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Choose Your Own Ending: An Arts-Informed Action Research on Creating a “Good Death”

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Running Head: CHOOSE YOUR OWN ENDING

Choose Your Own Ending: An Arts-Informed Action Research
on Creating a “Good Death”

by

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MSW Clinical Research Paper

Presented to the Faculty of the School of Social Work
St. Catherine University and the University of St. Thomas
St. Paul, Minnesota
In partial fulfillment of the Requirements for the Degree of
Master of Social Work

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

Abstract

Concerns arise as we approach the final days, weeks, and months of our lives. Doctors may be able to give us a medical prognosis of our remaining time on this planet but how do we find the answers to the other questions we may have? Grounded in the literature on what makes a “good death” this arts informed action research project used control, fear, spirituality, relationships, and legacy to create a branching plot style book for dealing with end of life issues. This format is an accessible way for both patients and social workers to discuss and explore ways of discussing these important issues. Description and rationale for use of these methods as well as a preliminary version of the book is presented. Implications for social work practice and further research, which include field testing this research product, are also presented.

Acknowledgements

This project would not have been possible without the support of many people. Thank you to my committee members, Tanya and Carolyn for supporting my research vision and challenging me to make my work coherent, adherent and true. A special thank you to my chair, Mari Ann for patiently providing me an opportunity to think beyond the more traditional methods of research and to go where my strengths led me. This support gave wings and direction to my many flights of research fancy.

To my parents who instilled in me a desire to ask questions, seek a deeper understanding, and to follow my dreams. I would also like to acknowledge the early alternative music scene which encouraged me to “do it yourself”, question authority, and not be afraid to stand out in the crowd.

To Chris for supporting me throughout my academic journey and staying with me on my many divergent paths. He has come to be bemusedly circumspect when I approach him and say, “So, I have this idea...”. And most crucially, to Annabel and Olive, my beautiful daughters for their understanding that the time and focus that my being in school has taken from them will be paid back in full by our increased opportunities an advanced degree can provide our family.

I am excited by this project because I have always had a desire to choose my own adventure and this research paper and the academic year it encompassed is an extension of that belief.

Preface

I returned to school to further expand my understanding of social work, its theories, and my specific role in this field. I struggled with how to devote an academic year of my life to a research question that seemed worthy of the time and energy it would require. I wanted my time to manifest a useful document. I wanted to be more than one of a thousand results in an internet search.

This effort is an arts-informed qualitative action research writing project. The preceding sentence probably brought a small chill to traditional scholars. I feel my research question, my subject matter of choosing a good death warrants a non-conventional approach.

This effort may be more challenging than a typical research paper. I will present the traditional recipe of a research question, a method for answering that question, the limitations of the method, the results, and implications for further research. It will look a little different. I will provide a road map and key of the themes throughout the paper to insure comprehension, rigor, and reliability.

The format of my arts-informed inquiry is a branching style game book, popularized by the series entitled "Choose Your Own Adventure" by R.A. Montgomery. This format mirrors the decision-making process we go through in life. The multiple themes distilled from the literature are used as points of discussion and decision points.

Writing fiction is a reflexive process that demands a saturated experience of language and context. My work focuses on fiction writing as a form of research practice. I emphasize the significance of fiction writing as an act of inquiry and not merely a form of representation. I

examine theoretical frameworks that recommend fiction as an ethically sound, fully embodied form of inquiry.

It is also helpful to be reminded that arts-informed, phenomenological-like inquiry-writing is based on the idea that no text is ever perfect, no interpretation is ever complete, no explication of meaning is ever final and no insight is beyond challenge. It behooves us to remain as attentive as possible to the ways that all of us experience the world and to the infinite variation of possible human experiences and possible implications and explications of those experiences.

Academic research is a well-honed technique for allowing both researcher and reader an avenue to a greater understanding of a specific topic, question or subject. There are prescriptive steps that thousands of scholars have taken to reach this penultimate assignment of the graduate school experience. When approached from a postmodern perspective this recipe becomes suspect. In 1979, Jean-Francois Lyotard, the French philosopher, sociologist and literary theorist said, “The world has grown too complex, too diverse in thought and ambition, for meta ideas to represent everything to everyone. What rules instead is a series of micro-narratives. The older, simpler industrial world was dying, and its place had arisen a more technologically driven world that centered increasingly on linguistic and symbolic production” (1979). One’s personal history, social class, gender, culture, and religion shape truth and reality. These factors, according to postmodern thinking, combine to shape the narratives and meanings of our lives as culturally embedded, localized social constructions without any universal application.

As social workers, it is our work to help guide people along their journeys. We are sometimes presented with situations beyond our experience or comfort zone. By applying this familiar literary format, it allows both practitioner and client the opportunity to learn about

themselves as well as the subject matter throughout the shared experience. It also allows for both parties to have a say in their level of participation. There is a resources and suggested readings section at the end for both practitioners and participants.

This research method is consistent with the rigors of more familiar graduate level research projects. It can be more challenging for writer and reader as there is not as well-worn academic/researcher path with arts informed action research. With greater risk comes greater reward. When the rigorous review of the literature is combined with the theoretically based application of this information to a method that has been shown to engage the reader on a personal level, a transformative piece of work was created.

To become a researcher who fuses the arts into research processes and representations is to possess a creativity and artfulness. It is to have a willingness to be creative and to not be bounded by traditions of academic discourse and research processes but, rather, to be grounded in them (Knowles & Cole, 2008).

