuss the biases and my place as an active researcher and activist on the subject

5.1 Research Questions

Being impressed by the escalation and saturation of death and dying topics on the website, my optimism on making new friends on the Internet shimmered and then dimmed when I soon realized that cyberspace was a lonely place to have a discussion. The first research question asked the question. Will people engage in a conversation about death and dying after interacting with online content on death and dying? People, whether they were friends or strangers, did not engage in an online conversation. They listened, they read, they surfed the website but they did not share their thoughts, experiences or wisdom on the subject.

I received three comments on my website in response to videos. I sent out 69 Facebook messages to hospices and death and dying organizations and did not receive one response or affirmation of my website existence. I have over 500 Facebook friends, all of whom I know. I sent out four Facebook posts on my website highlighting new videos. I received a total of 38 likes and 24 comments, most of whom were friends. Cyberspace turned out to be a lonely frontier of communication exchanges. This may be partly due to the short duration of the death and dying project, insufficient marketing and outreach

People will comment endlessly on someone's fantastic dinner or a new picture profile. They will pour out their hearts online if a celebrity dies but there is dead silence when a person shares stories on death and dying. Why? If I were to follow the logic of Rains (2011) who said that health related support was increased

when blog posts were associated the proportion of posts and comments, then I could say conclusively I had no support.

At the same time, I received many gratifications from designing the website, researching resources and reaching out to people, even if there was silence on the other end. In an earlier chapter I mentioned that bloggers receive more gratification from reaching out to the world, independent of whether people comment or respond. I felt better and grieved less during the production phases of website design as well as in those moments where I either wrote a post or shared a digital story.

This deafening silence on talking about death and dying on the Internet was limited to the online aspect of my constructed talking circle. In real life, I had 8 participants who willingly talked to me at great length and were willing to share the conversation with the Internet world. Out of eight people I asked to interview, all replied in the affirmative. There was a waiting list of people who wanted to be interviewed. It appears people are more than happy to talk about death and dying in the real world but less likely to have a discussion in cyberspace.

Moreover, if I were to rephrase the research question to, “Who might talk to me”, my answer would be quite different. Results from my quantitative analysis of users, visitors and hits illustrate that people visited my website and on many occasions more than once. Weekly website unique visitors were those individuals who had never visited the website before (at least on the same computer). On any given week 15 or more unique visitors viewed my webpage. There was a surge in unique weekly visitors when I marketed my outreach and in one case, 103 new visitors browsed my website.

Website visitors may not have commented on my website but they wanted information. The website stats show there were hundreds of visitors to specific pages as well and while most of the visitors were from the United States, there were about 200 from other countries.

I learned a little bit about my visitors. They did not like to talk or comment but they did not arrive at the site by accident as the referral traffic statistics indicates. They had an interest in death and dying. From my online polls, I discovered that 5 out of eight people thought about death regularly. I had allies! Four people thought that death was a continuation of an adventure and 3 people felt the presence of a loved one. I was not alone.

The talking circle, in which people actively engage in a conversation on difficult issues, allowing each to share and taking the time to respond, was a constructed communicative model which allowed for cyberspace sharing and responses. I would have to call the cyberspace aspect of the talking circle a ‘hesitant talking circle’ whereby one person (myself) lets it all hang out and along with her digital storytellers shares their thoughts on death and dying.

There is silence on the other end, but it does not mean a taboo on talking about death exists. This silence may support findings that people are just not sure how to talk about death. Ample literature and research has shown that online support exists for celebrity deaths, memorialization, grieving or a health issue. What we do not know is if people are willing to talk about death and dying in everyday life in cyberspace. The silence may have to do with my outreach strategy except for the fact that a number of my friends knew I had a website.

In sharp contrast to the cyberspace silence, eight participants willingly engaged in lengthy conversations on death and dying. Research question #2 asked,

‘What are the major themes people discuss when they talk about death and dying?’ I found seven major themes: Best Practices for Living, Preparing for death; What death means; What is a bad death; What is a good death; Death is not the end; and personal experiences with death. In essence, when people get together and talk about death and dying, this may be what they talk about.

Death and dying related literature discussed, researched and analyzed communication values within certain contexts whether it be in hospice or hospital settings, end of life scenarios or between individuals who experienced a loss. The conversations take place within a context of everyday life, meaning that there was not a reason or focal point of the discussion nor were any of the participants in the dying process. I did not specifically interview people to find out their personal experiences with the death of a parent nor did I ask the same questions to each participant. I just wanted to know what they thought about death and all the accouterments that go with it. The conversations were fluid, punctuated with stories, commentary, and reflection from myself.

What was surprising in the interviews was the intensity and elaboration of best practices for living. While I steered some of the conversations in that direction, for the most part these discussions arose out of a ‘next step’ after we talked about death. Talking about death and dying may lead one – and fairly quickly – to consider how to live a better life. It could also mean that people were relieved not to discuss death for too long. There is a certain silent gasp we may make as humans when considering death for too long and may feel an urgency to do something different – get rid of the husband, get a new job, find your dream or sail around the world. Best practices for living did not address external desires as much as a desire for more solidarity, more love, deeper friendships and living in the present.

Marcus Aurelius Antonius Augustus, Emperor of the Roman Empire and nighttime philosopher said, When you arise in the morning think of what a privilege it is to be alive, to think, to enjoy, to love.”(Brainy Quote, n.d.) The phrases and statements all 8 participants shared revealed that sentiment. Possibly when we think about death and dying in intimate settings with another, their bucket lists become sparse with external desires and became full with heroic imaginings of a world filled with love, camaraderie and community. It suggests philosophical and spiritual desires, not material. This consideration is significant and will be discussed in implications for research in a later section.

The third research question #3 was the least conclusive and successful in its findings. It asked, ‘If people were aware of their mortality, would their worldview of themselves, of others and how they live change?’ As I mentioned earlier, I was interested because of my own sorry fate. I was also trying to understand the contextualization of evil situated in a denial of death, which authors have discussed within a terror management theoretical construct. There is some evidence that indicates that an acceptance of our mortality motivates us to experience personal growth (Pyszczynski et al, 2006). I had already been armed with anecdotal evidence that people do change their lives when they have a life threatening illness but would they do it with the mere acceptance that someday they will die?

My answers were inconclusive because my research design was not robust enough to look at these variables in a concise way. People made statements, alluding to the fact that awareness of their death has shaped their lives. Most people did not desire material possessions as much as affirming the preciousness of each day. The fact that discussions on being alive trumped other thematic

discussions is an indication that when people think about death and dying, they also think about living differently.

In summation, the results indicated that other variables are needed to have a fully functioning interactive website and blog on death and dying. While people heeded the call to visit my website, they were silent once they arrived. People did, however, like F2F communication and engaged deeply with the interviewer. Major themes were identified as well as generating ideas on what people like to most talk about when discussing death and dying in an informal conversation.

Evidence was lacking to support any hypothesis that people will modify behaviors if they were aware of their mortality. There were anecdotes to indicate this may be so and the fact that people spent a lot of time discussing being alive might show promise.

The communication model I designed – the talking circle – was a useful model to understand the different parts of where and how we communicate about death and dying. Discussions on death and dying conjure up deliberative and thoughtful responses and reflection but naming it a ‘talking circle’ may have been too pre-emptive and optimistic. We did not all talk to each other – and this does happen in talking circles – but when we did, the conversations were respectful and honoring each other voices were highly valued.

5.2 Implications of Research and Future Scholarship

The introduction to this paper carried weighty reasons as to why more research needs to be undertaken in death and dying as it relates to communication. I identified three theoretical guides that informed and inspired me in the formation of the talking circle as well as supporting my initial desires to understand major

themes when talking about death and dying and the relationship between awareness of mortality and personal growth initiatives.

The case study design provided a unique opportunity to explore all these questions, which were born out of a desire to talk and discuss a matter of great significance to us all. It was important because the study provided new insights into how death and dying is talked about amongst acquaintances and friends as well as how death and dying is not talked about between strangers in cyberspace. Through quantitative analysis, themes were generated as well as categories within those themes, illustrating or rather deconstructing a conversation into thematic parts and subparts.

Does this matter? I think it does. It matters because this kind of study of deconstructing and analyzing conversations on death and dying has never been attempted before within this context – we are all alive, relatively young and are just ordinary people talking about an important subject. Terror management theorists have never attempted to test their theory through conversational pathways on death and dying. Wong (2008) states death acceptance may lead to motivational impetus for personal growth.

Through this small case study, I will be bold and suggest three potential emerging hypotheses: 1) conversations on death and dying generates a motivational impetus for personal growth and a deeper understanding of our common humanity; 2) when people talk about death and dying in everyday life, they will discuss certain themes and do so with relative frequency; and 3) when people will talk about living well more than they will about their fear of death.

In the introduction, I elaborated on certain theoretical constructs, which guided me into making certain decisions. Uses and gratification and computer mediated communication, as theoretical approaches, allows researchers to understand user and new mediums behavior as well as investigate mediated communication. There was a brief consideration of how bloggers needed to blog more than they needed to listen (Papacharissi, 2002). I might agree on this, and at the same time researchers in this field must yield to detail. I think uses and gratifications theory is only as strong as the subject matter they are discussing. They cannot say unequivocally that bloggers get more satisfaction from talking than actually listening to others. I personally ached, to listen to other people's stories and tried my best to make cyberspace friends. A direction for both CMC and U&G researchers could be to analyze a difficult and sensitive topic – death and dying – on the Internet. This is a fecund field of exploration, embedded into larger contextual areas of how difficult conversations and themes strengthen or weaken these theories.

Initially I argued that relational intimacy around a difficult issue could be more fully developed online. I was inspired by this notion because of the expansive discussions taking place online from grief sites to memorials. My quantitative results may have shown that I was wrong and that Walther (2001) who specializes in hyper-personal communication may have to revisit his assumptions that the online environment is preferable to offline and that self-disclosure, a communication phenomenon, purported by Jiang (2010) may have to be revisited at least when it pertains to sensitive subjects.

This brief discussion above does not indicate I tested these theories. I did not. But I was guided by their optimism, now dimmed by the reality that talking

about death and dying on the Internet, does not yield intimacy or a cacophony of excited voices.

Because I believe that my small study was important within the larger space of communication theory and practice and that further research on death and dying is essential for potential policy directives, considerations of elder care, and health care directives. My recommendations for future scholarship and activities are as follows:

1. Field of Communication. We need to explore death and dying related topics and its place in interpersonal and family communication. A robust trend should be underway to understand how this profound experience shapes our world-view, our communication with one another and the choices human beings make. Furthermore, more work needs to be done in the area of mass communications. For instance, does the endless violent drabble on television affect our denial, acceptance or apathy towards our own and other's death? Death and dying is a rich field for communicative exploration. Another area that comes to mind is the role of mass media via advertising, marketing and public relations in denying death (and aging for that matter). What are the psychological underpinnings of this?
2. Death and dying themes. The seven themes I have outlined as to what people talk about should be explored further. Because my case study was small in size, it might be a useful exercise to explore from a communicative point of view, areas of what is considered to be a good death. Evidence-based research needs to

be developed on this topic as health care for the elderly and the dying is depreciating and there have been recent reversal of trends towards better care for the dying. Let's put it this way: good care comes at a cost. Understanding what a good death also has policy implications for aging populations. It should not be a one-size fits all approach. Care should be focused people-centered, not system-centered. I also believe there is rich research awaiting us in making the links between death acceptance and motivational impetus for personal change. This has significant promise for mental health and preventive health measures. Secondly, I would look more broadly and with more precision into how we communicate on death and dying. For instance, a longitudinal study on a larger group of people might be interesting or a large undertaking which is survey driven and where variables can be tested more rigorously.

3. Interdisciplinary research We have not given adequate attention to this rich field of inquiry except in small, isolated pockets such as in fields of psychology, education, thanatology and health communication (and this is at the end of life). Communication theory and practice suffers, in my opinion from theoretical and research isolation. Death and dying is an area where interconnectivity will enrich death and dying research – fields like sociology, anthropology, and psychology are areas where communication scholars can team up on this important topic.

5.3 Limitations

Because of the qualitative nature of this exploratory case study, there were a small number of participants from whom data could be drawn. This is especially true of identifying major themes in conversations on death and dying where the data pool was small. This humble attempt to harness an understanding of how people will talk to me (website development), who will talk to me (potential new users and friends) and what they will talk to me about (developing themes of death and dying discussion) excluded a vast array of voices. Furthermore, six out of 8 participants were baby boomers, a generation more likely to discuss such unearthy matters. Convenience sampling has its drawbacks; unconsciously or consciously we are attracted to certain people over other kinds of people, which may have skewed how willing people are to talk about death and dying.

This limitation can be overcome in the future by having more control over sampling choices. This case study may proclaim that baby boomers talk about certain themes but it cannot equivocally say that this is a microcosm of what people talk about when they talk about death and dying.

Sampling bias was inherent in the instrumentation used to quantitatively assess how many people may have wanted to talk to me. I chose stat plugins which were easy to install and easy to use and did not test their validity. This can easily be overcome by testing the validity of statistical plug-ins for quantitative analysis on unique visitors and viewers.

Bias may have been inherent in my coding and analysis of phrases as well as identifying themes. I have reviewed the transcripts and the digitalized versions and my personality was not that of a passive interviewer. I was alert, hungry for

knowledge in as much as the participants wanted to share that knowledge. Bias may have occurred in my control of the conversation. At the same time, formal interview questions would not have worked. While I utilized thematic analysis, intuitively understanding that content analysis would not be sufficient in answering my open-ended research questions, I would suggest to mitigate these limitations, two or more coders should be used. This is a deeply emotional topic and, for pure objectivity, demands more objective analysis. That being said, I coded and re-coded several times and did my best to be objective.

5.4 Research Bias and My Place in the Study

I have been interested in death and dying for a long time. As an international human rights worker and one who witnessed slaughters, deprivation and other assorted acts of cruelty, I often wondered why are people so mean? It seemed so pointless and so void of rationality, especially in light that we, as human beings, are temporary tenants on planet earth. The nature of evil has captured my attention for decades and until my mother died, I was working on a thesis on the communicative processes that lead to evil and horrific actions by ‘good people doing bad things’. When my mother died, I left a world of interests and passions behind and transmuted into a lonely, pathetic person who wanted to talk about death and dying. Now that I think about it, I visited hundreds of websites, looked at the information and never commented!

My research into this inquiry was personal. I really wanted to know if people would talk to me and what themes would emerge when people talked about death and dying. People like me. But maybe not like me. I am ill and my third research question, the most problematic in findings but one that may hold the most promise,

came from a desire to figure out if people could make changes if they know they were dying.

It also came from magical thinking on how we can turn evil around. Mortality workshops, maybe? Instead of looking at evil from a particular perspective, I could be more positive, contribute to the death and dying literature, all the while pretending if people understand their mortality, maybe they would not be so evil. From an emotional point of view, and what I find awkward and incomprehensible is that for all the immense evil I have witnessed in the world, what brought me down to my knees was the death of my mother and best friend.

During the course of the research, I knew I had to be emotionally careful and objective as much as possible. I was an active participant in the talking circle. I created the website to my own liking. I put up resources I liked and sent out emails at my discretion. I was an active part of the development and implementation of the project.

The interviews were the most difficult for me in not controlling the outcome and getting people to say what I wanted to hear. During the interview, I revealed who I was, my motivations, my thoughts and desires to both make a connection with a person (I knew them all but not on this level) and because it was my talking circle I created. For the first two interviews, I tried to be more systematic, asking people what was a good death. This strategy felt superficial and forced and as a ‘talking circle’ leader, I started caring less about what a good death was and more about what people really thought about when the subject came up. So I changed the opening to, ‘what do you think about when you think about death and dying?’

Research is born out of a curiosity about our subject matter. I am not convinced we can NOT be biased. Qualitative research lends itself towards less

objectivity; we are active participants in the research, whether we like it or not. I tried to minimize these biases by coding procedures that ensured a level of analysis that could make a contribution and not be gunned down by my own grief and personal agendas.

CHAPTER SIX

CONCLUSION

Unless a magical potion to prolong or even eradicate the permanent ending of vital process in a cell or tissue, every person alive today will be dead in 100 years. Our temporary situation on earth has harnessed a wealth of cultural rituals, perspectives, philosophical meanderings, theories, and art. A natural process in the cycle of life, death has simultaneously has been diminished, negated, and its abuse of its irrelevance in popular American culture is evident in the numbing violence on television and on the streets. Death has lost its sacredness. But death is gaining luster as new research and Internet trends indicate that a taboo has been lifted and conversations, however limiting, are emerging as a key communicative moments to research.

The Internet was not an accessible pathway to interactive communication on death and dying. What I did find is that people want to talk about death and dying in real life. They want to have real conversations and I believe that understanding its epistemologies and how death creates meaning among the living can lead us all into new fruitful areas of research, personal growth and even societal changes on how we care for the elderly and the dying.

What is my magical thinking? I want all of us to be more sensitive to death and to its natural and unnatural occurrences. I want us to talk about death more so we can be kinder human beings. I want us to stop being cruel to one another. We need to stop killing each other. I want us to be in harmony with the earth, knowing it makes no sense to be selfish, and egotistical. I want us to realize the greatness of

the gift we have received, to embody our bodies with gratitude because we do not know how long we will be alive. Greed has no place in our lives if we truly understood our impermanency, our transient nature as human beings. I want us not to waste our precious time in front of the television but instead utilize that time to help our fellow human beings who may not be as privileged as us reading this paper.

I want us to talk about death to bring back the sacredness of life. Our sensitivity would assert our moral outrage at evil, urge us to care more for our fellow human beings, and inspire us to love more people, more deeply. I want to talk about death so we can recover our sanity as a species, understand that a denial of our death, denies our essence, our beauty, and our potentiality as human beings.

That is why I did this paper. There, I said it.

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APPENDIX A

CONSENT FORM

University of Hawai'i

Consent to Participate in Research Project:

Who will talk to me? An exploratory case study on death and dying in a cyberspace talking circle

My name is Charmaine Crockett and I am a graduate student at the University of Hawai'i at Manoa (UH), in the Department of Communications. The purpose of my current research project which will serve as my masters thesis is to create, document, describe and analyze a cyberspace talking circle on death and dying. I am interested in how people talk online about death and dying.

Project Description - Activities and Time Commitment: If you participate, I will interview you once, via a high definition movie camera. The interview will last for about 45 minutes. I will record the interview and send you the final in MP3 format for your review. At this time, you can request any edits to the final digital interview. I will be asking you a question, 'What is a good death?' and our conversation will ensue from that question. Afterwards I will ask you to answer two questions on a tape recorder:

- 1) Why did you choose to participate in this study?

I will use information from the interview and from transcriptions of the audio-recorded answers from the above 2 questions and send them for you to review. The answers to these questions will not be on the death and dying website but will be used in my analysis of the cyberspace talking circle.

Your video story on 'what is a good death' will be put on the website. If you would like for me not to use your name on the video and the introduction, please let me know. People will see you talking as it is considered a 'digital story.'

Benefits and Risks: I believe there are no direct benefits to you in participating in my research project. However, the results of this project might help researchers, including myself, learn how people think about death and dying and what they consider to be a good death. This will enrich the conversation and hopefully expand research into communication and death and dying. I do not foresee any risks unless by chance someone recognizes you on the web.

Confidentiality and Privacy: I will take steps to protect confidentiality and your privacy in ways that you communicate to me. For example, should anyone ask for your contact information, I will email you and ask for your permission. If you would like a

summary of the findings from my final report, please contact me at the number listed near the end of this consent form.