Table of Contents

Abstract.....ii

Acknowledgements.....iii

Preface.....iv

Table of Contents.....vi

List of Figures.....vii

Introduction.....1

Literature Review.....3

Methods..... 12

Data Collection & Analysis.....21

Strengths & Limitations.....23

Research Lenses24

Findings.....28

Discussion.....45

Conclusion.....49

References.....50

List of Figures

Figure 1. Action Research Model by Kemmis and McTaggart, 1985.....13

Figure 2. Solitary Confinement by Stan Moody 2011 pencil drawing.....30

Figure 3. Choose Your Own Ending, Molli Slade, 2017.....34

Introduction

As human organisms, we all die. Our physical plant wears out or is mortally compromised and our time in this form is over. Facing that prospect, we have a full continuum of responses. Just as there are myriad ways to die, there are myriad ways to think and feel about death and dying. What is a “good death”? Is a “good death” quantifiable? How can “choosing your own ending” help the end of life process?

Arts-informed research is a creative product informed by the review of the available literature, research, and data. Developing a guide to move someone through the hallmarks of a “good death” allows them to be informed and ideally attain a path of self-empowerment and self-determination that makes an overwhelming time of life more comprehensible and tangible to both the person facing the end of life and their family.

The purpose of this arts informed applied action research project is to further the tools available for clinical social workers and other helping professionals in engaging clients in difficult discussions about the end of life. This work will assist in facilitating discussions with the person who is contemplating end of life concerns and other members of their support network. I believe this project will appeal to a larger audience as everyone who faces their mortality has questions and concerns. I believe the familiar and nostalgic format of the branching style “choose your own adventure” book will lower apprehensions and discomfort and allow a self-empowering teachable moment to occur.

As society has become more accustomed to technology, it embraces the interactive theory of branching plot gamebooks like the Choose Your Own Adventure series (Christy, 2016). The format of these books is beneficial to educating people as a less personal (Garnett et al., 2008) intervention to discuss difficult end of life and dying topics.

The social worker's role in end of life processes is multilayered. While paperwork and coordination are vital, psychosocial concerns are equally important. Hobart discussed hospice workers desire for more educational tools that will help with difficult discussions with the person dying as well as their family members (2002). Hospice workers engage in emotional storytelling which they regard as having a therapeutic purpose (Cain, 2012). Creative endeavors help teach empathy, reduce feelings of alienation and aids in both intra- and interpersonal communication (Gallant, Holosko & Gallant, 2008). According to an Institute of Medicine recommendations for Patient-Centered Communication, healthcare professional societies should prepare educational materials and encourage their members to engage patients and their caregivers and families in advance care planning, including end-of-life discussions and decisions (2014). The recommendations also stated there is a need for more interpersonal training for medical professionals. They are often reluctant and not proficiently trained to have difficult conversations. This is where social workers excel.

This paper will address the literature available within the context of a "good death" and outline the benefits of creating a volume to be used by social work providers to encourage conversation and thoughts pertaining to end of life concerns. Arts-informed and action research method is discussed in depth, including strengths and limitations of the method, results, and the ethical implications of this type of research. The theoretical, professional, and personal lenses that informed my perspective and choice of research method are outlined. Finally, the findings are discussed with the implications for social workers, social work education, and future research. The themes of control/lack of control, fear, spirituality, concern for family members and legacy are consistent throughout the literature and help address the research of end of life education and how social workers can help with this process.

Literature Review

Gemma Balein's cross-sectional study of 35 patients, 41 of their families and 34 of the patients' healthcare providers. According to importance, the five most important attributes for patients were: come to peace with God, patient feels prepared to die, patient feels that family is prepared for one's death, patient does not die alone, and patient trusts one's doctor. The family members perceived the following as five most important: comes to peace with God, patient feels prepared to die, patient feels that family is prepared for death, patient trusts one's doctor, and patient has chance to resolve conflicts with family and friends. For healthcare providers, these were the five most important attributes at end of life: comes to peace with God, patient has presence of family members, patient knows what to expect from his condition, patient be free of physical pain and symptoms, and patient be involved in decision-making about treatment plan (Balien, 2009)

A qualitative study of 35 patients with advanced AIDS found 12 domains that define a good death: management of symptoms, quality of life, people present, dying process, location, a sense of resolution, patient control of treatment, issues of spirituality, death scene, physician-assisted suicide, aspects of medical care, and acceptance of death (Pierson, Curtis & Patrick, 2002). In a literature review discussing death with dignity, the themes include autonomy, control, privacy, freedom from pain, connection with loved ones, spiritual resources and preparing for death (Jacelon, et al., 2004).

A qualitative study of 21 older homeless adults and their definition of a “good death” revealed the themes of dying peacefully, not suffering, experiencing spiritual connection, and making amends with significant others (Ko, Kwak & Nelson-Becker, 2015). This study also

delineated themes for a “bad death”: experiencing death by accident or violence, prolonging life with life supports, becoming dependent while entering a death trajectory, and dying alone (2015).

In a study of spousal response to death and death quality, Carr (2016) found that dying well from a spouse perspective are best predicted by objective characteristics of the death, including its cause, suddenness, and timing. They found three critical components of a “good death”- having led a full life, accepting one’s impending death and not being burdensome to family members- are unrelated to spousal distress six months following the loss (Carr, 2016).

In the 2015 study, “Dying in the Age of Choice”, authors Csikai and Black argue that a longer life is not always a better life as medicine is able to prolong the disease and death process. They describe a good death as one that is being personally prepared, promoting one’s own voice, recognition of holistic sense of personhood including psychological, social, emotional, spiritual, and existential elements; a celebration of one’s legacy to others (2015).

Kristin Wright spoke with dying patients in her 2003 qualitative study considering how their relationship with life and death was different as a result of “death’s presence”. From her interviews, she delineated six relationships the respondents had with death. These relationships were deemed imprisoned by death, carpe diem (seize the day), carpe mortem (seize thy death), life and death transformed, silenced by death, and waiting for death (2003). This reflects a first-person perspective on imminent death. It is also important to understand psychological considerations of the dying.

Control in Decision Making

You may not control life's circumstances, but getting to be the author of your life means getting to control what you do with them (Gawande, 2004).

Much of the dying process is beyond our control. We cannot control how our bodies react to the wages of disease and the infirmities of age. A sense of control in decision making about one's health care and was a dominant theme in my research. Every study covered control or the fear of lack of control. Advanced health care directives, death with dignity and physician assisted suicide as choices were helpful for some (Black & Csikai, 2015). Physician Orders for Life Sustaining Treatment (POLST) or Medical Orders for Life Sustaining Treatment (MOLST) helped alleviate anxiety around death (Bomba, Morrissey & Leven, 2011). Good communication with healthcare providers is cited often (Balien, 2009, Allen, Hilgeman & Allen, 2011). In a study of 440 seriously ill patients and their family members, the most important quality rated was trust in their provider. (Heyland et al, 2006). Concordance between preferred and actual treatment is high in older adults who prefer treatment and lower in patients who prefer no treatment (Pasman, Kaspers, Deeg, & Onwuteaka-Philipsen, 2013). Family members of decedents who received care and died at home were more likely to report a favorable dying experience (Teno et al, 2004). End of life discussions are associated with less aggressive medical care and earlier hospice referrals. Having control over end of life care helped alleviate the fear of pain (Wright, 2003). Knowledge of the dying process, knowledge shared with family members, awareness of the probabilities of success or failure of treatments in order to make informed decisions and ease of physical pain are cited as examples of benefits of science in the context of religious perceptions of death and the dying process (Code & Poston, 2015).

Fear Comes in Many Forms

The Terror Management Theory (TMT) (Solomon, Greenberg, and Pyszczynski, 1991) posits that humans are motivated to quell the potential for terror in the human awareness of vulnerability and mortality by investing in cultural belief systems (or worldviews) that imbue life with meaning. Ernest Becker developed the basis for TMT from his understanding that fear of death or death anxiety is often regarded as the prime motivation for human behavior.

The fear of death must be present behind all our normal functioning in order for the organism to be geared towards self-preservation. But the fear of death cannot be present constantly in one's mental functioning, else the organism could not function (Becker, 1973, p.16)

Fear is a common theme in the literature. Fear of pain, fear of death and fear of dying alone are three areas of note. According to the folk wisdom of members of Alcoholics Anonymous, F.E.A.R. can be an acronym for Face Everything and Recover, Forget Everything and Run or (my favorite) False Emotions Appearing Real.

Fear of Pain. Fear of pain is a theme for both the patient and the family members' perception of the met and unmet needs of the person dying (Carr, 2003, Teno et al 2004). The absence of pain is expressed by all patients as a quantifier of a "good death". According to the Institute of Medicine (IOM, 2014), pain management is a fundamental component of hospice and palliative care. This care focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Fear of Dying Alone. The presence of friends and family was a primary concern in multiple studies (Ko, Kwak & Nelson-Becker, 2015, Balien, 2009, Proulx, K., Jacelon, C.,

2004). The anticipated presence of family was strong indicator for satisfaction at the end of life for patients and family members (Balien, 2009, Code & Poston, 2015, Schroepfer & Noh, 2010). Langner refers to sources of meaning for the individual such as “belonging to a group—the family, state, nation, club, university, sports team can be a strong defense against fear of dying alone” (2002, p.276).

In an Ethnography journal article from 2001 describing increasing societal loneliness and isolation, Klinenberg states;

For while in advanced societies the normative 'good death' takes place at home, it is even more crucial that the process of dying is collective, shared by the dying person and his or her community of family and friends.³ When someone dies alone and at home, the death is a powerful symbol of social abandonment and failure. (p.503)

Humans are interdependent creatures. Being ostracized by the community or the herd threatens survival. Seale compared fear a social death by many elderly in western societies as comparable to a live burial (Seale, 2004, p.973).

Fear of Death. According to Cicirelli (2011), death fears are normally suppressed from conscious awareness, but the mechanisms acting to suppress fears may break down when death stimuli are present and conscious fears may emerge. When fears of death emerge into conscious awareness, individuals may use defense mechanisms such as denying their vulnerability, distancing themselves or using distractions to deal with the threat. At a deeper level, the mechanisms of self-esteem and faith in the cultural worldview act to maintain the suppression (2002). Fear of Death or Than(a)tophobia is a DSM-V diagnosable condition:

“Thanatophobia (A through C are required)

- A. Attacks with the sense of impending death and/or conviction of dying soon, even though there is no objective medical reason for such fear
- B. Marked and persistent fear and avoidance of news which reminds of death (e.g. funerals, obituary notices); exposure to these stimuli almost invariably provokes an immediate anxiety response
- C. The avoidance, anxious anticipation and distress interfere significantly with the person's level of functioning" (Porcelli & Sonino, 2007)

People scared of death can help themselves in addition to therapy. "For instance, getting informed about death is the first step in overcoming the fear." (Doctor, 2008)

The Role of Spirituality and Religion

Spirituality or the connection to something greater, outside of one's self can take on many forms. As social workers, one must be careful to use their understanding of a client's spiritual beliefs as a starting point of their worldview and not one of clear definition Religious identification is a dominant theme in the literature. Religion is often seen as providing closure and comfort in the face of death, whereas science is deemed heartless and cold at life's end. Balien found that the person dying, their family members and their healthcare providers all ranked "Comes to peace with God" as the largest contributing factor to a "good death" (2009). It is the only factor they all rank of equal importance.

In two exploratory studies of religious and non-religious elders, they are found to differ in their attitudes toward death and toward the extension of life. Whereas those elders characterized by religious spirituality held attitudes highly favorable in their acceptance of death (i.e., looking

forward to an afterlife with God), they held negative attitudes toward extending life. In contrast, those elders characterized by nonreligious spirituality expressed sources of meaning other than religious and held attitudes unfavorable to approaching acceptance of death or even favoring a neutral acceptance of death. Rather, they could be said to be rejecting death and holding positive attitudes toward extending life (Cicirelli, 2011).