Voluntary Participation: Participation in this research project is voluntary. You can choose freely to participate or not to participate. In addition, at any point during this project, you can withdraw your permission without any penalty of loss of benefits.

Questions: If you have any questions about this project, please contact me at via phone (808) 282-8407 or e-mail Charmaine@igc.org. You may also contact my University of Hawaii thesis advisor, Wayne Buente at (808) 956-3360. If you have any questions about your rights as a research participant, in this project, you can contact the University of Hawai'i, Human Studies Program, by phone at (808) 956-5007 or by e-mail at uhirb@hawaii.edu.

Please keep the prior portion of this consent form for your records.

If you agree to participate in this project, please sign the following signature portion of this consent form and return it to ***.

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Tear or cut here

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Signature(s) for Consent:

I agree to participate in the research project entitled, "**Who will talk to me? An exploratory case study on death and dying in a cyberspace talking circle.**" I understand that I can change my mind about participating in this project, at any time, by notifying the researcher.

Your Name (Print): _____

Your Signature: _____

Date: _____

APPENDIX B

INTERVIEW TRANSCRIPTS

This appendix contains transcriptions from eight video interviews conducted with participants of the digital stories on death and dying.

The following are raw transcripts from eight video narratives on death and dying.

An interview with Michelle Nicole McDow (MNM)

CC: Hi Shellie. We are going to talk about my favorite subject - death and dying. I want to thank you for being a part of this interview. Like I asked your husband, what do you think about when the subject surfaces? It is not a subject that you talk about when you have people over for dinner. There is silence, so I am throwing out the question. What does come to mind when you think about death and dying?

MNM: I think about death differently - if it is myself or someone else dying. I used to tell my mother..... I am more concerned with the living than I am with the dead. I go into work mode so I recently had a death in my circle. someone my age who was a good friend in college and was loved and liked. He was a rising star and was working a couple of shows in Vegas. He was starting to do other productions and was working with Lady Gaga and Dancing with the Stars. His passing was unexpected. My immediate reaction was the people he left behind. I went into work mode. I phoned people like his ex-girlfriend because she needed support. I was organizing people in Hawaii. And it did not hit me until that night after I had talked to tons of people and looked at logistics and flights. Logistical coordinator and I were going to cry on the way there. I do not think it hit me until the funeral. I wanted to throw up because I did not know it was going to be that bad.

CC: When you say bad, what do you mean by that?

MNM: I was anxious about the funeral, I was late. I was alone and did want to get dressed. I knew I was going to see my best friend. I had not seen anyone in seven years.

CC: I think I saw some of the pictures in Facebook.

MNM: We were acting up at the funeral because that is what they did. He was in our group. It was bad to see young people dying like that. And they were all actors and actresses in Hollywood. I am more concerned with the health and wellness of those left behind. I really put my feelings into the back burner and go and cry alone. I am not big from soothing from the outside. My husband is a soother and touchy feely. I am not like that. I am cracking the whip. I take my medications to the funeral. Need a med? Need food? Because, people were acting out. That is how I am, how I get through things by getting busy and detail oriented.

CC: You are also a very caring person. You care.

MNM: I care about the things that people are unable to do. So I think, I have to do this because someone has to be there to do work. You cannot do the work when you are emotional. I am emotional but I do it in private. In public, I am in work mode and can't do that when you are crying. You suck it up. Hard Black women raised me. Suck it up, crying is for babies, dry those tears up. We did not have a lot of room for heavy emotion. You can get emotional but you have to keep going. It may seem insensitive but I thought while everyone is getting emotional, I will keep things going. I had to call so many people. Our college life and home life are separate lives. There are a slew of people parents did not know they existed. I have connections to all these other people.

CC: You are in a sorority.

MNM: We are all still tight. Now everyone is doing things across the globe but I had to call people and tell them the logistics. On and on. Give information - this is where the funeral is, the family is located. That is just me.

CC: When you went to the funeral, you made a statement like 'there is nothing like people grieving.' I went to a funeral this past weekend but everyone was 85 and over. It was expected. What was that like?

MNM: When you are with your friends, it is party time. You see a lot of your friends at a funeral, it was different. It is a different environment. Normally you are laughing and doing positive things. It is a weird feeling when you see them on these terms. When I am at home and run into people it is laughter. The funeral was somber, really sad.

CC: Because you do not expect it in your age group.

MNM: No. Especially if you went to college and survived college. I survived the hood and then college and thought I am home free until later on in life. I did not get into the gang wars. I went to college and I had no hit and run, no IUDs, no drug addiction.

CC: And then you got your masters.

MNM: Yes, you expect everyone to be doing good. We were from the ghetto. To survive the ghetto and college. This friend died two weeks after his 30th birthday. We were all turning 30 this year. If the teens don't take you out, the twenties will. But if you make it to 30, you are home free. We are coasting. It was so unexpected.

CC: What was it?

MNM: Pneumonia. It was untreated and probably misdiagnosed. LA is a weird place. They thought he had a rash and next thing you have a flesh eating disease. I do not know the details but he was sick but he did not tell anyone.

CC: That definitely was not a good death.

MNM: It may have not been a good death, but it was such a good life for him. We could not be upset because the whole top of the funeral was a bunch of young people. We were having a ball - he did a lot for 30 years. He was the reason I went into deaf studies and learned how to sign. I learned how to sign language. He is from the inner city like me. it is funny that you are doing this interview because the last time I was interviewed I was being interviewed on a summit and another friend had just died. Our class president was shot and killed who was my best friend's boyfriend. I got interviewed, it was around the time it happened and wanted to talk to me about what it was like someone dying. It was a horrible funeral.

CC: Oh my god.

MNM: We were in high school. He was the class president, he was going to college and had a scholarship. Everyone loved him. he was a likeable good guy and he got shot in his car. It happened all the time. It was awful. people were passing out in the funeral home. I had to break the news to my friend. he was a senior. The school was empty on the day of his funeral. My friend to prom with him. It was my tenth grade year and his senior year. Three friends died. One guy died on his way to college and died in an accident. Then shortly after that, in a top teens program, a big rig on the freeway hit

him and he died. And then Eric got shot. All three of those men were black on their way to college.

CC: How are the stories of these people that you knew at a young age...has that informed your life in any way? Has it informed in terms of how you see your own life? That is an awful lot for a kid to handle.

MNM: I lived in Los Angeles at the peak of the gang wars. And people died all the time, like every week. On the block, you had a friend who had a cousin or a friend who had a brother. We were used to funerals. I know about the wake, the funeral and the repass. We were familiar from a young age onward. The whole community. Everyone was there.

CC: Does that witnessing, that observation, those experiences as a young person - did it harden you or soften you or was it matter of life. Did you see anything odd about it?

MNM: I did not think it was odd but going to funerals with people you used to run with, it brings back a lot of good memories and it reminds you that you have a good life, in general. Every time someone dies, you go through a resurgence of wanting to live life. I had another friend who passed away and she was in my circle in elementary school and she passed before college. There was a whole crew from elementary school who were together at the funeral. That was incredible. We had a good time and it makes me appreciate life. I love my friends and I like making good memories and we made good memories in the last trip. It makes me appreciate my life more and to live it more. I did not have friends who died tragically on their own in gang wars or by suicide. Most of my friends were people who passed away were a fluke and that makes you angry sometimes. you know there are bad people and why take away a good person. They would have been a star and loved.

CC: Have you figured that out? Why all the good people pass and the bad people live until 95? Some of these dictators, for instance.

MNM: I do not want to think. I can say that everyone has a job to do while we are here. We are here for a reason. And when it is done, you go home. It is almost like you go to work and then it is finished and you go home. The people are at work are still there, but your job is done.

CC: You think it gets down to that?

MNM: Yes, they go off the clock. The rest of us are not off the clock, not yet and we keep on going. And I agree with Daryl that we should not check ourselves out but when God is finished, we go home.

CC: Sometimes it may not be pretty, is that it?

MNM: Sometimes, the way you exit is not that great. Sometimes the way you come in is not that great. My husband was not supposed to be born. He was born sick. He and his twin brother....

CC: When it is your time, then it is your time. In the meantime, what do we do then, how do we live the good life?

MNM: The good life is super enjoying life and not to the detriment of hurting people. if you are greedy and want to own everything. I mean, enjoying of being alive. I enjoy going into bed with cool sheets. I shake my legs when I get in. I love food, I am working on it but I enjoy food. How did this get created? I enjoy myself. Most things that I do, I am enjoying that.

CC: You enjoyed your job when you were with us?

MNM: I enjoy people of all ages, from all over the place. My husband says my Rolodex says nothing matches. I love stories, I love to eat. I love to eat with other people and nationalities. I am into the experience of life. Being in it.

CC: A lot of people aren't. Their bodies, minds and souls are in different places. One thing that I have always known about you, is that you are integrated.

MNM: I am not seeing life is peachy. I have had serious bouts with suicide when I was a teenager and when I was in college and when I was in Post College. I have gone through mental health treatments for feeling like I am not able to go forward with what I am faced with. In an upswing, I am very happy person to be around. I have highs and lows. I am not bipolar. In general, I try to enjoy everything I am involved in. If it is not enjoyable, I leave. I picked up a difficult career to be in but I enjoy it. When I was in college, I worked in a residential treatment facility. I had to give people showers and deal with poop and had a good time every day. It made no sense.

CC: When you talked about having a job on earth, is this part of your job? Your purpose?

MNM: Yes, right now I am not working but I am always working. I am the free social worker. I do it for everyone in my life. People call me up asking me for advice. I always wonder why people think I can do this. I am in Hawaii. People call. 'Can you do my taxes, can you help my father?' I am the catch all for everything. I do believe we have a job and I have multiple jobs on earth. One of my jobs on earth was to be my husband's wife. I was given this job because I have a sensitivity to mental health. I have sensitivities to not great upbringings. With my husband's case, I have been his wife, best friend, advocate, and lawyer. When he cannot get over the emotional hurdles, I do not want to set him back so I keep things floating so we do not end up on the streets. Sometimes he checks out. I have checked out and been to facilities. I am working on projects of my own. I started a business because I do not have a job.

CC: You have a job all the time. Maybe it is time you start focusing on yourself. I want to get back to this idea on the life that we have. To have a good death is to have a good life, right. You live well, you die well. Can you touch on that? You have by saying, we have a job to do. Some of us waste a lot of time, not knowing what is going to happen. What would you say, how can we not waste time. You have this idea of a good life...we are all mortal human beings. How do we live fully? Every time I saw you on campus, you are present.

MNM: I would say, my number one job is to be God's friend. That is why we were created. We are God's friends, first and foremost.

CC: What does that mean?

MNM: Well people were created as another entity, another aspect of God just like animals, angels and nature, and the planet. Everything praises God without being told. Humans get a choice. By being his friend, are taking care of his other friends. I am going through this, make all this cool stuff to eat and smell and enjoy and then I am going to make you suitable for the environment. We are to be enthralled with our senses - the rain, the smells. God wants us to enjoy life. No other being has the choices we have. We have a mission. We get to stop and smell the roses. Even if you missing senses.

CC: There is a lot to be grateful for.

MNM: There is a lot to take in. Sometimes if you can just step back and look at things. There is such beauty. You start thinking about why we were created. To be his friend. Adam and Eve were symbolic. Enjoy.

CC: We have made a mess of things.

MNM: We have screwed up. With God, I will say that he makes rules and he lives on rules like cosmic. Whatever you do, God has a rule to save you from yourself. People are unhappy for a lot of reasons. If you were God's friends, a lot of bad feelings would go away. He is always with you. People find God in strange places - being kidnapped, in prison. He is always there. People have to go away before they realize things. The most important relationship is you and him. Then comes friends, co-workers, families...all the way down to enemies. If we were his friend, things would be good. I think humans were built with a puka that only he can fill. You go through life with a void but he is that void. He desires to hang out with you, the same thing your friend wants and your husband. Think about how we relate to things and people. We usually do not stop to do that, we are distracted. We then lose the enjoyment of life. I get enjoyment because I spend time with God and your intimate with his word and you see the world as more vibrant and full of things to the point where you are happy. Thank you. Have you ever had waffles and chicken? Thank you.

CC: Well it sounds like if something were to happen to you, you would be okay with that.

MNM: No, I would not because I will be concerned about the people I left behind. Who will take care of the cats? I would be concerned, I would not want to leave earth because I have to fix things like pay off three bills. That is how I think. I worry about others and everything being in order and then I can go home.

CC: Is there anything else you would like to say? You have covered the lightness and heaviness.

MNM: I have said that life is so important... I tease my parents because I cannot imagine them apart. I tell them they need to go together because if one stays, they will be such a burden on us. They are so interconnected. I feel that when you leave this realm, you go back to the source which is where you came from. That is a good thing. There is no more pain there, no more of things we do not like. Suffering is over with and it just pure happiness and satisfaction. If you can get a glimpse of that on earth. That is life forever. It is a great thing, a beautiful thing. You are going home. Wow. That is awesome. It is tragic when you live a bad life and are not sure if you are going to go home or not.

CC: You are good to people.

MNM: Yes, you are good to people and you are God's friend. If you are his friend, it does not matter about religion. He will tell you what you need to do and how to be. When you have that kind of life, you are coming back to a home going celebration. They are waiting for you.

CC: Home going. I have never heard that before. So it...

MNM: It is that we are all trying to get there. The home going celebration. From the moment you are born, you are on a path to die. No one gets to stay. You are supposed to go home. You are on your way, the moment you are born. You are going home. All the babies who were aborted, they went home. There is a celebration. Eventually, we are all going to go home. I hope they have chicken and waffles there. And Jamba juice.

CC: Oh Shellie, thank you so much.

Interview with Darryl

CC: Hello Darryl. This interview is about death and dying. I have been conducting these interviews with all kinds of interesting people and now you are included in that circle. You know, it is a subject, how do you talk about it, what do you talk about. My first question to you is what do you think about, when you think about death and dying? What comes to your mind?

Darryl: I think about death and dying as a cultural experience. On a cultural level, some people see death as a transition, others a final pathway from life. For me, personally, there is a whole bigger story on this. Beyond the religious rhetoric of saviors coming to save us and the notion of heaven... I believe, I think human beings are like butterflies. We are caterpillars. In this essence, we are the caterpillars. Then we go back to God, to the essence of who we are. We are more enlightened because of the life we lived. I told Shelly a couple of days that I go looking up at the sky a lot. When I am in school, when I am travelling around the island, I am looking at the sky.

I think, we as people, have God and we are far away from what our ancestors did. In Africa, people celebrated when someone passed away. We still hold tight today in that tradition in the sense when someone passes away we have a repass. A repass is when people talk about the person's life, how they affected you. No-one talks about the way the person died. People talk about 'Oh I remember when so and so did this.' And people will play music. My Aunt just passed and my mom, my stepfather and aunt used to party and listen to music. When the Aunt died, everyone got wasted and had a good time. The funeral was sad but the celebration of the individual's life

was better. One thing about death is that it brings people together. When I pass away, I hope that I am asleep. I do not want to die violently.

CC: That would be a good death to you?

Darryl: A good death is a life well lived. Someone died in a car crash but they were the best person in the world. MLK was a great person. As far as a good death, I think of it as a good send off?

CC: You were in the military. I have never been in the military, lots of our young people are dying. What do you think about that?

Darryl: My second deployment was in 2004-2005. My experience is that I saw a lot of people die. Our base always got attacked and people died. Some of the things I think about are that young people should not go in the army. I thought after one incident I thought that young people should not be here. Older people should be there. Young people die and they do not get to live a life. In the Army, it makes you grow up fast. You are a man in the army. You are a warrior. I felt like kids got robbed. And that is on our side. In 2003, my first deployment, it was the first time I had been out of the country. The crazy thing about it, people kept talking about soldiers dying like on FOX News, which is a bunch of crap. I felt when it came to death in the military, it was very different from death in the civilian world. You could die today on a convoy mission and five hours later I am taking their spot. You do not get time to celebrate, to think about the person, how it affects you.

CC: It has to be somewhere. Here you are talking about tradition and the nature of the repass, the celebration and yet you did not have a chance to do that. How do you get that out? How do you honor that human being, your comrade?

Darryl: You can't drink or celebrate but they would have a memorial service. There is a pair of boots, a weapon, and a stick and then the dog tag hung over the weapon. They give a little, quick eulogy. Basic facts of serving the country well and died valiantly. Then you go back to work. My first experience of death as a soldier, I was on the road. I did not know I was taking a person's position. We were on a convoy. We get back and go into formation. We had a memorial service and did not know the person who died. I did not know the dude but I cried because the way he passed away was messed up. Low and behold, I was assigned to a mission, that I was taking the place of the man who died that had the same name and me and who was Black and just like me. People were being like, they do not believe in ghosts or spirituality. I heard him talk in my room and it was on me to hear him after he died. I was sleeping on his stuff because it usually takes a

week to get it out. The dude thought he was not dead but just being cool. I heard his voice, never met the guy in life. There was no opportunity for him to have others celebrate.

CC: You are in this war zone, you are seeing all kinds of things that you thought you would never see as a young child. Did you all ever talk about the possibility that you may not go home?

Darryl: You do not talk about stuff like that. It is not the real civilian world. We do not sit around and have conversations. Everyone wants to make it back home but you are so focused on the mission. Only one time I thought about death was when I loaded my weapon and left it in my tent. I was getting shot at but was trying to grab my weapon. I thought I was done, I could not reach my weapon in time. I thought I was going to die. Someone came to save my life and grabbed my jacket and we ran into a house. That was the only time I came face to face with my mortality. I saw so much. I saw a kid get hit in the head. People put labels on someone else's death. If you are a combatant, we do not think it is a life worth living. You attack me and attack our policies and put harm to me, I cannot feel sadness for them.

CC: You are not allowed to feel for them, for their family or if they had kids?

Darryl: No, they were not thinking about us. They want to take me out, if they had an opportunity. I saw a whole family dead. We were coming through a town. There was a whole family that was charred. He was holding the steering wheel but he had no head. No one said that we should stop. In America, if you saw someone dead, you would call the cops and try to assist. There, it was like that camera - a material object. Enough.

CC: So a good death, forget the good death. Is this under the banner of the bad death?

Darryl: If I had died that night, I don't know. I grew up in Philadelphia in the inner city and I was shot at before but nothing like that. No one wants to die in the street and get shot at. That is a bad death, if you die in the street. For some people, they may think that is a warrior's death. They died in the battlefield that is a warrior's death. Not me, that is a bad death. A good death, dying in your sleep in your old age. Not waking up. Those are things I think about. I also think about death affects people, especially if it is a close relative. I had a close relative who died. He shot himself. He killed someone and then shot himself in the head.

CC: Was this in Philadelphia?

Darryl: Yes, it was in 2009. My uncle, he was a city worker as an administrator. He had a dark side and was depressed and had anger. He was seeing someone on the side and she did not want to see him anymore. It was 630 in the morning and she did not want to take her daughter to school. Her car was parked. The 11-year-old daughter was in the passenger seat and then my Uncle went around to the passenger seat and shot the girl again. He killed himself. You do not get points for killing yourself. If someone is a Jihadist and says he is going to blow the cafeteria up. That is wrong, you are not supposed to shut down until god wants to shut you down. You are here for a reason and keep your head up and keep walking. You just have to take it.

No one wanted to give my Uncle a funeral. He was not going to get nothing. He did not deserve a funeral. His wife worked with my Uncle and the mistress. They all worked for the City. She found out. She had to jump through a lot of hoops. I think that is what I got... I do not have problems with dead bodies. We had to take him out of his casket and I dug the grave. I dug it so he could face east. We were the only two at his grave. No brother came to his grave. The son did not even go near his father. He was angry but more sad and scared than anything. People have a skewed way of looking at death like it is the final thing.

CC: And it really is not.

Darryl: No it is not. If a person did not die...in a revolution.... somebody has to die in order for someone to know this is serious. People are passing away, let's figure something out. If people did not die, people would think they can do anything they want. Death is the final call. If you tell someone, 'heh you better pay me back or I am going to take your wallet', that is serious. Paying money back. Death gets results. Do I believe in killing? No but death gets results and in some cases, it works.

CC: If it gets results and you were in the military. I want to ask this question. One would think that because we have seen thousands and thousands of young men die. I was around for the Vietnam war and they were just coming in the caskets every minute - you would think these deaths would be honored in a communal kind of way and that something would shift, wouldn't you? Based on what you said. But these young boys whose lives are just cut off. It is almost like unmarked graves.

Darryl: When you talk about war, there are so many things that play in war. It is not pretty and never has been. When you were coming up in the Vietnam Era, people had a voice. Nixon was listening. if it was not for the

soldiers dying in the way they were, the Vietnam War would not have ended the way it did. It did because people kept petitioning that they were dying for nothing. You have people dying for no reason but it got the results. It got communism not to spread, they had a foothold there (US). Is a loss of life worth getting results?

CC: Is it?

Darryl: No, it is not. You do not see Nixon out there. You do not even see the top Generals unless something bad happened like Saddam Hussein getting killed. The feeling is that these people are key players and their lives have to be protected. What about my life? I want to be protected. My first year in Iraq, we had no armor. I could have died in an instant.

CC: You had no protection, aren't you supposed to have that?

Darryl: You are supposed to have it, that was the thing. A specialist got up when Rumsfeld was out there and told him we had no protection on the cars or anything. We had no protection on bullets. They were blowing money but finally in 2004, they got us some new flap jackets and started getting armored vehicles. They made us feel the country did not even care about us. All the families got when someone passed away, was a flag. They charge you for dying in the Army. If you die on May 2, your pay stops and the family do not get paid. If you die in the middle of the month, the families do not even get a paycheck. Benefits are not paid and sometimes you see people die, you say life is not worth living. I have been running around this house thinking I have to get out of here. Shelli wants to know what is going on.

CC: You have seen too much, you have seen way too much.

Darryl: I am only 33. I say to myself. It may come off as suicidal. I do not want to kill myself but I do not want to be here either.

CC: What are you studying in school?

Darryl: Nursing.

CC: So you wanted to heal others? There is a dynamic that is going on. You have seen so much and so a lot of Vets have not had time to process everything. But at the same time, you are a healer.

Darryl: Yes, that is the thing. On my last deployment, I did a medevac van. I said that I did not want to be involved in killing anyone or be involved in anyone else's dying. I want to help people get through a sickness,

children especially. And if they can't get through it and they die, I want them to know that someone loved them and that they were special. You pass and you are going back to the essence of God. Give them assurance and they should not worry about it. If they are sick, they can get better and you will be a special person. I do not even want money. It is not a selfish thing. I want to be a part of bringing life in this world and if it can't be sustained, they left on a good note. That is why I am becoming a nurse. Not because they get paid well. I want to help. My cousin almost died and got shot eleven times. The main artery that goes from the heart and it supplies blood to the major organs. It was almost over and the doctor said it was over. I saw my cousin on the bed and kissed him on the head and told him I loved him. I said to him not to go and told him he was my hero. He heard me and I told him I cared for him. My cousin made it and the doctors called him a superhero. He was shot 11 times in the chest. He is in a wheelchair, he can talk. I called him, four or five months ago he was 2 seconds from death. The doctor told him he did die. Those words of encouragement, well he got better. Before I got there, they declared him done, he was not going to be on earth. His organs were not functioning, his legs were not moving. There was no blood circulation. He was messed up and there were all kinds of machines to sustain his life. He does not remember but I do and it works.

CC: I can't help but think that this is your purpose.

Darryl: I am looking for my purpose.

CC: It is obvious to me but it may not be to you. You are supposed to be a healer and help people. You have seen so much from living in Philadelphia. I lived in NYC for decades so I know Philly. You have been in the military to going to Iraq, you have seen so much. We can either destroy ourselves or we heal others with our wisdom. You need to use wisdom to heal people. That is a beautiful thing. That is beautiful. It just, I mean and to help others who have come close to death - whether it be vets or otherwise - to start helping them to have a good life. I have never been in the military but after seeing what you have seen, I would imagine it would be hard to have a good life without spiritual supports and a loving family and friends.

Darryl: When I came back, I struggled with suicide. I tried. I was dating Shelli then and we had a bad argument and I was in my room. She came in and wanted to take me to a hospital. I was admitted but that is how I was feeling. I thought I was not worth anything, that I had a part in other people's deaths. I felt guilty that I got to come back. I wanted to hurt myself and did not want to be here. I turned around because of my support system and the people I had around me. Just coming across certain individuals. It was a struggle to maintain all of that. There were people who saw worse, but

it does not matter because you saw something happen. I have to take medication, some to sleep, and some to not be depressed. At the same time, the thing that gave me the most help was just having someone stand by me. Most people walk out of our lives. My wife went through hell. You have people supporting you.

CC: There are so many more questions I want to ask you. This has been a great interview. I keep thinking about the dog tags, the boot and the weapons on a stick.

Darryl: Actually the weapon was standing up with a helmet.

CC: In the beginning, when you were talking about honoring a life and celebration, it is just a slap in the face. Is there anything you want to say about this topic?

Darryl: I have something. I think the reason we do not celebrate death so much because we have a lack of understanding of what is ahead of us. There is continuous propaganda on television, in magazines. We have a great appetite for death.

CC: You mean by appetite that we...

Darryl: No, I mean for destruction. When I say 'we', I mean we as a species, a group of people. You just cannot take some people that do not like that stuff, they were a minority. People see it on television, in cartoons.

CC: Doesn't that all make us more insensitive towards death.

Darryl: It is all desensitizing as to what death is. My ancestors had a whole different view of death. Death was a beautiful thing. When you die now, you go to hell forever. Because of the corruption in the Americas. People do not want to hear about God, they want to know about what is in it for them. I think people.... Ancient Hawaiians did not even see death as the final departure. They knew the ancestor was following the deceased and they were still connected.

CC: How do we get that back?

Darryl: We have to go back to our cultural incubators. We have to regain the knowledge and wisdom that was lost through the ages. People did not have television and an infatuation with killing other people. Ancient Africa or Ancient Hawaii was not like that. I think the way we get back to it all is to go back to our cultural incubators and learn what our ancestors told us.

CC: Also we learn it from the essence of life. I can remember in New York, when a woman was screaming for help. We have this human impulse to help. But somehow, that night, the impulse was lost. We have lost the impulse to feel and with all the technology...I do not know. During the Vietnam War, people were out by the tens of thousands. I do not see that anymore. It is almost as if it has nothing to do with peoples lives, so who cares.

Darryl: I do not know your ancestry. My thing is, during the Dark Ages, people saw others die because of the plague and so they got used to it. People died. That view has started to become a worldview because of colonization. There is a ramification. In Africa, we tear each other apart. Forty years ago, it did not ride out that way. Four hundred years ago, we had respect. If you were to visit me, you were welcomed. Now we close our doors to love, to compassion, to faith and trust. I do not want to use your tape.

CC: When we go back into our cultural incubator... I want to end with an action plan. This idea of going back into our culture, have you started that process?

Darryl: I have and am reading a book called 'African Civilization.' I started looking at how we can create a system of pan Africanism but now globalism. Well, my conversation with you today, I started reflecting my life. I am not doing anything wrong but I am not spending life doing meaningful things. Sometimes I just need to kick back. So like watching a reality TV show that is so meaningless that it helps me zone out. I could have taken a walk. I am spending more time outside, pulling out trees and plants. It feels good. I would like to work on that. We all have room for growth. This conversation has heightened my consciousness. We are past feudalism. We need to come together, talk to aunties and great grandmas and ask them what life was like. It was not always like this. We need to come out better.

CC: That is beautiful. Thank you, thank you so much for a wonderful interview.

Interview with Sally Fisher

CC: Hi Sally, how are you today?

SF: I am good, and you.

CC: Thanks for doing this interview on death and dying. I think I am going to start with a question, when I talk about, when I ask you about death and dying, what comes to you?

SF: Immediately, I thought I am less related to it than I used to be because I have worked in the aids epidemic. My first friend died of AIDS in 1981, before they had categorized it as HIV. He was a Broadway performer as I had always been involved in theatre. I loved him dearly. One day, he was just gone. He was in a Broadway show, one week and about three or four weeks later, he was dead. And, because he had not been feeling well but we did not know what was going on. People who suspected, did not want to deal with it. It was shocking to my system. It was also that period where everyone was becoming a healer and all that magical thinking was going on. How come we could not save him? Fortunately, I learned not to worry about that too much. It was not my job to save people but what I took on as my job was to help people decide what they really wanted to do with the rest of their lives, we did not know how long that would be for a lot of people.

CC: You said two things. You said you were not related to it as you used to be. What do you mean by that?

SF: Two things. One is that I am working in areas that have to do with life, fully. I am always interested in living fully, regardless of the circumstances. And the quality of life, regardless of the circumstances. The first AIDS workshop I did was the Actors Institute in New York. It was very different back in the eighties?

CC: Was it a result of the man who you cared about deeply about, passing on. You felt like....

SF: Initially, in 1981, yes but I did not do a workshop until 1985. it took time. First of all, it took more people. I had a friend named Max Navarra who was an acting student of mine, I was a teacher. He asked me to do a workshop 'for us' but I told him I could not until he told me who 'us' is. He said he had AIDS. I said that was information. We made a deal. He was in my acting class and he brought a saxophone to accompany his scenes. He did Macbeth playing the saxophone. And, he was awful. It was a sound you did want to hear. What would it take for you not to bring a sax to class. He said that I would have to do a workshop for people with AIDS.

CC: You had never done this before?

SF: No, but I had been working with people about the quality of life. So, quality of life, quality of death. I just created a workshop. I did some support

groups, tried some stuff, and wanted to know if it worked. We did a workshop, wound up with 22 men and 1 women. A nurse came. One of the guys had to be on transfusions every 2 hours. She came up and told me she was stuck there for the weekend and she asked if she could be a part of the workshop. I said okay. What I discovered.. the philosophy I go by about the quality of life is that life is not determined by the circumstances but what we do with them. That first workshop, people were in wheelchairs and gurneys and people had to lie on couches. I walked in the room and had to rethink my entire philosophy, it may not hold up and decided to buck up. What happened though it was true. In the circumstances, they look for the best to do and the most powerful they could be and the most present as they can be. There are some who whine and scream and complained the whole time. Just like everyday in real life without a disease. What I understood was that it was life but it was just exacerbated.

CC: And that is what I want to ask you next. A timetable. How do you, in your workshops....well after a few years, they became very famous. Everyone was going to your workshop. In that process, how do you deal with that fear. In the beginning of your workshop, I am sure there was fear. Or did you find that people were not afraid of dying. What did you find?

SF: I think people came to the workshops because they were afraid of dying or wanted to know what to do or be saved. Yet, it was very interesting because, like a lot of things in life, it all boiled down to childhood history and whatever relationship people were in. Those were the issues that needed to be resolved. What I discovered in that, HIV had not become a context for their lives. A goal was that. It was a piece of content in their lives and for them to be aware of it. It was the difference between 'you have AIDS, it does not own you.' You can own it and do the best you can while you are here. As drugs came into the situation, starting with AZT, it was hard on the body but it beat death. You have a choice - throw up in the morning or not get up. Most people chose the drugs. There was huge contention between groups of people. Everyone wanted their way to be right, a little like politics.

But the idea of being with people who were dying...I spent a lot of time with people who were dying, I thought it would be a good idea to talk about it with people because it was a subject that was hardly mentioned. As I said, there was a branching out of New Age because magical thinking makes you feel better. But when you aren't feeling better, it really does not help. You cannot pretend that everything is fine and if you think happy thoughts, you will live forever. It does not work that way. So, for me and in my work, it was to get people to get people to look at their reality and see how they could enjoy life best given the real circumstances.

CC: That is a tough one.

SF: Yes, it is but once you say to someone that you can go through this, there are 3 ways to do it. You can go through it praying you will be okay which is a good thing. You can be angry that life has cheated you and you are not going to be 60 and do what you want to do. Then there is - how can I hold this. How can I make this work for me while I am here? I used to ask people a question - how much of your time do you want to spend pissed off. It was a logical question.

CC: I would imagine that people experienced all three. It reminds me of the stages of grief. This process of grieving - the loss of a long life. What about for you? Because you saw so much. Everyone was so angry and I imagine you were too because people were dying prematurely and it seemed as if people did not care.

SF: There are several things: As far as people dying prematurely, most people focused on what they could do - for their health, taking their meds, switching their meds. The other thing they had was a community. AIDS created community in varying states and cities. For instance, at a certain point in the epidemic, there were 30 cities in the US and UK that did our workshops. We had an agency Northern Lights Alternatives. I had two partners who said 'let us make money for you so you can take it on the road.' I had to resign from my job. I travelled around for a couple of years and doing workshops in the US and the UK. These two partners were transcendental meditation teachers and they knew people all over the planet. It was insane but it was also amazing time.

The thing I discovered about death and dying that in the beginning two years, I thought.... well, I was a bad girl. We had a great time and we did not know what killed you. We just...it was love, sex and rock n roll. I was divorced, my kids were grown up and I was free to play. I did a lot. I have some ex lovers who died with AIDS. I have no idea why my immune system decided not to get me sick. Before I was sick, I thought I was one of the people. They say you need to teach what you need to learn so I think that it may have been part of it. As far as death and dying is concerned, the first person who called and said, 'so and so is dying, would you come and be with us?' And I said, 'of course.'. What does that mean, I asked. I went to a bookstore and found the only two books they had on death and dying. One was Kubler Ross who has that strict boundaries.

CC: She was strict and we now know that it is not that strict.

SF: Right, right. I have worked with her over the years. The other was Steven Levine. I brought him out to Los Angeles and had him do workshops and adore his work. It is pretty much, love as much as you can. He and Andrea are perfect examples on how to do that as a couple. I read that book. I was literally sitting outside of this dying man's house, leafing through Levine's book. I just went and looked at the man. Somehow, what I needed from him was easily transmitted to me. It was not a problem. I just intuitively somehow picked up on what he needed. He needed to know that somehow he had not failed. A product of the New Age was a little bit - people were blamed for dying and getting sick or if they had done it better, they would have been okay. First there has to be no trace of the guilt or blame. The other part of it was, to let people be afraid. The minute you say to someone that it is okay to be afraid, in my experience the fear lessens. It begins to dissipate. The permission to cry, the permission to be pissed off. Permission to be where you are. Most people try to make others feel better. I did not think I would want someone to try and make me feel better. I am of 'let me be angry.'

CC: Oftentimes, the medical model of death and dying.... let me intersect here for one second. We have a denial of death and dying in the medical establishment and they will keep you alive at all costs. That is why we have directives to put a limit on it. So, in that kind of denial - let me make you feel better - there is an absence of conversation, which you were having with people. To talk about it and face up to it. Would you agree that the medical establishment is trying to make you feel better.

SF: Doctors have an investment of making people do their job properly. Their job, they think, is to save lives. A lot of doctors working in AIDS were gay male doctors and they had a different take on it. Some of those doctors were absolutely fantastic. I worked with some of them and worked with health care professionals. They needed a place to cry, scream and yell and be taken care of that way and learn to be tolerant of their own humanity and what they call, frailty, which I call a person who cares. Around AIDS, in particular the nurses... some of these people would come in and out of hospitals. The nurses developed relationships with them.

They felt the loss and became part of the AIDS community. Louise Hayes used to do these sessions called the 'Hay Ride' and hundreds of people used to come because they just needed a place to be. Louise was reassuring. She was 'look in the mirror' and be happy. She was the first person to say that people did not have to die of this disease. Which was true, although I did not experience it in the way, she did. She had cancer and healed from it. Louise was of the belief you can do that. I am of the belief that sometimes you can

do it. When you can't, the alternative is perhaps sad, a great loss and certainly to those around the person.

One of the things I got to do which was very rewarding, is bring families back together. A lot of families threw their gay sons out of the house or tried to put them out of their lives. Suddenly, they get a call from their child saying he may not be around so long. Often I would be there when the parents came so they could be comfortable. If the person was in the hospital I would go to their house and clean up the place, put fresh flowers to make it nice for mom and dad. I had an agency in LA and we were all over the place. I worked in Dallas, NY, London and San Francisco.

CC: Would you say, that was one of the main ingredients to being alive was healing the rifts with the family? Was that part of it. The workshops were about living well, living to the fullest. Did you find that part of that meant that one should resolve conflicts with the family members?

SF: Yes. I also saw that people who had less conflicts, died easier. At least in my experience, people who were fraught and resistant and afraid, had not come to peace with themselves or their lives. Not that one is right and one is wrong but certainly one looked easier from my perspective. Also to have people whom you loved around you is a wonderful thing. Sometimes it was parents. So many of the people I worked with created second families. Sometimes were just hilarious events. Sometimes as a person was dying, the pizza was delivered. The pizza guy would be looking in a room going, 'holy crap, what is going on?'. Waiting to see how long we had to stand there with the deceased to see how long we would have to wait to eat the pizza. It is really life, a Woody Allen moment. He was one to something. There were all those things but it was extraordinary and the first person I held when they were dying, I felt such grace in the room. I swear, the presence of more light than normally. Those experiences have stayed with me and felt very privileged to be there. I have watched my children give birth to my grandchildren and that is one way I felt privileged. And dying was another. That was a very powerful thing for me to have my kids be around death and dying, very young. Especially my daughter, who lived with me and fell in love with a lot of my friends and felt the grief when they died. Grief is a gift. People resist it and do not want to feel all of it. What an honor.

CC: Yes, I call it an honor. To honor someone's passing. It is not depression.

SF: Depression comes when you do not allow yourself to feel grief. You are absolutely right, grief is a full expression.

CC: Did you find that grief gives us a door that opens to a deeper reflection on what life is? Its quietness.

SF: And also, a deeper reflection on what that particular life was to us. There are some real spiritual wonders and sensations that come along with grief. For those who accept and even welcome grief, then it even becomes heightened. It is hard to explain what it feels like but there is joy around it as well as sadness.

CC: It seems to me when I think back to those days when everyone knew someone who was passing or who had AIDS...the protests. I remember when you and I were in South Africa and there was a protest about needing less expensive pharmaceuticals. That was not that long ago, it was way past the nineties. I often thought back then that people had courage. There was so much courage, just courage. Bravery.

SF: Yes and activism was fierce. I was part of ACTUP in Los Angeles. I had a lot of arrests. My mother called my sister and said, "Turn on the News, I think Sally is being dragged away." But that was profound because I met so many extraordinary activists. Most of the people I knew around AIDS were gay men. I then got locked up with amazing women. Very few were infected but all committed to helping. That was a whole new world that opened. I became part of the leadership in the country. My first big arrest was at the White House. There were 65 of us. I was holding on to the mayor of West Hollywood and one of my partners from the Agency on the other. They kept picking the guys up on the bus. That is how I met the women. In jail. We are still friends. It was both, the good, the bad and the ugly.

CC: The fullness of life and the injustice of what was happening, because no one could figure out where it came from.