Research shows that it is not “either or” and that science and religion can exist and complement each other at end of life (2015). Spouses who report higher levels of religious participation report lower sense of burdensome with caregiving and lower levels of pain for their dying partner. Spirituality can provide hope for healing, hope for continued existence after death and an ability to make sense of what is happening (Code & Poston, 2015).

Relationships at End of Life

Concerns about being a burden on family members, or receiving unhelpful support is a consideration for those facing end of life. There is also concern about the trajectory of life to illness and illness to death and more communication with family about prognosis is considered (Trotta, 2007). This communication is vital to the families perceived qualities of a good death (2007). Recent polls show that Americans worry about the potentially high costs of care near the end of life and desire not to be a burden, financial or otherwise, on family members (Medicine, 2015).

Making familial amends was important to people who were homeless and dying (Ko, Kwak & Nelson-Becker, 2015). They are also concerned that past negative relationships would affect the support they expect to receive from family members (Schroepfer & Noh, 2010). End-of-life discussions are associated with less aggressive medical care near death. Aggressive care is

associated with worse patient quality of life and worse bereavement adjustment. (Wright et al, 2008)

Legacy

Legacy, or how one is remembered is a consistent theme. Having achieved something important or the belief that one lives on post death in the memories of others is a factor in increasing the idea of a good death (Wojtkowiak & Rutjens, 2011). TMT deduces that the suppression of our fear of death is a self-esteem buffer. Leaving a legacy insures our immortality and the perpetuation of our genetic and cultural pool and that our life had purpose and meaning (Cicirelli, 2002). People who are dying write their memoirs, ethical wills and may complete projects with family (Bergh, 2011) Mortality salience can be buffered by post self-awareness. "Imagining one's after death reputation minimized thoughts about death to baseline levels". (Wojtkowiak & Rutjens, 2011, p.142)

Summary

This literature review lays out the themes that are consistent in the materials reviewed as they relate to the perception a good death. The topics of control/lack of control, fear, spirituality, relationships with family, and legacy are able to be effectively addressed in the chosen format. Life is often described as a journey. We exist in a world filled with daily choices. Some choices are easy, "White or wheat toast?" Others are more complicated, "Does my life have meaning?" One of the final questions we may address could be "What is a good death"? This study is based on this question. How can we, as social workers assist clients in finding a satisfactory answer to this question? In order to answer these questions, I have used an arts-informed action research

method to create a branching plot style book that can be used with clients facing end of life decisions.

The purpose of this arts informed applied action research is to use the identified themes to create a branching plot gamebook style. This allows the reader to be an objective or removed participant but also to engage in social learning by participating in the storyline. Using these themes, the book will allow the reader to investigate outcomes of the choices they make along a journey of self-empowerment and enlightenment. In the methods chapter, the structure and validity of the arts-informed research process along with applied action research will outline how the themes were applied to answer the question of how does one achieve a good death?

Methods

This arts informed applied action research project utilized creating a written tool to assist clients in developing a better understanding of the issues they may face at the end of their lives. Applied action research was chosen as the means for social workers to address the struggles of clients seeking to understand the guideposts of a good death. An action research objective is to find solutions to a problem in a specific context. Basic research or fundamental research contributes to the development of knowledge/theory. Applied research is socially useful - application of the knowledge generated to social work concerns.

Action Research

Action research is useful in solving a specific problem such as the one presented. Several attributes separate action research from other types of research.

Action research...aims to contribute both to the practical concerns of people in an immediate problematic situation and to further the goals of social science simultaneously. Thus, there is a dual commitment to action research to study a system and concurrently to collaborate with members of the system in changing it in what is together regarded as a desirable direction. Accomplishing this twin goal requires the active collaboration of researcher and client, and thus it stresses the importance of co-learning as a primary aspect of the research process. (Gilmore, Krants, Ramirez, 1986).

It also has a social dimension - the research takes place in real-world situations, and aims to solve real problems. Action research in process is a cycle of planning, acting, observing results, reflecting on the results, revising the plan, and repeating the cycle. According to Stephen Kemmis, there is a simple cycle of action research model which follows in a cyclical manner

which has four steps: plan, act, observe, reflect. This is an illustration that demonstrates the action research process:

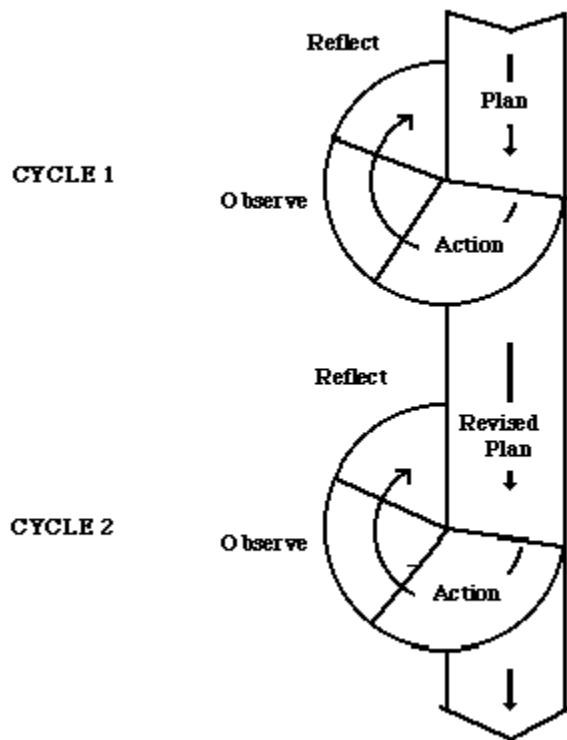


Figure 1. Basic Action Research Model (Kemmis & McTaggart, 1985)

In Ernest Stringer's book, *Action Research* (2014), he describes a simple format for developing an action-based research project:

- *Look*: building a picture and gathering information,
- *Think*: interpreting and explaining, and
- *Act*: resolving issues and problems.