SF: Health issues were not usually political hotcakes. They were not usually that had to be fought over. We did some amazing demonstrations in Los Angeles. We did a beautiful thing with the clergy. We had dozens of clergies and they came and sat in the LA County offices because the hospital had to have about 40 more beds. The clergy sat in there. I had Malcolm Boyd and all these great ministers. I had his bail money. There were people with bail money. Someone had a 100 bucks and would come to get you. It was great television. All of these collar being arrested and thrown into police wagons. People really cared and people worked very hard. In San Francisco, a lot of cops were gay and did our workshops. Then they would have to come and arrest us. They would ask, 'Do you want to be dragged for the cameras or do you want to walk?' That is what it was. It was indirectly about death, not directly. There was something about the prospect of death and the

amount of loss we experienced that saturated. There are so many people around now that were there then and still active. Here in NY, SF and LA. A lot of people. Those of us who are left are still doing something.

CC: The work never stops. Sally, when you were talking about your workshop and I know you published a book a while ago on being a warrior. The soul of it was finding the depth of life. I have not looked at the book in a long time but I think it was informed by the work you did.

SF: Yes, it was called life mastery. The workshops were called AIDS Mastery, taken from the Actors Mastery.

CC: For those of us who face a situation where we may pass on earlier than we thought, what would you say are the golden nuggets of living fully during this time of the transition? What was the soul of your teaching?

SF: I think it would be to discover what is nurturing for a person. Fun and nurturing the same things. I am an alcoholic and have been sober 22 years in February. I had a great time, I have to say, but it was a nurturing time. It had no long-range possibilities. And I did well. I did good work. I discovered the way I was living was not nurturing and thought maybe I could stop drinking and did stop for a few years. Someone said to me, "if you have not had a drink for five years, you are not an alcoholic." And I said, "that is right." I would love some of that wine. I did that for a few years and realized I was lying to myself. Most people do not wake up in the morning trying to find something to drink. I learned how to nurture you by not doing things that may make me feel good for a few minutes and then not good about myself.

CC: You know Sally, it is hard because we live in a culture, when you talk about nurturing, if I were taking your class as part of your mastery workshop. Most of us do not live our lives thinking about that. When you are telling people to nurture themselves, what did you say? I mean there is going to the spa.....

SF: Those things are important but in my list of what nurtures you is freeing yourself from the things you struggle with by resolving them in one way or another or just letting them go. Some things are not resolvable, in particular those things that involve someone else. I have no control over anything, I can influence things but the minute I think I can control things, I can't. I cannot make someone love me, I can't make you agree with me. What I can do is adjust how I hold the whole situation and how willing I to

let you have your opinion and let me have mine. And that was something was freeing for me. I learned that somewhere in EST or therapy.

CC: But you passed that on in your workshop. Essentially, nurturing is not having your friends tell you they love you. You are talking about freeing yourself from the bondage that prevents us, from what?

SF: So often, we think that in order to say, "I love you" to someone or would love to be friends with you, it has to be *Quid pro quo* we have to know that someone is going to saying, yes. We often go through life and do not say anything and they are waiting because they are afraid. Or we do not grab enough of life because we feel we have not earned it or do not deserve it. Or something from childhood says, 'do not be greedy, there will not be enough for other people.' When people say us that they love us.... If a parent abused us and then said they loved us, then love gets very tricky. And very often, people will look for someone that makes us feel the same way, our parents did. That is the real clincher is how we feel about ourselves. We are a consistent presence in all our relationships. When we are willing to nurture ourselves - and part of it is taking baths and putting food in our bodies that will help us. I have no hard and fast rules about any of this because it is different for each and every person.

CC: But you worked with people in helping them find the things?

SF: Absolutely. Most of the workshops I do are about asking questions and people answer. Everyone knows what he or she needs to know. It is inside of each of us. But we forget or no one told us we had the answers. That is why I like to work with visualizations because it relaxes us enough to let go of things and trying to figure things out which is a waste of time. It allows us to see things.

CC: Your bucket list that you had in these workshops are very different from the bucket lists of television - like go hand gliding. Your bucket list connects you more to the essence of life.

SF: For some people, hand gliding does it.

CC: Yes, I know but you know what I mean.

SF: Yes, I want to go to Istanbul.

CC: I went last year and want to tell you about a conference next year. It is a conference relevant to you and me. It is an International Peace Conference.

SF: I have done most of my bucket list from the ridiculous part and I have had amazing relationships in my life. In this part of life, I am having a good relationship with myself, which is, I guess, the point eventually. I also think that service is an important thing.

CC: I think we both know of the importance of service. Did you talk about this in your workshops about giving service?

SF: I always do because I think the best way to get attention away from us, is to put it somewhere else. And to pay attention to someone else. For a lot of people who are not able to do a lot of things, if they can make someone else's day better, they begin to experience personal power and have something to contribute. I think we forget to how wonderful it is to contribute. Remember the 50th Anniversary of MLK or the original march. I wrote down what a lot of people said. There were amazing speakers like John Lewis who had been there. Oprah said a variation of the quote that MLK said. I wish I could remember the exact words but it was about being fully ourselves when we are in service. I love that Oprah said it. It has always been my experience. In workshops whether it was the Mastery Workshops or Taking Care workshops, which was for, care providers and activists, for those people, too, it was different because to work with them, you have to convince them that it is important to take care of us. If we are going to be of full service, we have to be in the condition of being able to give service. Or it could be martyrdom. The idea of being of service is useful. You need to get back what you give. That is the balance. The kabbalah says that the desire to give and the desire to receive have to be in balance.

CC: It is always harder for a lot of us... well it is easier to give than to receive. In some cases. In terms of these workshops you gave for people who were dying, who probably had the clock, which was faster, you had this bucket list of giving service, of nurturing..... what else was an element to live fully? The reason I keep going to this is because the Buddha said that to have a good death is to have a good life. The idea that I am a baby boomer, the prospect of death and dying is a little closer than what it was 20 years ago. Our parents are passing on, our friends are getting cancer, this trajectory of life. We often forget to live fully. Maybe it is just myself and I am projecting it on the world, but there is this sense we are wasting some time and we need to amp it up a bit in terms of what is the meaning of life. We have so many diversions. When we are on the bed in transition that it may be a regret is that we work too much. That we did these things, I am trying to get at the soul at what you taught to people.

SF: I guess the soul of it is that 'do something you love with you life with whatever time you have. Whether it is six weeks or 60 years. There are still people who are walking around that we thought would be going. We lost people who we didn't think we would lose. And not only AIDS. A friend who was a wonderful Hollywood producer was making a left turn on Pacific Coast Highway was killed. A woman rammed his car. He had lived through cancer, drug addiction and was having a great life. And that was it. He had a great life. He was all over the place and happy. I think for those of us, once the shock wore off, we thought 'he got to be happy.'"

CC: Would you say that was an element?

SF: Yes, I do not think people understand, until you sit with them, that happiness is an inside job. It is not necessarily an outside job. I have been fortunate - I have three kids, four grandchildren and live comfortably. My children are doing things in their lives they enjoy doing. I am thrilled for them. I firmly believe that we do know what we want and some people need to adjust to the idea that they deserve and they are capable of making it happen. Sometimes you go for it. We have a right to go for things, 100%. It doesn't mean we will get it but go for it and take what you can get. At least you have run the race. I used to have a photo of my youngest daughter who ran the Chicago marathon. There is the picture of coming in at the end, triumphant. It looks like she came in first. Not at all. But she did the miles. She was thrilled. She had a group she ran with. They cycled to get their legs stronger. She committed herself fully. She was thrilled when she finished, it did not matter there were groups ahead of her. Kenyans.

The thing I think is important is to be responsible for what is going on. I am thinking about the politics of our country and the world. I say to someone when they start complaining. I ask them what they have done. If they say, no then I say that I am done with the conversation. You can have an opinion but complaining should not be done unless you do something about it. You have to pick your battles.

CC: Part of my mission in all of this, is how do we live more fully? We get one chance at this, you know. This is a very big topic. Is there anything else you would like to share on all of this. Death and dying means different things to different people at different times in their life.

SF: The most important thing is to accept the reality of the death of someone or your own when it comes. I almost said IF but that does not seem very truthful. One of my wishes is that I actually become graceful around it and I go out fighting. But the one thing is that I feel in a way, I have done well by doing good. It is such a pleasure. I have a good life and I have a good

time. The absence of having to deal with death so much, my life is less intense. I can turn now to politics and babies. My experience around death and dying and shaped my approach to everything and how I see life. I am so grateful every day. I have watched so many peoples last day.

CC: That is a beautiful way to end this interview. Thank you for your beauty, for your friendship and for being Sally.

SF: Thank you for being part of my life.

CC: Thank you so much.

Interview with Meleanna Meyer (MM)

CC: Hello, thank you for doing this interview on death and dying. I think the first question I want to ask you is when I even saying death and dying, what does it bring up for you?

MM: Great question. Transition. Death and dying is transition of points of entry and departure. It brings up an ouch... passing. There is a lot of emotion attached to death and dying. I have had intimate experiences with death and dying, I am happy to say that it conjures is also hope, believe it or not because this is not the only lifetime we have so it makes that whole conversation a lot easier for me.

CC: What do you think happens afterwards, when you say that this is not the only game in town?

MM: The affirmation continues has to do with energy. I liken that to the experience that I shared earlier about my son and energy in terms of his dad's passing and likening his dad's energy to the energy of a tree. When a limb falls, that energy does not dissipate, only an aspect of that tree is finished. I have affirmations in my own life that as energy continues through the energy of a tree in terms of its growth and flowering that we do the same. I have to believe that. It is an animus way of viewing the world as well as Buddhism thrown in there.

CC: When we are talking about this, where to your ancestors fit in?

MM: They fit in all around me that is an unusual question. They fit in well, thank you. It is the whispers of the wind or raindrops. Do we have to categorize anything? No they are all around. That side of things in terms of energy - akua - I feel them around all the time.

CC: So there is a continuation when you are talking that there are other things, there is a thread through generations.

MM: Forever, something I deeply believe in and witnessed in my own family. We have to spend more time with the question - all of us - to be able to make those connections.

CC: Do you think that making those connections, no matter what culture we are in, where we are from in this world, no matter who are ancestors are - do you think that can mitigate fear that people have, this boundary between you live and then you die?

MM: Absolutely but I think that is the word - the notion of thinking we have the answers. If we were alright with just being, then we could get out of our way and not feel that tension of needing an answers. We do not have the answers, end of discussion. What more do you want to say? Do you really want to know more about death and dying? Well guess what, you are really not going to know until it happens. Death experiences, they are a different category. But I think that is the humor in all of this - mystery is unknown and death and dying is that. I think the emotions for us are things we carry because we love those who pass. That is the connection with the experience that is painful. You can't help but make it painful.

CC: Loss is huge and you have experienced it. Grief is significant.

MM: It is very real and what are you going to do except process it.

CC: Process it. Before we move on to another subtopic. Someone told me, I still cry over my mother. Not as often, not everyday. I cry and someone about a year after my mom passed said, 'Aren't you over it?' "Have you not finished grieving?" as if there is a beginning and an end. Grieving is honoring someone, it is not depression.

MM: Grief is a different thing, it is actually affirming that you care, that you are still engaged. I will tell you a funny story that just happened in the last year about timing and grief. I had lived with this deep cranberry, pain color for almost 30 years in my bedroom. Just this year, I said okay I have had enough. Just this year after 32 years of John passing, I painted the whole side of that room a beautiful light blue and white. So it not only took me 30 years. In another words, there is no rulebook or timing for anyone's grief. It could take lifetimes and it is important to remember the notion of timelessness. Time is an arbitrary thing in terms of being on the clock. How long will it take, as long as it takes.

CC: It is part of life. I hope people grieve for me. We have had discussions before about death and dying. In an earlier conversation we were talking about death and dying in a different way, a bigger way, in a cultural way. We started talking about the death and dying of a culture as mirroring our own. Can we talk a little bit more about this? I have been thinking about this for weeks, about this circle of life and death and then this abrupt stopped that is stopped due to external influences. So cultures are dying because of imperialism, all these things that are happening. Can you talk about your thoughts on that? It is a big conversation but I am also hoping in my writings that we can talk about these other issues, how we can prevent the death of a culture, the death of a community, the death of a person. To me, you are a person who keeps things alive, very profoundly actually.

MM: Thank you for sharing those thoughts. I believe as a creative, we have an obligation to nourish and to keep things alive - voices, memories, stories, and language. So in terms of culture and community, without that active participation, we then we will be silenced on all those different levels. We can keep the memory of a person alive, not only individually but also communally and for the planet - sustaining cultures. Those are profoundly important for diversity, for the richness of humanity. For me, the death of a culture is the most profoundly disturbing. We should never be at that place, that dislocation, depression and silencing. We dishonor a people to take their voices and spirits away. That is what happens when a culture dies. For me, Hawaiian culture in the sixties, actually from 1896 the silencing began its downward spiral and it was only until the early fifties or the sixties, people said we had to do something or this culture will die. We were on the brink of extinction. Without your language, you have nothing. You have no ability to tell your story. The death of a culture is a tremendous loss.

CC: People do not really see it like that.

MM: No they don't, they do not have a clue.

CC: When we hear we have thousands and thousands of language, it is like biodiversity. People do not understand that is the death, the disappearance.

MM: Forever, that is the extinction. We are talking about not reviving something. Even if you save it on tape, and I am a cinematographer... you have to be able to practice. I think that is what our lifetimes are for, it is for practice. It is the practice of care; it is the practice of attention and focus, for appreciation of people.

CC: What do you think, to keep a culture alive, are the most important things to do in ones life? It not only keeps alive the culture but your family, your friends, and your community.

MM: Big question. What do we do to sustain ourselves? We are the culture, we are the culture bearers. Telling our stories, learning our language, learning our protocol, learning to understand how things are done. We are all guilty of not doing that well enough because we all have backgrounds where our culture could have used more support. It is not something that belongs to one person. Each of us does our own good work. How can we support our cultures? By walking the talk, practices, taking the time to learn the stories, the language. I am a student; we are in that boat together.

CC: What about for people who do not feel they belong to a culture; they do not have those roots? What would you say - to keep the earth alive? I think keeping ourselves full and alive, each moment is precious is connected to the preciousness of the earth.

MM: Yes, it is a culture of caring. There is a culture of ecology in the sense of maintaining an understanding a focus of things. This whole notion of care is not contingent on who you are but how you are in the world and what you do. It is important because I am Hawaiian, Chinese, and German. All of those aspects are important but first and foremost being a human being, for me is important. How do you sustain a culture? By getting involved, by engagement or whatever fashion you choose. It is not only culture and care, it is cultivating care.

CC: To keep the earth alive, to keep ourselves alive.

MM: Exactly. I think it goes back to what you were saying, the whole notion of aliveness. As a creative person, that is what I support and honor with the people I work with, the children I work with, the people I pass in my life. What is your spirit like? You can see it in their eyes, their language, the way they treat each other. The whole notion of death and dying. They should be worried about zombies because they do exist.

CC: That brings me to another thing. You are so interesting; you are so interesting to talk with about things. When you are talking about the zombies, whenever I see a zombie movie that is how we are living. We are not alive, we are not dead but we are living in a materialistic state that is dulled us. So in a sense that we are... it is like a slow death of soul, the essence of who we are.

MM: Absolutely. You see it in pictures of people who have lost hope. They have gone beyond the pale of their emotions. I am not kidding about zombies, I am tongue and cheek. It is a real thing I have seen in photos of Hawaiians in the early twenties when they had no hope, no aspiration to continue when there is such great loss. One can be living and dying slowly is a very painful thing. That is why the whole notion of 'living into your life' makes sense to me. We have to just claim those things that we love and desire, to make change, to be a part of so that we can become the people, be enlivened. Otherwise, why are we here? Those things are very real to me.

CC: Yes, why are we here. It reminds me of an article I read in one of those magazines, the idea of meaningful conversations is dying in our culture. Everyone is so transfixed by the technologies; the diversions and we have millions of them. We shop; we do social media but that the death of important conversations about the meaning of life is disappearing.

MM: I hope to God that is not true. I do think the distractions are problematic; all this technical stuff is distracting and very detrimental to the culture, to the conversation. The whole notion of a meaningful conversation... you have to become engaged, be willing to look around and ask questions. The whole notion of meaningful is to find again and not really blame technology. Each of us and our diversions. There is so much more to the conversations, it is not a one-sentence answer that we can put out easily.

CC: You know, I am going to change the conversation again because my mission in this interview is to get your different thoughts on death and dying. One of them, we read in the newspaper today about the navy yard, about the 12 people dying. We know we do not have gun control laws, so people are killing each other, left and right. When we think about death and dying, and then we think of these lives cut short all the time, all around us, every day. Thousands of children. It is tragic and yet because we... let me ask you this. If we were more connected to the preciousness of life, do you think we can feel more for these people who thought they were going to be alive for a long time, they just died. There was not ritual, no ceremony. There was an abrupt, cruel ending.

MM: I don't think we can hope to create anything more than what comes of our lives everyday. We are not in a place where ritual matters for so many of us. That is something that is profoundly important that we need to reclaim. Unless we reclaim things like that... for me, I feel like there is not a lot of hope. Ritual is important in passage. Coming into the world and parting. We have to find a way to reclaim things that are important. Like time. It is an artificial thing on a watch but there is so much about loss that we need to take the time to reflect. Life does not hold a lot of weight and meaning.

When I talk about ritual, I am talking about ritual; I am talking about the importance... I guess sacred things like passage, entry and exit. Honoring birthdays and retirements and things. Unless we do those things, we are a part of the madness. All this rush towards things, the violence in this American culture are just symptomatic of the gross disconnect. If we had more reverence for things and time in its proper place... we would be better off, all round. We have been all around the conversation. I am not sure what thread is in this. Death and dying are part of our life ritual; it does not belong to something else, the end chapter of our time here, this particular passage of time. I feel great sadness for all the people in the world whose lives are cut short. Is there anyway to energize that, to have people understand this. Not unless it is intimate to the person, things do not change. Death and dying is very abstract unless you experience firsthand - death of a loved one, a near death experience. Death and dying is still an abstract concept.

CC: Do you think it is abstract or do you think we are just in denial? It is interesting, there have been a lot of recent discussions on death and dying in magazine and it seems that we, the baby boomers, are starting to talk about. We made all the noise in the past and it seems we are being very vocal so there is less of denial because we are talking about it.

MM: It is about time we talk about it. Our generation did the raging in the sixties and the drugs and so it is good that people are being introspective because they are important issues.

CC: We want better elder care and health care and we are demanding. What are the ways you think that death and dying can be less abstract for people.

MM: As we age, the notion of being honest, more real and authentic. Being able to say okay, cut the posturing and the posing and just to embrace the feeling of aging, or our mortality. It is important, that is how we can better deal with death and dying, by just acceptance. Acceptance is a hard thing but I do believe it is a practice, like other practices, you have to work at it.

CC: Does the practice of it, inform the choices you make?

MM: Absolutely, it is a revelation actually. In the practice of doing comes the better being, comes the revelation, comes the knowing. Absolutely in the practice. That is what is joyful for me about being creative. You get to experience something every day, which allows you to feel that aliveness. What you were talking about. It is being alive in our dying, that allows the

experience to be the most profound. I feel that, in my own mother's passing. We were present and it was so amazing.

CC: What was that like to spend two weeks with your mother at her bedside? Did you feel closer with your sisters, did you bond, and did you experience AHA moments in that process?

MM: You could not help but get a lot of epiphanies about your foibles, about your insecurities, our own joys and collective joys. It was a constant conversation that was much more spiritual being with that many people. Having this woman who was passing, who was beloved be that person who is the conduit in her silence. She was for all of us. It was a profound journey with her and alone with all of my siblings. Death and dying has that cache, as I say, of allowing those things to happen if you are present to the experience. In an of itself, is a conversation but experiencing it, it is something else. It is important work that we can do together, if we choose to.