Building on the Action Research model from Kemmis and the Stringer format; the framework on which this project is built was developed. I grounded this method in the relevant research based

on the question of what makes a good death. After reading the gathered literature, recurrent themes developed. As a practicing social worker, clinical experience is used to process what would be a useful application of this knowledge for clients and clinicians. A background of creative writing skills and affinity for the arts propelled me towards using an applied action research method to create a useful tool to communicate the themes developed from the literature review in a useful and substantive form for both audiences. During the core action research cycle theoretical frameworks can help, for instance, with diagnosis as well as providing a basis for 'conversation and mechanisms for collaborative sense-making and joint action planning and action' (Coghlan & Brannick 2010, p. 93). An arts-informed research model would complement the applied action research purpose by creating a tool that was both accessible to clients and academically sound.

The Arts-Informed Process

Arts-informed research is a way of representing research work that remains firmly rooted in qualitative methods. Arts-informed research isn't necessarily focused on the arts at all, reflecting instead a researcher who has been inspired by a work of art, art methods, or a body of work to attempt to represent their research in a novel form or format (Eisner, 1997).

Arts-informed research blends the systematic and rigorous qualities of social science inquiry with the creative and imaginative qualities of the arts resulting in a greater capacity to reach audiences beyond traditional halls of academia. The intention is that this kind of research appeals to a wide audience to make a difference not only in the lives of ordinary citizens but also in the thinking of providers, policy makers, politicians, legislators, and other key decision makers (Cole & Knowles, 2008). This is also the criteria for an action research project.

Through arts-informed inquiry, researchers reflect the diverse forms of knowing that are part of everyday experience. Whether the art form is literary, visual or performance, this relatively new qualitative approach allows art to inform both the process and results of scholarly inquiry. The relationship between the purpose of the research (related to knowledge advancement) and the developing competence of the chosen art form is crucial. Other criteria for arts-informed research is to have intentionality, researcher presence, aesthetic quality, methodological commitment, holistic quality, communicability, knowledge advancement and contributions (SAGE, 2008). My attributes as a researcher are outlined in the criteria as follows.

Intentionality. Arts-informed research has an intellectual and moral purpose to improve the human condition. The concept of "Choosing your own ending" represents a philosophical shift. Using this format in my research was a very intentional choice. In modern western medicine, patients often feel that they are being pushed along an increasingly invasive and depersonalized path that ultimately leads them to "failure" i.e., death. This project was envisioned as a means to help clients and practitioners reclaim some control in this process. By accompanying a person in discovering the dignity of making informed choices at the end of life, social workers are increasing self determination a central tenet of our work, and empowering clients to successfully navigate their deaths rather than end their lives as victims or failures.

Researcher presence. Researcher presence, or how the voice and artistry of the researcher-as-artist is heard in the project in the creative text and explicit reflexive self-accounting. I have a lifelong passion for words and the power of a specifically chosen sentiment. I have spent years honing my craft of writing. I have excelled in writing classes in my academic career. I have written speeches, eulogies, training manuals, love letters and lengthy apologies. As the

researcher and the generator of the instrument, I am fully accountable for the validity and outcome of this project.

Aesthetic quality. The quality of the artistic elements of an arts-informed research project is defined by how well the process and form serve the research goals. The result of this research is a short book modeled after the “Choose Your Own Adventure” series created by Raymond A. Montgomery in 1979. The structure of the book is to create scenarios which the reader makes choices as to which path they want the character to take. The books began with a warning: “You and YOU ALONE are in charge of what happens in this story.” This phrase reminded readers of their active participation in creating a narrative within the book's multiple endings. This format is familiar to many as this series was exceptionally popular with juvenile readers in 1980-2000. Using a style that has a strong popular culture foundation and widespread familiarity also enhances the reader's ability to address the issues as it is being presented in a non-academic and accessible way.

Themes distilled from the literature review of what is a “good death” guide the process. Throughout the literature review, there were consistent themes of what patients, families, and professionals deemed qualities of a "good death", these themes included spirituality, control, fear of pain, legacy, concern for family members and making amends. The idiomatic phrase "a good death" has as many definitions as there are individuals on the planet. Therefore, no manual or tool with prescribed steps would be effective for everyone. This format is ideal to illustrate the multitude of possible endings.

Methodological commitment. Arts-informed research must strictly hew to the principled process, procedural harmony, and attention to aesthetic quality. The methods this research

product are based on critical, humanistic and post-modern theory. Critical theory is applied to the idea that death and dying are the mysterious realms left for physicians and the medical field to interpret and define. Using a humanistic lens, this project relies on the theory that humans seek self-awareness and positive self-regard. Post-modern theory adds that the culturally dominant paradigm in end of life education needs to include multiple options and points of view encompassing all participants. I used reflective writing as a means to understand and disseminate the data to a larger audience in an accessible way. The data and themes disseminated from the literature were applied to the branching plot story in a philosophically diligent and format adherent way. The format of a branching plot book enables the reader to address only the themes that are of concern to them or to absorb the whole volume as needed. The resources section at the back allows for further discussion or education with a social worker or other support systems. This also supports demystifying the end of life process and empowers individuals to make informed choices.

Holistic quality. A rigorous arts-informed text is imbued with an internal consistency and coherence that represents a strong and seamless relationship between purpose and method. Addressing end of life education and information is a crucial task for the person dying and their support system. This work was researched created, and edited with the intent of producing a tool that will empower people in a non-threatening way at a very vulnerable time in their life. The medium chosen was designed to be an accessible entry to a difficult topic. My research lenses correlate with this mission.

Communicability. It is crucial that the resulting product of an arts-informed project maximizes its potential for audience engagement, meaning making, and response. The familiar format of "Choose Your Own Adventures" books maximizes this research project's ability to

reach a variety of audiences. By the nature of the project, the reader is engaged in the process of learning as they follow along with the thematic guideposts. The format could be adapted to video or other languages to increase accessibility to the information. The structure of this instrument reinforces the NASW social work code of ethics and ethical responsibility to self-determination, dignity, and service. (NASW, 1996).

Knowledge advancement. Arts-informed research advances a field of knowledge in a generative rather propositional way. It must bring new insight into the topic arena. Knowledge is advanced in a self-directed manner. Readers may choose to engage on one topic or the whole volume. Social workers can engage with their clients directly in reading it with them. They can engage with them in answering questions or accessing additional resources as needed, such as advanced health care directives. The epistemology of understanding the hallmarks of a “good death” are crucial to people feeling empowered during the process of self-discovery.

Contributions. Sound and rigorous arts-informed research have both theoretical and transformative potential. The former acknowledges the centrality of the So What? Question and the ability of the work to provide insights into the human condition, while the latter encourages researchers to imagine new possibilities for whom the work is targeted. I bring the perspective of a seasoned social worker who has spent a career figuring out how best to communicate with each of my clients. I have relied on my intuition and both personal and professional experience to meet my clients “where they are at”. This skill set informs my choice of instrument. I believe giving a person a map to understand what a journey might entail prior to asking them to embark is essential. End of life issues and death is scary because it is unknown. If this tool does not specifically resonate with an individual, the aim is for it to start a discussion or conversation between the reader and their support system.

Ethical Implications

It is essential to consider the ethical implications of this research method and product. There are three areas to consider; 1) use of copywritten material both format and images, 2) arts related ethical issues 3) scope of practice for the clinician and unintended consequences of emotionally charged material for participants.

I have addressed copyright concerns of the branching plot style book by changing the title of the product and verifying legal use of the format. The name of the famous series is protected but the style of the book is not. The Library of Congress has defined choose-your-own stories as “Branching-path books; Choose-your-own adventure books; Choose-your-own fiction; Gamebooks (Choose-your-own stories); Interactive fiction (Choose-your-own stories) ; Making-choices stories; Multiple plot stories; Plot-your-own stories” (Library of Congress, 2011). I have made a diligent effort to identify and cite any original art work or graphics. Some images are public clip art.

According to Savin-Baden and Wimpenny, the traditional research stances toward ethics are based in the philosophy of positivism, where the view is that something is only meaningful if it may be seen or measured or that science should be focused on objectively determined observable phenomena and on measuring what one may observe (2011, p.82). They recommend the ethical criteria measures of; reliability and validity, trustworthiness, bias and rigor, beneficence and non-maleficence, veracity, participant validation and member checking, triangulation, and informed consent. This consent is especially important as it relates to this projects content.

The themes and topic of this product are end of life issues. It is important that clinicians are aware this subject matter is within their expertise and ability to support the participant.

According to the NASW Standards for Social Work Practice in a Healthcare Setting (2016):

Knowledge and skills that are essential to social work practice in health care settings include, but are not limited to, the following areas:

- Physical and mental/behavioral health
- The interplay between the physiological elements of acute, chronic, and life-limiting illness and biopsychosocial–spiritual health and well-being
- Concepts and theories associated with lifespan development, neurobiology, and behavioral change
- Grief, loss, and bereavement
- Depression, anxiety, and other mental health conditions

These skills apply to any social worker working with clients and end of life issues, regardless of the setting.

The subject matter of this research project may have the unintended consequence of retraumatizing a client as they address these consequential end of life issues. It is important that the product and the clinician working with them provide support and follow up after working with this book. National crisis hotline numbers and other mental health resources have been provided at the end of the book to address this concern.

Data Collection & Analysis

Data collection involved reviewing the themes that emerged in the literature review, (already presented herein). Themes related to a “good death” were reviewed for applicable subject matter, inclusion of patient, provider, and family feedback about perceived outcomes. Data was also collected about theories of learning, and how clinicians can support clients in their self-discoveries. I also reviewed literature on the structure of branching-plot style books was also collected in order to verify suitability of using this medium for the project, as well as providing general guidance for writing it.

Data collection centered on intervention strategies that can be used to assist clients in constructing what a “good death” means to them. After the five themes from the literature were identified, data was collected to help me create a means for addressing the theme in the branching plot style book

Using the themes culled from the literature review, I delineated various paths readers can choose. I applied interventions common to clinical social work practice to guide readers in their paths to the end of the book. I used the second person point of view to facilitate a more personal connection to the material, consistent with other books of this type.

I addressed issues of validity and reliability by using standard qualitative data analysis techniques; investigator responsiveness, active analytical stance and reflexivity.

Investigator responsiveness. Investigator responsiveness, or openness to new information and data is vital in the arts informed process. There is a truth to creativity that will either resonate with the audience based on its truth or will fall flat. Keeping field notes kept me aware of the many perspectives I have viewed for this project. There is not a lot of published precedent for

this arts informed action research method. I have not followed a step by step recipe beyond the basic outline of good clinical research.

While writing the tool, I was struck by the role of spirituality either in its professed primacy or equally adamant denouncement. I had broached the theme area was ignorantly cavalier attitude. Throughout the process of writing, I realized the profound depth this area has and how it can affect all the other thematic areas I addressed. I did not look beyond the duality of Christianity and atheism. There are so many more textures of spirituality. I could have continued to branch that chapter for another ten directions. I wanted to get to the "big spiritual truths", but I only scratched the surface.

Active, analytical stance. This process was a cycle of collecting data, action, reflection and repeat. The use of an active, analytical stance meant critically thinking about the product I was creating and being willing to edit and redirect as needed. I was concerned that my audience for this book may not be ready for this slightly irreverent approach to the somber subject of a good death. Research also shows that the ability to laugh in a death and dying state of mind is a healthy coping mechanism. While some may be turned off by this format, others will positively identify with the format and have their anxiety reduced by its familiarity.