CC: Well, Meleanna is there anything else you want to talk to you about. I wanted to get your thoughts on a few things. Is there anything that comes to mind when you think about this topic, for yourself? For instance, I know as a baby boomer, I think I have a finite time, how am I going to live today.

MM: Well said, we do have a finite time. I think of this as a last chapter, or the last ten. I am coming to the emotion of immediate needs of continuing to do the things I love the most - to eat chocolate; to tell my children I love them, to do things that will make a difference. As this point in our lives, the conversation is real about death and dying but right now it is more about life and living in a deeper way.

CC: I don't think life would have any meaning if we did not die. I definitely do not want to be around forever. That thought frightens me more.

MM: We have to have an out that is the cool part.

CC: Thank you for a great interview and for taking this time.

MM: You are welcome my dear friend. Aloha.

Interview with Susan Schulz

CC: Hi Susan, how are you today?

SS: I am fine.

CC: Thank you for participating and being part of this digital storytelling series on death and dying. To open up, let me just ask you, do you think about death and dying a lot or is it something you rarely think about it? When someone says to you, 'do you ever think about death and dying', do you?

SS: Yes, yes.

CC: In what ways?

SS: I do, quite often. My mother died two summers ago and I was with her when she died. I had been chronicling her Alzheimer's before that and so I was thinking about her death long before she actually died. My father died in 1992 and I was there as well. Those two events have been very important and I think about those events a lot and because I think about those particular events, it becomes thinking about death itself.

CC: In what ways? How did those two events - the loss of your parents - did it change your views about death and dying? Did it deepen your awareness about your mortality?

SS: We were talking earlier about baby boomers who are not really familiar with death. I find it a little scary that I did not experience death until I was in my early thirties. I became aware of death as a process, not as a moment that one-minute you are alive and then you are dead but as dying as a process that takes a long time. I think with him, it took the better part of a year because he had aplastic anemia which means your immune system shuts down. So he kept getting sick but he was preparing for it during those months and I got to see some of that when I visited him and the last time was the last four or five days of his life. It made me aware of the process and it provided a wonderful model because he did it very well. The question on the web site, 'What is a good death?' and I have thought about that. It is not the death itself that is good or bad but it is the process, of how you do it. If you are an older person like he was then you are able to approach it consciously and operate on the fact that you know this is going to happen. You can make peace with yourself and with other people. That first event a good one to witness.

CC: He was empowered. One of the issues on death and dying is that most people still die in hospitals where you have no power. You have no access to being empowered. It sounds like your father was empowered, that he had control.

SS: He was in a hospital. At the end, he spent a lot of time in the hospital that year because he had a lot of blood transfusions. He was in the hospital and he had wires sticking out of him. There was that sense that he was not in control of himself but emotionally and spiritually it felt like he was... control is such a hard concept - who knows what that is. He was still conscious, a part of the process done well.

CC: Of acceptance?

SS: Of acceptance, of a generosity, really that I had not expected of someone who is about to lose what you think is everything but clearly that was not at issue.

CC: You are a writer, well-known writer, and local celebrity. You write about a lot of issues. Have your ideas about death and dying because you have lost your parents... have they informed your writing and in what ways?

SS: The two of the last three books - dementia blog 1 and dementia blog 2. So I covered the last six or seven years of her life, partly a journal, a chronicle of things that happened. The second volume has dramatic moments where people with Alzheimer's are talking to each other. But one of the things I face as I approached the subject was how do you grieve for somebody who is not dead yet. Because there is a lot of grief involved in having a parent with Alzheimer's who is losing memory, losing control, which was a hard issue for my mother. Losing personality, losing her speech and she was a talkative person. You go through this grieving process but there is the question of where it starts and where does it end?

As an English professor who teaches poetry, I have read a lot of elegies. But elegies are written after someone dies. And you are trying to do up the grief after the person has died. If you are lucky, you can say everything is resolved at the end of the poem, which may not be true but everyone is trying. In my own writing and thinking, how do you write an elegy for a person who is alive? That became a lot of writing and a lot of thinking.

CC: What did that final elegy look like? Can you talk about it a little?

SS: The final elegy that I wrote for her came upon me, I did not expect it at all. It was after she died and after I finished the blog and I sat down to write it like a goodbye to the blog. The purpose for this blog and it is over and I was going to say goodbye to the blog, which was odd because it was to the blog, and it was my mother. What poured out were pages and pages of memories of her before she had the disease, back in the day when she was a

storyteller. There were lots of memories and I think of that as my elegy for her. Mostly what I wrote about her in the last years was very much in the present tense. It was 'I am sitting with my mother and this is what is going on.' There was a way, there was an attempt in the present tense that would preserve memories that were otherwise would be gone. A lot of the work was written at the moment something was happening or very shortly thereafter.

CC: I am sorry I have not had a chance to read it. I do not know why I have gotten to that. Someone said we actually experience two deaths. One when we actually die and the other when the last person who knows or remembers us, dies. It is an interesting way to look at all of that. When your mother had Alzheimer's did you feel you were witnessing two deaths? Did you feel like you were losing your mother when she got the disease or did you feel she was just transforming?

SS: That is, I have not heard that particular thought before. On a personal level, as an only child, that after she died there was nowhere to share her life with, that I could not have siblings and everyone sits around and talks about mom. She did this, she did that, she was annoying, and she was funny. It was only I and that may be one of the reasons I was writing so obsessively. There was a sense.... the thing about Alzheimer's, it is not only forgetting themselves but they are also forgetting you. Someone said, the biggest question that children of patients ask each other is 'does she still remember you?'.

That is the question. I am not sure that matters because even after my mother did not know who she was, I felt a bond with her and I came to see it as a transformative experience because we could actually relate to each other more easily than we had when we were both conscious and had our chins out. There was a transformative quality but it takes awhile to get there. You do not just see your mother forgetting things and you think she has transformed. It is a long process and for that reason I do not think that Alzheimer's being as awful as it has been portrayed. It can be if you do not have the resources to take care of someone, it can be awful. If you do, it can be a period in which you find a different way to relate to one another.

CC: Thank you for that answer. I am spinning a little in different directions. You told me you were an only child. I am an only child. And I think, did you feel, especially when your mom passed, did you feel really alone in the world? I felt, I had to take care of everything. My mother was a bit of a wild woman and she sort of alienated her family. Added to that I was adopted and I felt like an orphan after my mother died. Did you feel like a bit of an orphan? In part of your grieving, did you feel lonely?

SS: that surprised me. I have family; I have a husband who has family. There is no shortage of family around, really. But I was surprised at the extent to which my sense of time had shifted. There always had been an aspect of time that went away. It felt much more edgy, like there is less give in time. Maybe this is too abstract.

CC: I know exactly what you are saying.

SS: There was a sense of now it is just I, which is what I did not have when my father died. My father was stable and balanced character than my mother. My mother had not been herself for quite some time. There was still a sense that I am someone's child even though I was acting like the mother. That disappeared.

CC: Did you write about those feelings? I think it is very profound when we lose our mothers if we are only children.

SS: I am not sure I wrote about that directly. The project about my mother, I rather consciously decided to write about her, about the people in the home rather than about myself. A lot of the books about Alzheimer's, they end up being about the person who is writing the book. It becomes the WOE is me and it becomes difficult. People with Alzheimer's tend to be locked away and if you do not have a parent or spouse that has the disease, they are missing, behind locked doors. I wanted to show that part of the story.

I am not sure I addressed what you are asking me about the feelings of personal grief afterwards. I tended to deflect a lot of that by writing about the paperwork I had to do, some of the travel arrangements I had to make. A lot of feelings inked out that way. You become the person who is signing for her. My hope was that other people in reading it would have the feelings. It would not be 'Susan had those feelings.'

CC: Something we can all identify with. Did you feel that your mother had a good death? What does that mean. First of all what does a good death mean to you? Second of all, did you feel your mother had a good death?

SS: Yes, I feel my mother had a good death. It was the years before that were less good - a weird word. After my father died, she became very anxious and depressed and somewhere in there it blurred into the Alzheimer's. It was not a happy time of her life and then after so many years of the disease, which knows what she was thinking or not thinking about dying but certainly as her daughter I was feeling she may be ready. When she died, it was a very sad. It was not horrible or awful or anything like that. A lot of the judgment words we put on death are troublesome because death just sort of is something that happens and we are sensing something about it that

terrifies us. Maybe it does not need to terrify us. That is what happened with Alzheimer's. It did not terrify me as much as it used to.

CC: I think, the denial of death. We have a taboo upon until recently about talking about death and dying. Part of this project is to open up the conversations. As a baby boomer, it becomes more interesting to think about. I often think the way the medical establishment talks about a good death or how people are talking about it - getting the papers in order.... so it is a good death for other people. You are taking control of your destiny, you are doing the directives. There is that sense that requires a conversation with your family. But I also think about the Buddhist idea of to die well, is to live well. If we live deeply and well and we can do the great send off and not have regrets. There is also the idea of a bad death and that we allow millions of people to perish.

SS: I agree with you there. When you look past the middle class venue that I have inhabited all my life. I have a son from Cambodia and if you look at that history and see how many people were slaughtered and allowed to die. That was horrible that that happened. That people were not only allowed to die, but were made to die based on someone's great idea. I think that is horrible. Within our ordinary lives, from the vantage life of my ordinary life, that sense of the good life. You are fair and kind to people, then your death or leave this life without regrets of your own. You will leave people free because they will no longer attached to you by way of anger, of loss, feeling horrible feelings.

CC: I actually never thought about that.

SS: That was the feeling I had with my father. I used to suffer terrible depression. The main facet of that depression was the feeling of loss. It was not about dying, it was about loss. Another thing that was interesting when my dad died. My depression.... when my dad died I did not fall into a depression. A part of it, he had no left horrible feelings behind. He had left a smooth, even plane. When my Aunt died, his sister, a few months after my mother. She just decided that it was time and had family who loved her and came to see her. And they miss her a great deal but do not sit around and talk about the good times they had with her. They do not have, 'if only.'

CC: I actually had not thought about this. We all want to be kinder people. This idea of not making other people suffer when we leave. Do you think that is a two way street?

SS: Yes.

CC: What can we do? So I have a friend whose mother passed away and she is still angry at each other. She lives with that. They were never able to make peace before parting of the ways.

SS: I do not think the relationship ends when that person dies. I know my mother who had a terrible relationship with her mother was angry until the end. Full of anger. But I could see her, at certain times, trying to negotiate that, realizing certain things that had caused her mother to act the way she did. I think if you try to stay open to the other person, even if they are gone, you are still talking to them. You might be talking to them more. You can still try to shift the conversation or ask questions. Consider that everything is not what it seems, perhaps.

CC: Have you had experiences like that?

SS: You mean with conversations like that?

CC: Yes. When you say, my friend still may have a chance, if she opens her consciousness, to continue with the conversation and find peace and forgiveness.

SS: I just read a book by an Italian philosopher on forgiveness, a very fascinating and dense book. I cannot remember the names, but I will show the book when we are finished. He goes through all these things, which are not forgiveness. One of the things we do is we forget. We forget why we were angry. But he says that is not forgiveness. It is almost like an arbitrary decision you make in the moment like done. You just do it freely and arbitrarily. It is not because you forgot or that you will feel better. There are no reasons. I have thought about how you go about letting go of things. There have been some odd experiences since my mother died. Just to make it short, she grew up in a small town called Meadville in Pennsylvania and there is a small college called Allegheny College where she went. Since she died, I have made one good friend who grew up there that is Korean American. She and I have this joke because we meet people who have connections to Meadville. This little town of 16,000 people...we have met other people....

CC: It is interesting.

SS: It is a funny moment that my mother would have appreciated.

CC: One point before we wind down a little. I asked you about experiences. I am very moved by the idea of being forgiven and forgive long after a person is gone. I have had these conversations with others.

SS: I am not sure that I have.

CC: Have you ever felt her after she passed?

SS: After she passed, I felt a ball of light. There is some interesting things right after she died. While Alzheimer's did was to provide a cushion and to have time to have those conversations before she passed. The only analog I can think of is when you lose a friend, or have an argument and you have this conversation in your head. It feels like it never gets anywhere. It does not to the friendship any good. You come to realize, you have a Buddhist principle. You create the dialogue that you are creating to drive yourself crazy. It may be based on certain events but your interpretation of them is your interpretation. Trying to get a little bit of detachment from that righteous position is really helpful. With the mother-daughter thing, one of the crucial moments was after Brian and I got married, I was seeing a psychologist. Part of it had to do with how furious I was with my mother because she had not come to my wedding. Partly because one of the times I had seen her not too much earlier than that, she tried to disown me. She said, never to come back again. I was trying to get her to apologize. That is why I was seeing the psychologist who said that I thought I could have a conversation with her. The psychologist said I could not, so drop it. I realized I was in the conversation and I dropped it. You can do this, after a person passes. You can stop feeding into it with your own narrative because now they really cannot have the conversation. And that might make it a little easier to clear the air.

CC: Also so we do not have to live in anger. Especially if we want a good life, we want to let that stuff go. Is there anything else you would like to say about this subject that you would like to share? Otherwise I want to ask you one more question.

SS: Go ahead and ask me another question.

CC: Being that you seem to be aware of mortality, there is a lot of denial of our mortality. It is the survival mechanism but you have a deep awareness of it, you have accepted it. Has that awareness of your mortality changed your priorities in your life? Has it instructed in how you live, in terms of relationships?

SS: There are real slippages. When it is working well...I think I have a bit of luxury of being in my mid-fifties. I do not necessarily have to worry about dying right now. It offers a freedom to contemplate it. This is important. When I was with my mother, I had the luxury of not being her primary

caregiver. I could visit her. There was a luxury of having the time and space to wonder why all of this is important. People who are there all the time may not have that luxury. That is one thing I would say. I think that if you are aware of mortality, then. What does John Ashbury say...in your late thirties, the things in the world acquire a sheen to them? You begin to be aware of how things change, you become more aware because you have to let them go. It is important for people to think about.

CC: That is beautiful. Anything else?

SS: Thank you for doing this project. I look forward to sending it around to people who need it.

CC: I have learned so much about this process. I thank you and am sure the people who watch this will learn a great deal.

SS: Thank you so much.

CC: Thank you.

Interview Nancy A.

CC: Hi Nancy, how are you?

NA: Hi.

CC: Thank you so much for being here. As you know I am doing digital stories on death and dying. you are a wonderful complex woman who thinks deeply and I would like to know... do you think about death and dying as a baby boomer? is it something you think about or something you rarely think about?

NA: On one level, I think about it a lot, maybe more than I should. And on another level, I do not think about it enough and will explain it more. I have been thinking about death and dying from a very young age, in part because I had people who were close to me - family members and even friends - pass away in the first 20 years of my life. Usually this is not a period where people die in your life. so that happened. when I was 21, I read the Tibetan Book of the Dead.

CC: At Twenty-one?

NA: At 21 years of age. It had a profound impact on me.

CC: I am sorry, let me ask you. Why did you read that book at 21?

NA: It fit in with other reading I was doing that was not necessarily about death but was spiritual reading. It was less about death than about spirituality and passing through different planes and dimensions. But I recognized from that book, and I am now 63, and it was a long time ago. One thing I held, there are times as we are dying, and immediately upon dying, within that culture and tradition you can have a good death. If people are helping to guide you, you can go to a better place. When I was 23, my father died and it was very unexpected. I was so disappointed that I was not able to be there with him. Not to go through the Bardo because I think he would have gotten that, but to at least internally and spiritually be there and lend support to him. I am not sure how it would have been. It was my father who I loved dearly but I felt I would have been helpful to him and strong for him as I have been for other people in my life as they have been passing. I feel comfortable with that, not that I am thrilled but I recognized it is a part of our stages. I recognize it in myself to. Another thing that had a strong effect for me, not so much spiritually, but more in terms of efficiency. When I was about 35, I heard someone speak at the Unitarian Church and he shared about taking care of his father in law and how for him and his wife, when the father in law died, he had nothing in writing, how hard it was for the family. The man was encouraging people to really take care of final affairs, not because you are sick or dwelling on death but that you want to get it over with and you will actually feel better. I made an internal promise by the time I was 40, I would have a will. by the time I was 40, I had a will. it was all written down.

CC: Things have changed, I bet.

NA: I need a new will. That is why on one level, I say I do not think about it enough. A little over a year ago, I came very close to death and ended up in emergency room with a poisoning from a pill I took that I was allergic to. My organs were already starting to shut down and my heart was going to stop and I would have died. I could have been alone in my office. it just so happened I was not alone at that time. But I realized, I better get on it and take care of these final affair things. But I have not done it. It is important but I have not prioritized it enough to take care of it. It could happen tomorrow, I am not going to be here forever.

CC: Wow. So there are two aspects: there is the spiritual aspect, what we are talking about that I think we think about more as we age because we get closer. The average person, the lifespan - we get closer to the end game.

There is the spiritual aspect and the practical and some people would argue that a good death is preparing for all of that. What do you think about that?

NA: I do think it is both. you can have all of your ducks in a row and still be suffering or in pain and if it is not physical it could be emotional or spiritual pain. So I think part of a good death is making sure you are having a good life with every moment you have. People will frequently say you are dying, you are going to wish you did not work so much and do the bucket list type of things and do things you love. I have to say when I was in the emergency room, in the ambulance a year ago, I was not preparing to die but I was not feeling like 'I did not do this or do that. " I felt at peace at whatever was going to happen next. I think that when your times comes, you can be at peace and be able to let go of the things you need to let go of. Sometimes struggling makes it a harder death, not a good death.

CC: Like Susan Sontag. Sometimes as I interview people and I talk more and more about death and dying, I often think that all the lonely people like in hospice that no one came to visit. How can we, as human beings, help each other in that way. Often we are so busy... we live in such a busy culture, we are not there for people even though we would like to do. Probably millions of people die a very lonely death, which is not a good death, is it?

NA: You die a lonely death if you are lonely. In the end, you are going to die alone.

CC: That is true.

NA: I can only speak from my own experience and I have not died yet. I try and stay in touch with people and call and let people know I am thinking about them. Send an email, write a note. If someone does that for me, it makes me feel good. if I go to bed and night and die in my sleep I can think about how a person thought about me that day. I have noticed some people find it difficult to be around someone who is ill or terminal.

CC: Why is that?

NA: I am not sure. It has not been something that has been difficult for me. I am willing to sit with someone in the hospital. If it is someone I did not spend a lot of time with, I feel there is something false to show up and hold their hand while they are dying. But if they are comfortable in having people there, and I am close to them I will be with them. But sometimes people, visitors can talk too much. if someone is sick and they are having trouble breathing, they do not want to have a conversation. A couple of years ago, a

friend was dying of cancer and I went to visit her frequently and bring her what she asked for and did what she needed. I tried not to bring my own stuff into the room. Sometimes I would tell her a problem and that was good. It was still valuing her advice, it was not like 'oh you are dying so I am not going to tell you what is going on in my life.' Trying to find that balance, you know. Sometimes she did complain to me that about some other people who were too pushy about their own agenda - I need to make kale juice for you. But she could not tell them as she knew their intentions were good. She knew she was dying and so she was in charge of how things were going. She was not thrilled about dying but was resigned to it.

Over the last few months, especially. At one point, she called people over and said 'it was time.'. she wanted people near her. She was a spiritual and religious person. She was religious in a comfortable sort of way. She did not die that night. She went on for another month or so and there was another time and called us over. I was there for a couple of hours, and other people were. We were singing. I did not know if she was hearing us. There is a look sometimes in people's eyes - their eyes are open but they are not really focused where they are seeing something far away, that we cannot see. She would get a smile in her face that she saw someone she could engage with but we were not seeing that person. It was just good to be there with her. At 11, I had to go home. Other people were there and she did not die alone. It was a good death and I was not ready to have her go.

CC: Being in control?

NA: At least having a role in making some of those decisions. some of us can get too controlling. I would like to hope.... I did have another friend who knew she was dying and so she wrote up her own obituary. She asked me to edit it. the first thing I said was that it was really long, really long. I look at obituaries at it was long.

CC: Was it like a big celebrity type of obituary.

NA: Yes, that kind of long except she was not a celebrity. She was a good person. She did not let me do the editing. She said she had the money and this is what I want' and she took the job away from me. It was her death, she controlled a lot of it. She knew what crystals she wanted, what sprays she wanted and in the end it was not comfortable for her but she had all the elements she wants. As deaths go, I think she felt it was a good death for her.

CC: That makes me think of something else. We can navigate our own journey in this. Because of the medicalization of our death, sometimes the

control is out of our hands and I think that is changing through the hospice movement. You are talking about taking control of the journey and not letting the medical establishment take over. Still to this day, most deaths happen in the hospital and you know what happens in a hospital. You don't have control.

NA: Many people shy away from this and you do not have to be terminal to know what you want. Our friend the other day was sharing how she spoke with her mother in terms of what hymns she wanted, what colors people should wear. You do not have to be on your deathbed to talk about those things. I am very open to having gatherings where we sit and talk about things in terms of what we want. We need to help each other and remind each other - do we want a big party? The big things: burial or cremation we think about. What songs do we want. I think people would want to do what makes you happy and it is a burden for other people to make those decisions. If you can do it beforehand. To make it easier for people who are still alive.

CC: That brings to mind something you said and about the taboo in talking about death and dying. It sounds like, from what you said, it is changing a lot. Do you think the baby boomers are leading that charge. What you are talking about is having friends and spending time talking about death. Previous generations did not do this. We are a generation that not all of had children, not all of us have husbands, we are independent, and many of us live alone. It is not the hierarchy of kids and this and that, so I think that it is really important. Do you talk about death and dying to friends? Do you talk about the issues around it?

NA: I have on occasion, if it comes up. I do think it is the boomer generation that is the cutting edge on this. But I would not say it cuts across the entire generation. One of my friends who is close in age and is interested in all of this. She put together a dinner party with this as the topic hoping we would talk about this. She did not have a clear-cut path on how the conversation would go but wanting it. I was down for it, right away. There were four or five other people there. No one else wanted to go there. It kept getting deflected, it was not comfortable for people to do.

CC: It is the biggest moment in our lives, the finale. Certainly, if we consider it more, we might waste less life. I certainly waste time. It is the biggest moment of our lives, our departure. Did your mother want to talk about it?

NA: My mother did not want to talk very much about it but I am grateful she was willing to plan, she had the foresight to plan. She had the burial plan taken care of very early. Maybe it was because she wanted to be next to

my father, so that is why she had set it up. But she had also her insurance policy she set up. She set up things ahead of time. When she had to have surgery, we had to fill out the advance directions and I was able to ask here questions regarding life support. If she had not gone into surgery, I am not sure she would have been that comfortable. My mother was one of the people who tended not to visit people who were dying. She tried to stay away from that topic. As far as death being the most important moment, I do not think about that moment as being the most important as much as being the most final. For me, it is holding it there - this is where ends...how do you want the road to be as you move towards it?

CC: That is beautiful. I loved how you said this. Some of us have choices, not all of us.

NA: Not all people have choices but there is some element of choice or determination, even if there is another power, or is even successful in taking that choice away, like Nelson Mandela who spent 30 years in prison and he did not have a lot of choice. But he kept a determination of spirit that could not be diminished. I think about that a lot. People who are dying in there eighties and nineties. We used to say they were older people. Now seventy is the new fifty. it is only because I am in my sixties. I can't say in twenty years I want to do this and that but realistically I can't say that as I may not be here. Thirty years I will not be here. That is finite that in a way did not feel like that when I was in my thirties or forties.

CC: We do not think about those things when we are younger unless we experience death of a family member or a good friend. You said something about that we know the final end and we have a choice on how to navigate that end. What are some of the choices you are making now that you see that end. Can I ask about that?

NA: You can ask about it, I am not sure I am going to be very good at articulating it.

CC: The big picture.

NA: I mentioned about the bucket list. I really do not have one. I have tried to push myself into thinking about what I would want in my bucket list. I want to be a better person, be kinder, more accepting, treat myself better as well as treating others better, be healthy and be less judgmental. I have no desire to jump out of a plane and if I never went to another country in my life, it would be okay. As much as I appreciate and am enriched by other cultures, I do not have that bucket list. I am not adverse to it and if opportunities come up, I am not adverse to it. But I am very much a... I do not want to sound new age... but I am kind of in the moment.

CC: Your bucket list sounds more spiritual, being present for other people. Being present for other people...

NA: And myself. I think I have a long way to go to be present for myself as well.

CC: That links into what you are saying in that having a good death is having a good life. I think we miss a lot of opportunities, not seeing it. That is what gives life its preciousness. Is there anything else you would like to share about death and dying, a story...any thoughts over the years that you now have a chance to share.

NA: I do remember when I was a student at the University here and was an older student, I was in my mid twenties. I had a small symptom I was concerned about and went to the health center. The doctor there got professionally excited because what she told me - she told me that I have a tumor on my pituitary gland. I looked up the gland and it was in the middle of my head so it was in the center of my brain. She was excited I guess because it was a cool find for somebody who probably just found STD's. She should not have told that to me. She sent me to an outside doctor and have a bunch of tests done. I had to wait for the results of the tests. There was a three to four weeks time period between the tests and the results read to me.

During that period, I thought that if there was a tumor in my head, I was not going to let them open me up. At that moment, I was clear. It may be that my days were numbered. my life was so rich. Every taste was so rich and every color was so deep. If you only think you have a little bit of time left, every moment is that more precious and special. Even though the doctor was nuts for telling me that, she gave me an unintentional gift. Like you said, only because we are aware of our death, that our life can be elevated to higher and higher levels.

CC: That is beautiful and it is a beautiful conclusion to this interview. Thank you so much Nancy.

NA: Thank you so much for your work. Thank you.

Interview with Katherine LI

CC: Hi Katherine, how are you?

KL: Good.

CC: I am so glad you agreed to have a conversation on death and dying. We have talked about it in the past, mostly about people who have been close to us. It is a subject that interests you and will interest our audience. Here is a quick question: What is a good death, what immediately comes to mind, what do you think about?

KL: I guess that would mean, death on my own terms, as much as that is possible. When I think of what that means, I think of the intensive care unit where people are hooked up to every life extension and protocol. How much is too much? A good death to me would mean for me to decide.

CC: It is about empowerment, about making decisions and not relying on the decisions of doctors and the medical establishment. While you answered this, the other thing that comes to mind is that you are enlightened. You think a lot, feel a lot and you are on a spiritual journey so when you, the good death - do we really die, what does that mean? You have so much knowledge on what is out there and so many perspectives on the world, do we actually just die?

KL: No, our body falls away but the energy that animates us, continues on. Of there is no evidence. Recently I read a book called 'Dying to be me' by Anita Moorjani which I would recommend if you have not read it. It is her journey of a near death experience. She had stage 4 lymphoma and was in the hospital. It was certain she was going to die. She had a near death and came back to tell about it. A lot of things she experienced, meeting people who have died before and experiencing this energy beyond the body and time and space. All that is essentially important is love and loving others and being fearless. Fearless to be yourself. That inspired me because it confirmed my own near death and out of body experiences. When we are broken free from this 3 dimensional form, we come to the understanding we are connected. How do I verify that? I cannot scientifically because I cannot. It is something I feel and something I intuit and gives me a fearlessness about death. I will go on and I am in an earth suit. I may come back or go on to something else.

CC: That has a very calming effect on our perception and how we view life. We are taught that there is a thick boundary between life and death and that is it. When you say, we go on and we break free from our earth suit, how does that guide you, this knowledge, how does that guide you into living and the choices you make when you are alive.

KL: One, that I am here for a short ride. I do not have a lot of time to get caught up in fears about the next move. It helps me to tune into things that are greater than myself and that is not something I can define by any religious terms or spiritual terms but is a presence that comes with peace of mind that is reinforced by mindfulness practice, being in the present and not letting any of the exterior events, or current events.

CC: Like the recent government shutdown.

KL: I was not. I knew they were going to work it out. Of course you have an emotional reaction, it is very distracting and that is one of the things we see in the mainstream media which is to stir people up until they cannot think clearly. It is a big distraction and quite dangerous for our democracy. That is another topic.

CC: But it is also dangerous for our spiritual growth. We have this knowledge that we are here for a short time. We are giving a lot of power away to distraction.

KL: There is so much more we can do in this world.

CC: Like what?

KL: It does not seem like it is very hard to bring us all up. Raise us all up, if we tuned in to the spiritual power that is in all of us. There is an enormous amount we could accomplish in this life and in this world. Eventually we will get to that point. I call this stage is growing pains for the human species. We are going through this transition where people will understand these concepts, more easily. It will not be foreign or strange to people. Like you said about this clear line between life and death - there is a lot of gray that people are not comfortable with but until we learn to be comfortable with the gray, we will be caught in these binaries that we are caught in. Like the government shutdown. One way or the other. People are not comfortable in these in between places.

CC: The complexities, the nuances. Do you think, because we have to have a growth spurt as a species. Not all people feel that way, of course. We have had this taboo about death and dying for the longest time. Not all cultures have it. We conveniently compartmentalize our death - we do not talk about it. Death education is a relatively recent curriculum in the K-12. Do you think if we had more knowledge of our temporary status in this earth, do you think that would shift the consciousness, in terms of maybe a more equitable and loving society?

KL: I do understand what you mean in terms of thinking that death is something far away. Within the medical system, we push it off as far as we can. We think we can become immortal somehow if we take the right medication, do the right medical procedure. There is a sense that I do not have to die. There is an avoidance that gives us this fear and avoidance about death and dying. Having spent time in India, I believe they are more enlightened because they are aware of the natural process - life and death are not separated. I can illustrate that with a story in India. A friend of mine had a baby in India and I went to visit her in the hospital. We were in the waiting room. It occurred to me the place where people were this: on the right was the maternity rooms and the left side of the waiting room was reserved for cardiac arrest. You would never see this situation in a western setting where the wings are separated by floors. There would be no way sitting next to someone whose father was dying. So being in the middle of those experiences and in the waiting room where people had vastly different experiences and expectations, gave me a clear insight of how close life and death is in India. Another example, when I was 30, I went to Varanasi and I went to sit by the burning deaths and watched the corpses - putting the body on pyre, the burning of the pyre and the body, how the ashes were put in the river. When you are that close, the lines are not thick as you say. There is blurring of the lines, they were much more accepting and enlightened because of it.

CC: Those kinds of ceremonies, how does that differ from our funeral? Our process is the funeral, you go to the church. Is there a difference? There are lots of studies that show Western culture is in denial of death. Does a different kind of ceremony play into the acceptance. Do you know where I am going with this? People pass, we go to the funeral, we talk about the memories. We do not talk about the reality, so much. Is the process different so that we can be more accepting of our own mortality?

KL: From my own personal experience, it is part of life. It is what happens. There is a cycle of life. You have a sense there is reincarnation and the principle of karma, that this is not the end for people. A lot of studies including researchers who have done work on reincarnation of children, who can remember their past lives, have been able to describe stories of reincarnation. Where children will say, "I want to go home". The parents are surprised as the children describe details of a past life. They can describe other places. It is astonishing, a small child could do this and describe another state in India. You have the sense that this is not the end. In the Christian culture, you get a one shot. You come into the earth and you better not sin. You die and it is over and it is so sad because there is so much you could have done, if you hung around a little longer. You do not have that

sense in other cultures. In India, you will come back and it is not over. There is something reassuring that it is not a one time deal.

CC: The human propensity is that if we do come back, I want to come back as someone cool so I better live my life right. I do not want to be harmful to others. But, this idea of reincarnation is also somewhat of a motivator to have good life. I think where karmic traditions and Christian traditions meet, is that if you do murder a bunch of people, you may get in trouble. There is a meeting ground. But in Christianity, you do not have another chance. You go forever. You have read a lot, have done a lot of research. What sparked your interest in death and dying? Has it been a lifelong thing? Or is it something that happens in our baby boomer years?

KL: I am not sure it is an interest, maybe a passion to grapple with this issue or just flow with it. I had an interesting experience when I was 8 years old. It was the earliest awareness of death and dying. I was in a grocery store with my mother in Wilmington, Delaware. We were in Pathmark. At that time, there were no cellphones. At that time if you had something on the list, that was it. You could call and have someone paged. This was not unusual to have phone calls and paging with my mother and father and the shopping lists. So, we were in the grocery store. I was holding my mother's hands. I was small and I was eye level with the milk. Before the loudspeaker, came this intuition that my grandma died. She looked at me, astonished - what was I talking about. The loudspeaker came on, an announcement that here was a message for my mother - It could have easily been a message, 'don't forget to buy the bread'. We went to the service and the only message. Go home said the message, as soon as you can. When we went home, there was a note on the table to go to the hospital. We went to the hospital and my grandmother had died. How was I able to pick up the information over the airwaves, I have no idea. But it was the first time I had the experience and since then, I have had several experiences before the announcement was made. Probably, since I was years old.

CC: What went through your mind at that young age? We do not have a lot of awareness of death at a young age? You were little? Did you think that something was wrong with you?

KL: I did not question it at that point. There was emotional charge, my mother was upset. Plans for the funeral, all that you have to do when someone dies. The shock was so pervasive throughout the family, no one looked at me. It was later, that we had a conversation about how I knew my grandma died. I had no reference and could

not explain it. When I was having more of the experiences in different kinds of contexts - spiritual experiences - I started seeing that other people had experiences. When you have an experience like that, you think you may be the other one until you hear others having that experience. I thought, at 8, everyone had those experiences.

CC: We have this premonition, we have an intuition, whether someone comes and says goodbyes. I do not understand the mechanics. After a person passes into the next realm, have you ever experienced people coming back or communicating?

KL: Yes.

CC: Could you tell me a story? I think that a lot of people and, some people, like my friend Mona who said, 'Dad came to visit me today.' It is a knowledge and may be a matter of fact.

KL: I do have a story and it is about my paternal grandmother. She was a person who was strong and very sensitive. She had two near death experiences herself. I grew up, as it was, where death was not something to be feared. She told these stories and so I knew there was an experience beyond this realm all of my life. Especially since my grandmother had two of these. At the end of her life, we had a deal. I said to her that when she died she should give me a sign if there was something really going on. She said fine and she promised and if there was something after death, she would do it. There was nothing specific in terms of a gesture. It was left to the imagination. She had a heart attack and two strokes and she was on the East Coast. I was at my father and stepmother's apartment in Waikiki. We were having dinner and suddenly I was on the floor in the fetal position. My father was alarmed. I knew the whole left side of my chest, there was pain and pressure and heat coming from my left side for a few minutes. After five minutes, it passed and I got up and went home and to bed. My dad called, 'your grandmother passed to the other side.' I asked him what time and it was the exact time when I had that experience. Of course, I wondered if that was the sign that she promised. That was the first sign.

The second day I went to work at a surf rental shop. I got there, it was a small place, the size of your office. I worked for a French guy and he asked me if I wanted to work that day. I said that work was good for me. I realized I had to go the Bank and deposit a check. I was gone 20 minutes, and came back. He went off and I stayed at work and waited for the sign. I was not sure what it was. I wanted her to be clear, it was 24 hours. Anyway, the next day I go to work and there was my boss and he was pale. He said there was something he needed to say. He said that the day before when I went to the

bank, I had received a phone call. The person on the other end asked to speak to Kathy. That got my attention because no one calls me Kathy except my close friends and family members. I asked, what she said. He said that 'the woman asked for Kathy and when I told him she was not here, she said to tell Kathy that her grandmother was alright.' How do you explain this? I talked to my Dad and his response was silent. And then he said that the two of us were so close and that it made sense, within telephone wires there is crystal. That is one of the great transmitters of energy. So then I did research - this is so common. That is how people are communicated with on the other side, the telephone. This is what happened to me.

CC: Did you have any further communication with grandma?

KL: No, I can feel her presence but that kind of direct, no. If I were to answer the phone, I do not know what I would have done.

CC: She could have called, knowing you were out.

KL: I imagine that when you are on the other side, you know everything. You just know, that is what the author said. Everything slows down in the realm.

CC: It is kind of exciting in a way to know that the journey continues. The title of my blog is Journey to the Unknown. It is not the END or the END is near. It is a continuation. It gets you a little less fearful and maybe more grounded in the now, would you say?

KL: That is exactly what it does. I am anchored in the present.

CC: I am impressed with the journey you are on. Most of us get caught up. We stress the small stuff. I think it changes over time, as a baby boomer, I noticed that we have started the conversation on death and dying like a lot of other things. Technology has supported the conversation, social media. It is becoming public and less private, solitary thoughts. Grieving is more well understood and accepted. Do you think that baby boomers are more aware of our temporary status here? What can we do? Do you have words of wisdom for the baby boomer generation - things we never thought about before, we are thinking about now? We are thinking about wills, just stuff, and the practical stuff. I have a friend who wants to have a directive party. She has the party, we eat and she has the paperwork.

KL: That is interesting you say that. When my brother and mother were rendered incapable of making decisions on their own in the ICU in two different places within one year, I was called forward to be that decision

maker, which eventually led to their deaths. I was put into a situation where doctors were asking me to make decisions. I came back from these experiences on the most adamant campaign to get everyone involved with their own advance healthcare directive. I did a project with the kupuna on Molokai and had seminars on advanced directives. I gave people the opportunity to look at the paperwork. How do you fill out an advance healthcare directive? How do you choose someone to be your medical proxy to make decisions on your behalf. And carry out the wishes of the advanced healthcare directive. It is a great way to be empowered and have those things in order. I live in the moment, I am able to do that because my ducks are all in a row. I do have an emergency card that tells who to call, where my doctor is, where my directive is, who my spiritual contact. I make it as easy for people so they do not have to figure out what to do. When you take care of all those things which requires confidence in yourself. Why don't I give the best gift to others and alleviate stress for others. If you can reduce the stress. It is practical tip and opens up an amazing conversation for family members. In this country, it is a taboo subject and if you can sit down and say, 'this is what I am thinking about?' And talk to others about directives. An amazing opening can happen in the family. A lot of people put off their wills until they are dead.

CC: One day a couple of weeks ago, I was thinking that I fly a lot and what if something happened. You want certain things to go to certain people. We have all these ideas, especially those people who may not have children. But I have not done it yet Are you suggesting that a practical tip is to write a will, that we can change later on but to get something down?

KL: In some circumstances, people do not have relatives. If you do not have it written and it ends in the courts, you can lose the value of your property to the court system. You want to do it and protect yourself and go where the assets should go or those assets will get swallowed into the system. It is important to do that. That is why I can live in the moment because my ducks are in a row. I do not have that anxiety. I am not a comfortable flyer but it is not because my papers are not in order. Anyone who wants to live in the moment, empower yourself. You have to take certain actions to give yourself a level of comfort. I have talked to everyone in my life. There are no 'I am sorry' to be said. I have taken stock and understand all of it. Is there something we need to do to reconcile the relationship. I live peacefully because I have no outstanding apologies to make. You have to sit down with yourself and take stock. The process allows you to be more peaceful.

CC: What else? When we talk about Tolle or the millions of people who are living in the now, none of this is mentioned. You are giving a specific, a very important take on how we can live better in the now. Taking care of

business, resolving conflict. What else? You must have a trunkful of tips that are different from the norm.