Strengths & Limitations

One strength of this research method is that it results in the creation of a useful tool for clients and practitioners. The branching plot style format is tailored to respond to particular needs of clients. The whole book presents a matrix that makes a good death easy to understand. As an applied action intervention, it reinforces the dignity and empowerment of self-determination. Placing more control in the hands of the learner clearly connects the concepts of constructivism and experiential learning and provides participants with active agency in constructing their own understanding of delivered knowledge to enable deeper learning (Mundy & Consoli, 2013).

Limitations of this arts informed action research project include the fact that it is not generalizable, per se and shares challenges with other types of qualitative research including subjectivity of researcher. There may be readers who do not feel their story is being described. Literature was biased towards Western civilization and perspective. Other religious perspectives on death and dying were not addressed and incorporated into this project. The lack of culturally diverse perspectives in the literature also limited the voices represented in the themes. While there are universal truths about what makes a good death, it is impossible to capture all the possible variations. As a researcher, I have done my best to address these limitations.

Research Lenses

When approaching a research project, it is important to understand “where you are coming from” on a theoretical, professional, and personal basis. This provides validity for your perspective and a base of understanding for the reader that you are steeped in the literature and the work has a theoretical foundation. Life is about making choices on all levels. We are faced with decisions hundreds of times a day. This chapter outlines the theoretical, professional, and personal lenses that informed to this project.

Theoretical Lenses

The theories that guided me in this research project are humanistic theory, terror management theory (TMT), and Kubler-Ross’s “Stages of Death”. The humanistic theory was originated and popularized by Carl Rogers and Abraham Maslow throughout the 1960's and 1970's. Both Rogers and Maslow regarded personal growth and fulfillment in life as a basic human motive. Maslow is also credited with the development of transpersonal theories within the humanistic framework. This school of thought centers around the individual's spiritual relationship to themselves and their world. "experiences in which the sense of identity or self extends beyond (trans) the individual or personal to encompass wider aspects of humankind, life, psyche or cosmos" (Walsh & Vaughn, 1993, pp 125-182). These theories resonate with my world view that we are on a journey of self-actualization. George Kelly expands on this by including the idea that individuals are also scientists, experimenting with their life choices. All individuals are free to choose, create whatever constructs they choose in their attempts to give meaning to their experiences. These perspectives enhanced my view that people want to have an active role in their death process. I expand that to include the families and loved ones' experience as well.

Terror Management Theory developed by Ernest Becker in his book, *The Birth and Death of Meaning* in 1962 and revised in 1971 was the first elaboration of TMT. In the revised version, he included his understanding of the human fear of mortality which he called mortality salience. He argued that human beings, like all living creatures, have a physical body that is born and then dies. He states that “the fear of death that humans experience, though, lies not so much in the death of the body but in the death of meaning, for it is meaning that defines the human self and society” (Becker, 1971). I think this ties into the Humanistic theory that people are on a quest throughout their lives. This theory informs my research because it describes a heightened state of “fight or flight” borne out of the fear of the unknown. I believe that that is a transformable state.

In 1969, Dr. Elisabeth Kuebler Ross published *On Death and Dying* in which she outlined a conceptual framework for how individuals cope with the knowledge that they are dying (Kuebler-Ross, 1997). This framework is called the Stages of Death and is also referred to as the stages of grief. She outlines the five stages people go through when processing their or a loved one's passing. These stages are denial, anger, bargaining, depression and acceptance. This identifiable process can provides an important reference point. I also understand some may not identify with this framework of steps. Some may never move beyond a particular stage and they may not happen in the prescribed order. I accept these contradictions and yet see this structure as helpful to me as the researcher.

Professional Lenses

As a community-based mental health social worker, I have had the honor of sharing in my clients' lives, thoughts and feelings. I worked on the same team for almost eight years.

During that time, I experienced the death of about twenty clients. Some of these deaths were

expected as a result of a terminal illness, but most were not. Our organization incorporates advanced healthcare directives into their goal planning, but many clients are resistant. I believe they felt so marginalized by their illness and the stigma surrounding it that they felt disempowered from making those decisions. I was able to have some powerful conversations with a number of clients about self-determination and what they believed about death and dying. I am proud of the fact that at least two of my clients completed their directives. I also watched clients in hospice reunite with long-estranged family. The grace they displayed as they allowed their families back into their lives was awe inspiring. I saw such calm and wisdom in the insights and self-awareness they expressed.

This perspective is biased due to my case management perspective working with people diagnosed with severe and persistent mental illness. I believe I am searching for validation that everyone can become a self-actualized individual and that that is a value for everyone else. I often reflect on Maslow's Hierarchy of Needs (Maslow, 1943). I want to ennoble my clients and believe they could experience Maslow's pinnacle of self-actualization. I am also realistic that they may be surviving in the lower level of safety and security. I am biased that my clients want to strive for self-actualization. In some cases, their lives had been objectively horrible and they experience a lot of current trauma and marginalization. The amount of work needed to come to peace with that history may have been beyond their capacity or desire.

The literature I gathered described what a "good death" is from multiple points of view. It describes the perspectives of patients in hospice, people who are homeless, family members of people who are dying, doctors and social workers who work in hospice. I have gathered

information on death rituals around the world. I have articles on families' experiences before, during and after the death of a loved one.

Personal Lenses

My personal perspective on a “good death” was deeply informed by my experiences as a person who was once drug addicted and homeless. I learned a lot about death, dying and the resilient but hypocritical “will to survive” crouched in a dirty alley shooting drugs. I knew and saw many folks in the grips of active addiction overdose and die. How do I make peace with those being “good deaths”?

Growing up, I was the neighborhood helper and felt a personal responsibility to reach out to the elders in our neighborhood. I also incorporate a strong influence of both grandmothers and the treasured times I had with each of them. More recently, I have taken an active role in my parents' care as they manage their lives with an Alzheimer's diagnosis and chronic and progressive back pain with attendant opiate addiction.