KL: I got my tips from writers and researchers. I have collected the gems. Realizing that I am responsible for my life. Nobody owes me anything. My happiness is not someone else's responsibility. It is up to me to be in this world and whatever I define happiness to be - it is all up to me, it is not external. You are the captain of the ship of happiness, you are responsible. I am responsible for my journey. When you understand this, a lot of things change. A lot of times we think it may be someone else. It is not going to be someone else.

CC: Yes.

KL: I have a friend.... I have another story, this is good. A friend of mine, well we were good friends in Japan. He brought me to Japan. While in Japan he got testicular cancer. That takes on a whole new dimension in a friendship when you take care of someone who has cancer, especially in a foreign country. He, I think, did some evaluation as to having survived that. What was important to him, next? When he came back to the US, he was married to a Japanese woman and was in a high level executive position in a corporation. He had a high status position. Underneath it all, he is really an artist and felt he was neglecting that side of himself. He wanted to go back to being an artist but he did not know how to break it to his wife. She enjoyed all the perks of his high status position. So he did something clever, and presented his wife with two versions of his eulogy. One version was that of a corporate executive. The other one was of the artist. He presented both versions and of course she chose the eulogy of the artist. He is now a very successful artist with his own business. Their lives are a lot happier. In essence, writing his own eulogy and how will we be remembered at the funeral. It gets you thinking about what you are doing in this life.

CC: Another good tip. Two tips actually in one story. The first tip being, doing what we really want to do. The next tip of looking to the future to see our now. To see how we want to craft our NOW. Beating the cultural expectations of success, mostly financial to really going after the big passion. It is never too late, is it? Those are some very good tips and advice. Is there anyone else you want to add before we sign off? This has been a wonderful conversation.

KL: I guess I will end with another conversation. When I was in South Africa with a friend of mine, we were travelling to Peru and we were on a long bus ride. We both like to read books. She was reading 'Out on a Limb' by Shirley MacLaine. We are on a bus and told me to read it. We arrived in

Cochabamba and she runs back to the room and told me that Shirley Maclaine was in town filming 'Out on a Limb.' We got to be extras on the film. It was a gorgeous setting, high in the mountains with the indigenous people. I wanted to talk to her. She is a rock star and I was nervous. I was trying to figure out how to walk in the crowd and bump into Shirley Marcaine. I walked past her and could feel her energy. As soon as the scene was over, I went up to her and told her I could not believe I was given the opportunity to talk to you. I just read the book. And I talked about her experience. She looked at me and said, 'everything you need to know, is inside of you.' You know all the answers, she said, but you have to tune in. Your internal GPS is working but you have to tune in. That is your final comment.

CC: Beautiful. Thank you for a wonderful conversation.

Interview with Leslie Novosel

CC: Hi Leslie, how are you doing today?

LN: I am doing fine.

CC: Well, I told you about my project and you are interested in death and dying. I am going to start off with one question and then we will see what happens in the next 20 minutes. I want to know your feelings about what is a good death? Having said that, it means a lot of things to a lot of different people.

LN: The first thing that comes to mind is what a good death does not mean. The reason why I say, I lived through two experiences that were horrific with people I loved very deeply. I come from New Orleans and my Dad's very old world. He believes in doing everything you can to keep the person going even if they are ready to go. I really did not know that much about him but I was the person in the family taking care of his mother. I took her from New Orleans and took her to Austin and lived in a nursing facility for two years. Then it was time for her to go. She was 96 at the time. So my daughter who is the perfect partner when there is a crisis due to death, we are just such a good team. We found this out after the experience. We are in the hospital with my grandmother and singing songs to her. We sang Amazing Grace and we held her hand and kissing her. She wanted a cheeseburger. She would start laughing. We knew it was going to be a sacred experience. She started bleeding internally. My father called from Florida and gave orders to

resuscitate, no matter what. When he heard that she was bleeding internally, he said she had to have an internal exam. My grandmother had been raped and had psychological problems. Right before she died, she had to have an internal exam to see why she was bleeding from that area. It was horrific for her. The doctor even said, why is your father making us do this? I did not know, I cannot control him, he has power of attorney.

I pleaded to my father. She went through the painful exam and they said her bodily functions are shutting down. Then my father wanted x-rays. I am holding her hand. We saw the light change in her eyes and to be present in that moment. She transitioned to a different place. She started talking to God. She was having a conversation. She was talking to this whole other being. We get another call for my father which meant that they had to bruise her chest. All the doctors and nurses were begging me to talk to Dad and help him change his mind. I could not. So, I said that she is gone. I am not going to stay if you do this. He said fine. And so we left. I could see my grandmother in the emergency room in critical care while they were working on her. She passed with people sticking tubes on her and pressing on her ribs. It is a horrible experience and I know, I do not want to go that way.

I had another experience. I am very close to my grandparents. This time, it was my gramps. I was closer to him than any other male family member. He loved me multiple times. Every time I was with him. I cannot tell you how much he impacted my life and made me feel worthy of my life. When he was dying, I just knew he was tired and wanted to go. My dad did not want him to go. I flew from Austin to Florida and I crawled into bed with him. He was all curled up and in pain. He was moaning and I put my arm around him and counted his every breath and did not sleep for two days. That is when I realized how sacred, hospices where. I realized the nurses were earth angels. They were giving him morphine for the pain. My dad did not want my gramps to die so he ordered the nurses to pull back on the morphine. But my Dad was at home. My daughter and I were with my gramps. I pleaded with the nurses to override my father and they did.

The next day, my father came back to hospice and complained that the nurses were giving him too much morphine. He decided to take him home. While my gramps was writhing in pain, he could not even stretch his legs, they moved him and put him in an ambulance and took him home. It was so beautiful, the hospice. I told my father that if you take him home, I had to go home. I looked right in my father's eyes and I said, "God forbid, if I am with you when you are dying and I am not going to give you any medication." It was probably the meanest thing I have ever said to anyone but that is how cruel I thought it was. I flew home and said goodbye to gramps and I was sitting out in a patio chair. It was one of his caretakers at home and they

said that gramps had just left. As she is talking, I see something moving in the grass. Something told me I had to go outside. I hung up the phone and walked outside and saw in was a Monarch butterfly. I sat down and picked it up and it was huge. I walked into my apartment and I clicked my Apple and took a picture. I took it back outside and I said, “bye, gramps.”

That was his way of saying goodbye and to tell me he loved me and thanking me for the things I did to try to make his death a better experience. I know how I do not know how to go.

CC: Have you forgiven your father?

LN: No. I know why my father behaves the way he does because of things he experienced in his lifetime. I think it was the meanest thing you can do to someone, but I think my Dad does not know any better.

CC: That is what I am thinking. You said some very important things and one of them was – is it possible, a question that come out for me – is it possible that a denial of one’s death not only affects the well being of others but it affects your own good death?

LN: I think that everyone has a right to, there feelings about death and his parents, in my opinion, trumped everything. He did what he thought was best. I do not think he wanted to hurt them, that is all he knew. In that way, I can forgive him but it was hard, it was so hard because he did not trust me to make the decision. Before those two events, I had an experience, I had just had surgery and the nurses came in to see how I was doing. One of them took the clothes and put them on my stomach where the surgery was. It was an outpatient section. I could feel myself going and crying out Help, Help. I could feel myself going.

CC: You mean you were transitioning.

LN: Yes, I was transitioning. And this is why I am not afraid to die at all. It was the most incredible, most peaceful, comforting, relaxed feeling I have ever had. I could feel the light pull me and I could feel myself going. This feels good, I thought. I know when I go, there is a phenomenal life waiting for us. They brought me to but it forever changed how I looked at death.

CC: Do you actually see it as death? Do you see passing on as death. We have firm boundaries. From what you are sharing and from my own experiences, maybe these boundaries are more fluid. Ever since then, you have not been afraid. This good death, what does it mean to you. What does it mean in a medicalization process. Let’s start with the basics. How would you like to go?

LN: That is a critical conversation that I would like to work on before I answer. There is this website about conversations on death and it has all these tools. These are critical conversations to have with your family so they know ahead of time, that is what mom wanted or what dad wanted. They feel comfortable that they do not have to make the decisions. A lot of people are afraid to talk about it. Well, some people.

CC: That is one of the reasons I started this project. Death and dying is a taboo, talking about it. We are afraid to talk about it, which leaves us in hospitals. It is hard and no one quite wants to leave. I think the conversation is changing. The Internet may have contributed to that. We have communal celebrations. Baby boomers may be taking the charge, we are loud to begin with. When you say you will have to think about it more, what comes to mind when you think about a good death.

LN: That is a good question. I am not sure what to say. When I think about it, I think about it for the people who are around me. What would my death be like and make sure it is good for people around me. I think about Oregon and the laws they passed. I think if I have a fatal disease, I am going to Oregon. They do not want you to suffer through pain and be debilitated . I want to have a voice in my death if it is not the result of a traffic accident.

CC: I think we can do that more because we can write our own directives, when to pull the plug.

LN: I have never taken the time to do. I have not written a will and I do not have a plan. It is something I should take more seriously. This conversation is solidified that for me. We have to have conversations with family members and friends. That will help it to have a good death.

CC: I heard someone say that to have a good death, is to have a good life? What do you think about that? There is so much loneliness in this society that we are not helping others to have a good death .

LN: That is a good question. Are we helping others to have a good death? Probably not. I think hospice is. I think hospice is the only organization I can think of, they do such a good job and we have so much to learn from that. They are angels. These are humans on the earth who know how to help the loved ones transition but the family members. It is amazing. It is not something you have to afford. That helps the loneliness factor, we do not have families and spread out all over the country. It is wonderful to know about these humans. This is their life's work.

CC: The idea of a good death is much bigger than what we think it is. Your passion is helping young people. As a mentor, as a friend and you teach. You are motivated by your passion in life. You want these kids to have a good death, to live well. Is it too much to ask, how you can help them have a good death?

LN: These kids are the most vulnerable. They are kids of color and have reading problems. They quit going to school. If their parents do not have the resources they will fail in the system. The system is set up to fail. The number of children who are young adults who have died are not good deaths. One was tied down to the bed. Another, shot in the head walking home from school. The things you see and how they are treated by society. It is inhumane. We lock up more children than any other country.

CC: And they die early.

LN: I am sure they do. I have seen a staff and pick up a child and slam the kid on the concrete floor, I could hear his head crack. The blood was running down the hallway.

CC: If we – all of us – want to die a good death, why aren't we more sensitive so they can fulfill their human God-given potential in life. Why have we let them fall through the cracks? People with mental health illness lose about 20 years. We know the stats. Why are we not sensitive towards young people whose chances of living until 80 are pretty challenged. Why are we so insensitive to all of us?

LN: I think there are a group of people who care but there are groups of people who just want to make money. It is a big business. They make money off food, uniforms, and the shampoo. It is a big business and all of these people making money are the ones who lobby and who support political figures. It is such a moneymaking opportunity, jobs for people who work in the prison. What if we worked with the staff? Can we really help people. Can this cause them to shift in their thinking, more so than in their churches. But to have conversations on death and dying and like this.

CC: It is starting but it is slow. You brought up a good point and there have been studies. Current studies point to the fact that if we were aware of our mortality, we would be better human beings.

LN: There you go but we do not even think about it. Kids do not think about it. The adolescent brain is not fully developed. The part that regulates behavior and thinking rationally. That is not developed until you are 27.

CC: But people are in charge of these young beautiful creatures. What do you think of that idea – if we were aware of our mortality, we would be more compassionate and loving. Do you think that talking about it more. There are death cafes where you can talk. Can we ask ourselves, what is a good death for me, for my family and community. You and I are about social justice, while we are alive. The powers that be are not behaving better. I do not know where I am going with this.

LN: It is a personal growth opportunity. It is so powerful and because death is so taboo, I never considered it to be something that can shift lives and paradigms. I think it is a brilliant idea.

CC: We have been talking for a while now. Do you see how the question, 'What is a good death' can be more complex than originally thought?

LN: Yes, you can take it so many ways. At first I thought I know how I do not want to go but then I started to think about spirituality and how I believe there is an afterlife. I believe we are energy, and we may go somewhere else but we will be with people who we love. They are still with us. Not everyone believes that. There are so many signs that it is obvious.

CC: If someone were to ask you, 'How could I have a good death,' what would you say to them?

LN: I always go back to life. You can have a good death if you know in your heart that you lived right. You lived loving and being kind, being a good friend. Just doing right. Living with consciousness. But you have to be pretty evolved to do that and we get lost in our society. Dad may have to work two jobs. Maybe some introspection on this topic could change this around. It may not be the job, it may be the people and have a retreat with everyone and start thinking about these things. It is an opportunity.

I do not think people get punished for our wrong doings as long we live right and make amends if we hurt people. For me personally, I would not have regrets, I am not afraid to die. I would be ready anytime the universe is ready to take me.

CC: If we were less in denial of death, right, and more accepting of it, our lives would somehow shift a little and be less evil. We live in a society that denies death, and this is where I am trying to go with this - is that I have this hypothesis, if we share more about death, maybe we will accept it more which could have ramifications in the world.

LN: I think that is a brilliant idea.

CC: Could you talk about that a little more?

LN: Well, my conversation with you today, I started reflecting my life. I am not doing anything wrong but I am not spending life doing meaningful things. Sometimes I just need to kick back. So like watching a reality TV show that is so meaningless that it helps me zone out. I could have taken a walk. I am spending more time outside, pulling out trees and plants. It feels good. I would like to work on that. We all have room for growth. This conversation has heightened my consciousness.

CC: You are being with the earth more. I normally do not talk this much. I do not want to die having regrets that I wasted time. I know of too many stories of unresolved angry, they could not forgive their parents. What do we have to do to clean up our lives. If we were more accepting of death, would that make us into better people?

LN: Yes, at first it was hard grasping at what you were thinking mostly because of my experiences. It has helped live my life with that in my mind. With respect to other people, they're not in that space. Things would change. Having conversations would give people things to think about. Because of this conversation and knowing I would be having it, I had an experience with my daughter. Today she had a tragic experience happen and it seems like every time I talk to her, I say the wrong thing. Today I was so supportive because I was thinking, what if I am not here today. How do I want her to remember me? At the end of the conversation she said "Thanks, mom." I cannot tell you how much that meant. She had never said that before.

CC: Maybe talking about death more, can get us more in that sensitivity mode.

LN: Of course it would. Not all would embrace it. Our generation is into self-growth and becoming more enlightened, at least people we know. For the most part, people are good and they may get stuck in certain places. There are truly few evil people. If they knew more, to stop and think about all of this, that it could have a huge impact.

CC: Anything else you would like to share?

LN: No. I hope we do grow and evolve and pay attention to what is going on – in other countries, in Oregon and in hospice. And have a caring society.

CC: It is pretty brutal for a lot of people.

LN: It is.

CC: Thank you so much.

APPENDIX C

FACEBOOK COMMENTS

The following are interactions that took place on Facebook from September 15 – November 30, 2013

September 15, 2013

[From the researcher] Dear Facebook friends, I have started a new blog on death and dying and will be posting every other day. Would love to hear your comments, thoughts on some of the digital stories! It's a new adventure, - all self taught and while not a cheery subject nor a popular one, a necessary one. if you live in Hawaii and would like to be interviewed on death and dying, please email me. If you live in NYC and are interested, my next trip is around the corner from September 20 - September 29, 2014. Thank you so much for reading this! Here is the website!

<http://www.journeytotheunknown.net>

1. Donna Donato, Diane Williams, Colleen Kelly and 8 others like this.

2. 1 share



3. Michelle Nicole McDow Ill do an interview September 15, 2013 at 12:08pm · Unlike · 1



5. Karin Sariola Blanco Gill I was at my Mothers side when she. passed at 97 last month. Daily I hear of friends' passing. I would contribute. September 15, 2013 at 12:12pm · Unlike · 1



7. Hugo Orozco I would love to see you during your trip to NYC if you have time in your agenda. September 15, 2013 at 12:13pm · Unlike · 1



9. Charmaine Crockett Great Hugo! i will be on 42rd and 1st on

10.

sunday, mon, tuesday wednesday and then downtime the rest of the week. Would love to catch up....i would love to interview you on my little video. i think you would have a lot to say on the Guatemalan horrors, your perspectives on the larger picture of death and dying, etc. xo September 15, 2013 at 12:22pm · Like



11. **Hugo Orozco** i know alot about death, saw a man being killed,
12. when I was 5 or 6 years old it was the first of many more and still counting, I learned that death make and change human history and make history unforgettable . September 15, 2013 at 12:22pm · Like



13. **Charmaine Crockett** message me your phone and i will give
14. you mine! A reunion September 15, 2013 at 12:23pm · Like



15. **Hugo Orozco** ok I will do it now. September 15, 2013 at
16. 12:25pm · Like



17. **Michelle Nicole McDow** Hey Charmaine Crockett my
18. husband deployed 4 times to Iraq and Afghanistan...he said u can interview him September 15, 2013 at 1:52pm · Unlike · 1



19. **Stephanie J. Castillo** I'll be in NYC still. Maybe we can try
20. again. September 15, 2013 at 2:58pm · Unlike · 1



21. **Charmaine Crockett** thank you Ms. McDow and Karin, will
22. email you!!!! September 15, 2013 at 3:31pm · Like · 1



23. **Tim Sekac** What's prompted this Charmaine? September 15,
24. 2013 at 9:43pm · Unlike · 1



25. **An Hemenwaay** yes. beautiful. September 16, 2013 at 2:14am
26. · Unlike · 1



27. **Carol Plummer** Sounds interesting September 16, 2013 at
28.

2:34am · Unlike · 1



29.
30.

Charmaine Crockett On a lighter side, being a baby boomer, has spurred an interest! Personal losses which have led to a deeper inquiry of life, meaning and cosmic wonder. And then there is the darkness of cruelty, of life undermined, cut short by cruelty and war where life has no value where being a witness is excruciating. The absolute loneliness some of of elders suffer, how we allow this slow dying of others. It is this complexity i want to explore as well as the afterlife, energy.... kind of a big palate actually....it was either taking up this or stamp collecting on Sunday afternoons! September 16, 2013 at 6:09am · Like



31.
32.

Jo An Gaines Check out Marilyn Schlitz's 'Death makes Life Possible'. Shown at IONS Convention . September 16, 2013 at 6:26am · Unlike · 1



33.
34.

Charmaine Crockett love her! spoke with her at the IONS SF conference..did you go this year? September 16, 2013 at 6:32am · Like



35.
36.

Charmaine Crockett Tim, i also have had it for quite awhile but never came out of the death and dying conversation closet... i found no-one could see it unless i led them to the conversation. September 16, 2013 at 6:37am · Like



37.
38.

Jo An Gaines I did go to IONS conference . There is an amazing film on death/dying done by IONS. September 16, 2013 at 8:40am · Unlike · 1



39.
40.

An Hemenwaay www.thedeathstore.com/ WELCOME Check out <http://thedeathstore.com/>! Home

41.

Page [THEDEATHSTORE.COM](http://thedeathstore.com/) September 16, 2013 at 8:58am · Unlike · 1 · Preview



42.
43.

An Hemenwaay Rest in fleece: demand soars for woollen coffins

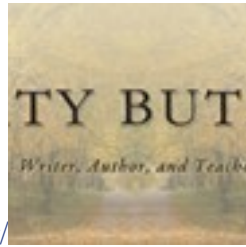
44.

Sales rise by 700% as growing number of Britons choose eco-funerals over traditional services

45. REST IN FLEECE ://www.theguardian.com/.../eco-funerals-fleece-woollen... Rest in fleece: demand soars for woollen coffins Sales rise by 700% as growing number of Britons choose eco-funerals over traditional services THEGUARDIAN.COM|BY HELEN NUGENT September 16, 2013 at 9:08am · Edited · Like · 1 · Preview



46. An Hemenwaay <http://katybutler.com/site/knocking-on->
47.



- [heavens-door/](#) Knocking on Heaven's Door | Katy Butler "Exquisitely present[s] her personal story and an examination of the medical profession's handling of end-of-life care."... KATYBUTLER.COM September 16, 2013 at 9:02am · Like · Preview



48. Charmaine Crockett Thanks dear AH. i hope i can interview you next
49. week, at the very least if we don't have our power women breakfast club meeting, i may wither from despair. September 16, 2013 at 9:05am · Like · 1



50. An Hemenwaay ://www.elephantjournal.com/.../warning-graphic-why-
51.



- [we.../](#) Warning: Graphic. Why we should not let our Loved Ones (or Ourselves) be "processed" by a... "Writing as someone whose church operates a green cemetery... ELEPHANTJOURNAL.COM September 17, 2013 at 12:27pm · Like · Preview



52. Celia Owens in case anyone is around, I also want a wool felt
53. coffin. Will try to make the arrangements myself, but just in case I don't get around to it.... September 18, 2013 at 12:59am · Like



- 54.

An Hemenwaay I want to be put outside in the wild so the birds and critters can eat me... or, if that doesn't work out, I want to be cremated and dumped asap in moving water. September 18, 2013 at 5:04am · Edited · [Like](#)

October 22, 2013

Fascinating interview with Sally Fisher - global activist, best selling author, mother and grandmother - on death and dying, the AIDS movement and how to live well. Visit www.journeytotheunknown.netand be sure to continue the conversation! — with [Sally Fisher](#).

55. [Donna Donato](#), [Cinda Johnson](#), [Rosemary Hughes](#) and 3 others like this.



56. [Sally Fisher](#) You asked fascinating questions... Thank you
57. Charmaine! October 22, 2013 at 3:25pm · [Unlike](#) · 1



58. [Slaine Mc Roth](#) · Friends with Sally FisherTis always good to
59. hear Sally Fisher laugh. What an amazing beautiful woman . ☐ October 23, 2013 at 12:02am · [Unlike](#) · 1



60. [An Hemenwaay](#) Grief = honoring the departed. this interview
61. is so beautiful. miss you both very much xxx October 23, 2013 at 4:43am · Edited · [Unlike](#) · 1



62. [Sally Fisher](#) Miss you too An ~ next time Charmaine is here
63. we've got to do our 3 way breakfast. October 23, 2013 at 9:22am · [Unlike](#) · 1



64. [Charmaine Crockett](#) you got that..... you are one busy woman
An!!!!!! thank you so much for your loving comments on death and dying, it means a lot October 23, 2013 at 12:51pm · [Like](#)

October 25, 2014

living in the NOW and keeping alive culture. Would love to hear your thoughts on the blog! Check out www.journeytotheunknown.net
<http://www.journeytotheunknown.net/archives/378>

65. [Cinda Johnson](#), [Susan M. Schultz](#) and 2 others like this.

66.
67.



Carol Plummer Thanks for sharing this, Charmaine. Enjoyed it as I navigate my own transitions! October 25, 2013 at 2:38pm · [Unlike](#) · 1

68.



Celia Owens love the idea that a culture of care is not about WHO you are but HOW you are. beautiful. oxox, c November 10, 2013 at 5:21pm · [Unlike](#) · 2

Want to let Facebook buddies know i posted a new digital interview on my death and dying blog. Daryl is a war veteran. From the streets and violence of Philly to the horrors of Iraq and now back home, he shares about death and dying in war and his dreams to be a healer and peacemaker.

www.journeytotheunknown.net

69.

Ann Oshiro-Kauwe, Susan M. Schultz, Michelle Nicole McDow and 16 others like this.

70.

2 shares



71.
72.

Eric Michelson wow where do I find your blog
Char November 10, 2013 at 12:57pm · [Unlike](#) · 1



73.
74.

Charmaine Crockett the link is above journeytotheunknown
xoxoxoxox November 10, 2013 at 12:59pm · [Like](#)



75.
76.

Eric Michelson ooops doy - and you're doin' ok? November 10, 2013 at 1:00pm · [Unlike](#) · 1



77.
78.

Sally Fisher I'm eager to meet Daryl, but alas, I have to wait 'til tomorrow! I'll email you after ~ it's a great blog. November 10, 2013 at 1:07pm · [Unlike](#) · 1



79.
80.

Charmaine Crockett yes! we need to catch up, have a quickie stop in nyc en route to eastern europe.....miss talking to you. xoxoxox November 10, 2013 at 1:07pm · [Like](#) · 1



81.
82.

Sally Fisher Let me know when you'll be flying

thru.... November 10, 2013 at 1:08pm · Unlike · 1



83.
84.

Marie-Jeanne Fethiere oh wow ! this is interesting....good
work love xxx November 10, 2013 at 2:07pm · Unlike · 1



85.
86.

Kimberly Corbin Can't wait to watch it
Charmaine! November 10, 2013 at 5:58pm · Unlike · 1



87.
88.

Charmaine Crockett see you next May Inigo, i ache for the
Burren but know you are taking great care and unleashing its mysteries with pen,
pencil, oil and pastel. November 11, 2013 at 7:47am · Like



89.
90.

Sharon Jackson wow.....well done....xxxx November 11,
2013 at 8:37am · Unlike · 1



91.

Charmaine Crockett Thank you Ms. Jackson, would love to interview people in
Belfast next summer. November 13, 2013 at 2:04pm · Like

An Hemenwaay to Charmaine Crockett

November 20, 2013 · Edited ·

" "We pay for another day in I.C.U.," she said. "But we don't pay for people to
understand what their goals and values are. We don't pay doctors to help patients think
about their goals and values and then develop a plan."

But the end-of-life choices Americans make are slowly shifting. Medicare figures show
that fewer people are dying in the hospital — nearly a 10 percent dip in the last decade
— and that there has been a modest increase in hospice care. At the same time, palliative
care is being embraced on a broad scale, with most large hospitals offering services."

www.nytimes.com/2013/11/20/your-money/how-doctors-die.html...

Unlike

Unlike · · Share

92.

You and **An Hemenwaay** like this.



93.
94.

An Hemenwaay



<http://press.uchicago.edu/.../book/chicago/D/bo3641373.html>

Death Foretold The book Death Foretold: Prophecy and Prognosis in Medical Care, Nicholas A. Christakis is published by University of... PRESS.UCHICAGO.EDU November 20, 2013 at 11:37am · Like · Preview



95.

96.

Charmaine Crockett thank you dear An....really interesting - our generation is really going to be talking about this more and as i told my friend over lunch - we are not going to go down silent on the issues."
xo November 21, 2013 at 4:46pm · Like · 1



97.

An Hemenwaay " I want to be alive when I die " ~ I may not have this quote fro Hi Charmaine, I hadn't heard the impetus for your creating this blog, and having done so, am quite touched by it. The only thing I have to share about death and dying is the recent death of Nancy's mom. She was 92, and has been on the slow decline to death over the past few years. She lived alone up until exactly 9 months prior to her death, when we managed to get her in a sheltered housing unit for elderly that was on the corner of our street. She had a beautiful apartment overlooking two canals, and enjoyed the view very much. She was so close by, that my children were able to stop by after school for a cup of tea, or do some shopping for her, and of course she had Nancy visiting regularly to take care of whatever needed doing. She missed her home, but more and more, she missed her parents, whose pictures were hanging on the wall to make her feel at home, even though they had been dead for decades. It was interesting to see how the circle was round. The mother becoming the child, and looking more and more to her own, long-dead parents. She said more than once that she had had enough of living, that she shouldn't be here anymore, but that was the extent of it. She was too tired to live anymore. You know in Holland that you can , as an individual, take steps to end your life if you are of sound mind, if it's too much, but her general christian belief wouldn't allow her that option, nor did we bring it up. Her last day was a beautiful day, and Nancy, feeling something was up, spent a lot of time with her in the morning. A short trip outside in a wheelchair, a coffee in the square around the corner. Some sunshine on

her face. Nancy took her back, and went off to our garden to do some gardening, something she learned from her mother, and received the call less than an hour after she left her that her mother was dead.

The dutch handle death quite differently. The undertaker came with an ice machine to place under her bed, in the expectation that she would be lying there for several days. Indeed she was, but by Monday, she was picked up and brought to the crematorium. We went as a family to visit her in her apartment the day she died, something we felt it was important for the children to experience. It was all very peaceful. 10 days later we had the funeral, which was a bit long by my reckoning, but my sister-in-law wanted there to be an english minister presiding over it, hence the week delay.

Nancy is still a bit torn up about it, but life has gotten back to normal.m

Edward Whitmont quite right but that is the general idea.



www.interhomeopathy.org/edward-whitmont-in-perspective

Interhomeopathy - Edward Whitmont in perspective Interhomeopathy: International

APPENDIX D

FINAL THEMATIC ANALYSIS

Participant	Codes	Key words/Issues	within a larger context of a statement
final themes			
Death is not the End			
Daryl	Afterlife	ghosts in room	no time to mourn or celebrate life
Katherine L.	Afterlife	grandma returning after death	experience beyond death
Katherine L.	Afterlife	transmitters	they can talk to you after death - energy
Leslie N.	Afterlife	not afraid	personal experience of dying and the afterlife
Meleanna M.	Afterlife	life	it continues on

Susan S.	Afterlife	relationship	relationships continue afterlife
Shelly M.	Afterlife	source	you go back to the source
Katherine L.	no boundaries	gray	no clear line between life and death
Katherine L.	no boundaries	binaries	we are more comfortable rather than thinking less boundaries
Katherine L.	no boundaries	physical space	some cultures more accepting of less boundaries
Katherine L.	live more than once	reassurance	it is reassuring that you do not only get one shot at death
Meleanna M.	live more than once	lifetime	we do not have one lifetime so I am hopeful and this makes things easier
Number of Counts	12		
Number of Individuals	6		

What Death Means

Meleanna M.	What is death	Cultural experience	perception of death depends on culture
Katherine L.		ownership	Being in control of the process
Leslie N.		Life	How I do not want to die
Katherine L.		Transition	Death is not the end, points of entry and departure
Darryl		happens	it is something that just happens
Katherine L.	Thinking about Death	living	Thinks about living more than dying
Nancy A.		death	Thinks about death a lot
Sally F.		not related	Works around death all the time
Susan S.		judgment	it just happens and it terrifies us when I think about it, I want to be a more present person for other
Leslie N.		memory	
Leslie N.		Opportunity	powerful to think about it
Daryl	Death as a cultural experience	perspective	how one dies depends on culture
Daryl		repass	celebration of life in African tradition not sadness
Daryl		wisdom	We have to go back to our cultural incubators
Katherine L.		no separation	In india, there is no separation between life and death
Katherine L.		Death	Death is part of life, it is what happens

Meleanna M.	Death as an experience	answers	we need to get out of our own way, we do not have the answers
Meleanna M.		not knowing	do we really know until it happens
Meleanna M.		ritual	death is part of the life ritual
Meleanna M.		abstraction	you need to experience it to make it closer
Shelly M.		off the clock	some of us are on the clock and off the clock
Shelly M.		things happen	some of us do not enter well or leave well
Susan S.		process	death is a process not a moment
Susan S.			how well do we do the process/
Daryl		butterflies	alive, we are caterpillars and then we become butterflies
Daryl		going back	you become the essence of god
Katherine L.	Death as spiritual experience	Energy	our body falls away but the energy continues
Katherine L.		Freedom	we break free from 3 dimensional form and understand connection
Leslie N.		Energy	we will always be connected to people we love
Meleanna M.		Transition	Birth and Death - points of transition
Meleanna M.			
Number of Counts	31		
Number of Individuals	8		
What is a good death?			
Daryl	A good death	well lived	a life is well lived
Katherine L.		send off	a good send off
Katherine L.		control	death on my own terms
Katherine L.		decision	make my own decisions on how to die
Leslie N.		people	I need to ask myself how to have a good death for people around me
Leslie N.		voice	I want a voice in my own death on how to die
Meleanna M.		culture	culture and tradition can guide you to a good death
Nancy A.		good life	a good death is taking every moment you have in living

Nancy A.		with others	having others around you when you die
Nancy A.		control	not too controlling, just enough, "someone I know wrote up her own obituary and it was pages long"
Sally F.		resolve	a good death is resolving conflicts, you can die easier
Susan S.		conscious	being aware and accepting
Susan S.		acceptance	makes it easier for yourself and for others
Number of Counts		12	
Number of Individuals		7	

What is a bad death?

Leslie N.	Irresponsibility towards one another while we are alive	bad life, bad death	we are not helping others to have a good death
Leslie N.		young people	Vulnerable kids die young,
Leslie N.		parents	no resources for their kids
Leslie N.		early death	not a good death
Leslie N.		Sensitivity	letting people fall through the cracks
Leslie N.		money	People care about money
Sally F.	Memorializing	no trace of guilt or shame	letting people be afraid of death
Sally F.		permission	to cry and be angry
Darryl		no time for memorial	in war zone, quick eulogy and then everyone would go back to work
Darryl		no celebration	We do not understand death and what is ahead of us
Susan S.		writing	as a way to preserve memories
Darryl		killing	dying in the street and getting shot at
Leslie N.	Bad death		she was dying and they got a gynecologist to go up her vagina to see why she was bleeding. Then she died. My father made the medical team do this"
Leslie N.		medical overkill	tubes pressing on ribs
Nancy A.		struggle	struggling makes it worse

Nancy A.		lonely	if you are lonely in life, you will have a lonely death because that is how you feel
Number of Counts	16		
Number of Individuals	5		
Preparing for Death			
Katherine L.	Preparation	directives	Need to have conversations with people
Katherine L.		confidence	when you take care of directives, you have confidence
Katherine L.		live in the moment	have everything set when I die so I can live in the moment
Leslie N.		will	need to write a will, no plan
Shelley M.		concern for others	I need to work out how others will be taken care of after I leave
Nancy A.		final affairs	you want to get it over with so you can live more easily (wills, etc)
Nancy A.		plan	plan the funeral, the songs, no burden for others when you die
Sally F.		family issues	resolve family issues before you die
Darryl	War	combatant	life is not worth living, cannot feel sadness for enemy
Number of Counts	9		
Number of Individuals	6		
Personal experiences with death			
Meleanna		husband died at 22	I had to explain death to my children
Daryl	Family	family member killed someone then killed himself	personal experiences
Katherine L.		grandma died	personal experience of intuition as a child
Katherine L.		grandmothers death	personal experience as sacred
Leslie N.		grandfathers death	personal experience of hospice workers as earth angels

Susan S.	Self	mother passing	alive in our own dying, I was present
Susan S.		mother passing	allowing life to happen and intimacy
Susan S.		family members	experience early in life
Susan S.		mother and father dead	two events very imporant as thinking about death itself
Susan S.		father died	no horrible feelings of him, it was a smooth even plane
Daryl		in war	got shot at and left weapon in tent, someone came to save my life
Leslie N.		died	had near death and out of body experience
Nancy A.		surgery	saw myself while I was crying and asking for help
Nancy A.		allergic reaction	almost died but I was okay with it
Nancy A.		emergency room	felt at peace with next step, let it go
Daryl		young people	should not go into army to die, older people should
Daryl		family dead	no-one stopped for enemy, just let them rot
Daryl	Community	gang wars	lived through the gang wars, made it out on the other side alive
Daryl		teenager	if you survive, you are home free
Shellie		the streets	everyone died and everyone else went to wakes
Susan S.		Cambodia	had a son from there, they were made to die on someones idea
Sally F.		lots of death	epidemic of deaths through singular disease - AIDS
Number of Counts	21		
Number of Individuals	8		
Best practices for living			
Meleanna M.	Being in Community	peace	people working together as human, mass appreciation instead of mass destruction

Meleanna M.	Living (best practices for a good life)	contribution	we should contribute to a betterment of humankind across races
Meleanna M.		Creativity	keeping things alive - memory, stories and language
Meleanna M.		death	death of a culture is dishonoring life
Meleanna M.		language	without language, we have nothing
Meleanna M.		community support	we need to walk the talk, practice
Meleanna M.			we are in this boat together
Meleanna M.		stay in touch	always follow up when you think of people
Meleanna M.		illness	illness creates community
Katherine L.		love	loving others
Katherine L.		fearless	fearless to be yourself
Katherine L.		tuning in	connecting to the spiritual power that is in us all
Katherine L.			we can do so much
Katherine L.		being responsible	I am responsible for my own life
Katherine L.		no blame	It is never someone else
Katherine L.		dreams	doing what we want to do
Katherine L.		the future	see our now
Katherine L.		expectations	going after passion, not money
Katherine L.		tuning in	we have all the answers and can tune in
Leslie N.			a good death is a good life
Leslie N.		live right	living with consciousness
Leslie N.		meaning	wasting less time
Leslie N.		growth	we can live with meaning at any time
Leslie N.			being aware of this conversation has heightened my consciousness
Meleanna M.		conversation	consciousness
Meleanna M.		caring	we need a culture of caring
Meleanna M.		aliveness	being alive is key to a good life
Meleanna M.		hopelessness	without hope, we are not alive
Meleanna M.		ownership	claiming things we love and desire, to make change
Meleanna M.		ritual	important in passage
Meleanna M.		taking time	finding the sacred in the everyday
Meleanna M.		letting to	being more honest, more real, more authentic
Meleanna M.		mortality	embrace it, accept it

Meleanna M.		acceptance	it is a practice, we have to work hard at it
Shellie M.		death	everytime someone dies, we go through a resurgence of life
Shellie M.		friendship	most important thing in life is friendship and appreciation
Shellie M.		reason to live	everyone has a job to do in life
			we have to do our job and then when we are finished we go home
Shellie M.		death	love everything
Shellie M.		love	life can be hard, I have had mental health issues but it makes us stronger
Shellie M.		life	how do we want the road to go as we move towards death?
Nancy A.		road	being a better person, more healthy, less judgmental
Nancy A.		bucket list	live in the moment
Nancy A.		moments	each moment becomes vital and very deep and then you don't die
Nancy A.		near death	life can be elevated
Nancy A.		awareness of death	I helped people decide what to do while they were alive, to live well
Sally F.		alive	it is the quality not the quantity that matter
Sally F.		quality	we can be angry or accepting if we are dying,
Sally F.		choice	we need to love as much as we can
Sally F.		love	less about ourselves, more about others
Sally F.		service	it is an inside job, not external
Sally F.		happiness	love as much as you can
Sally F.		love	being responsible for your life
Sally F.		responsibility	accept the reality of your death
Sally F.		acceptance	doing for others
Sally F.		good life	being kind and fair to others
Susan S.		good life	want to leave people free
Susan S.		no regrets	not to leave anger behind, loss and horrible feelings
Susan S.		attachment	awareness of our death, you are aware of the depth of life, the sheen
Susan S.		mortality	

Daryl	Spiritual matters	do not kill others	I wanted to commit suicide, guilty then found others for support
Katherine L.		the short ride	tuning into something larger than myself, a presence,
Katherine L.		being in the present	letting go, letting god
Meleanna M.		living more deeply	do things that make a difference, living deeper
Shellie M.		God	God is our friend, we need to always remember that
Shellie M.		Praise	being enthralled with our lives, with God, with abundance
Shellie M.		spirituality	spending time with God you feel the vibrancy of life
Shellie M.		Kabbalah	the desire to give and the desire to receive have to be in balance
Number of Counts	67		
Number of Individuals	8		