I incorporated these experience into my project by addressing the fact that there are innumerable ways to age and die. I believe we have many chances to leave this world as “at peace” and “present” as we want to be, regardless of our circumstances. I have a personal bias that I am supposed to create a new wrinkle from all this data, research and thought. I feel at a deep level that what I have experienced in my life allows me to be able to understand the end of life, death acceptance, and transformational healing during the end of life process. This informs the book I created and the findings I distilled.

Findings

The findings of this project begin with a description of the themes as it pertains to this project. Included in the description is the application of the related intervention to the theme it addresses. The research and the arts informed action project that represent the results of the themes cultivated from the literature show to have a congruent purpose. The themes were; control, fear (fear of pain, fear of being alone, fear of death), spirituality, role of family/support system, and leaving a legacy. The branching-plot style structure of the learning tool further supports the investigation of these themes. This triangulation of data, structure, and researcher reflexivity deepens the understanding of end of life anxieties.

Observational Data

There is a lot of literature about a good death. I was surprised how quickly and consistently the themes developed from the research. Each point of view I cultivated (patient, medical professional, family member) had the themes I had identified with only minor variations in emphasis between them. This suggested some “universal truths” to the subject matter. This was encouraging.

I would hesitate to encourage a future student to undertake an arts-informed project such as this. There is limited academic precedence and structure to do this style of research. It is important to stretch the predetermined boundaries of what is traditional research. Keeping field notes of the process revealed long stretches of "flying blind". The creative process for me demands a long period of fermentation. I struggled to come up with a topic, I struggled with a method, I struggled with the action of creating it. Every step was hard. I have outlined this process in the attached field notes appendix (appendix A). I was compelled to complete this

project not only to get credit, but by the idea that I was contributing to the emerging body and validity of arts-informed research and mental health and well-being of future clients.

There is a limit to this project. All of the themes could have had their own 34 pages. There is a limit to the context of each theme. There was an irritation between wanting to enlighten my audience to the perceived universal truths of self-actualization and the realization that this project was limited in its intended audience by the very nature of the themes and the structure of the instrument. Within the literature I reviewed, the themes described below are universal.

Sense of Control in Environment

The literature clearly showed that the more a patient was involved in their care the more they had a sense of control. In post mortality follow-up, family members perceived communication with providers as essential to their belief their family member had experienced a good death. A 2006 quantitative survey on what matters most to patients and their families resulted in the following:

Seriously ill patients and family members have defined the importance of various elements related to quality end-of-life care. The most important elements related to trust in the treating physician, avoidance of unwanted life support, effective communication, continuity of care and life completion. Variation in the perception of what matters the most indicates the need for customized or individualized approaches to providing end-of-life care (Heyland et al, 2006).

Advanced health care directives, death with dignity and physician assisted suicide as choices were helpful for some (Black & Csikai, 2015). Sense of control was also supported by maintaining a sense of normalcy in daily activities. Maintaining a routine helped clients address their emotional concerns such as fear.

Fear Comes in Many Forms

This theme and its subthemes: fear of pain, fear of being alone, and fear of death was a dominant concern in the literature and the resulting product. I used the Terror Management Theory (TMT) which states that:

humans are motivated to quell the potential for terror inherent in the human awareness of vulnerability and mortality by investing in cultural belief systems (or worldviews) that imbue life with meaning, and the individuals who agree with significance (or self-esteem)” (Greenberg, Pyszczynski, Solomon, 1986).

This theory guided application of interventions in this theme area. Each kind of fear has specific interventions and was given its own chapter in the gamebook. An example of the branching plot style is shown in fig 2 below:

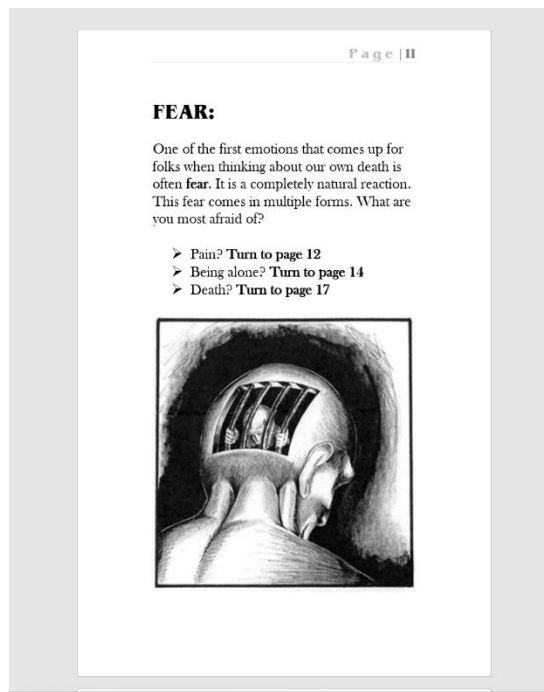


Figure 2. *Solitary Confinement* by Stan Moody, 2011

Fear of pain. This theme was addressed in the literature as palliative care. Multiple articles cited patients and their families fear of pain being a top concern. This was addressed in the project with details of the hospice program and how to access this service. Research showed that involvement in hospice increased likelihood of effective pain management. “Patients, families and professional care providers have identified effective symptom management as an essential component of excellent end-of-life care” (Johnson, Kattner, Houser & Kutner, 2005).

Fear of being alone. Relationships with family, which includes all of the identified support team was determined to be a major theme. Perceived support by family at end of life increased patient satisfaction. A study about homeless men with terminal illnesses reported that an aspect of bad death was dying alone

The theme of dying alone was more immediate among this group of participants who had limited supports and constrained social networks. To our participants, dying alone on the street was seen as the most undignified death and confirmed rejection, marginalization, and negligence by society (Ko, Kwak & Nelson-Becker, 2015).

This theme intertwined with the relationships with family theme. The interventions recommended in the project included making amends and use of hospice volunteers to establish a sense of community. Also noted as effective was use of in-home hospice as opposed to institutionally based care.

Fear of death. This theme was addressed in the literature that discusses psychosocial interventions, education, and addressing spiritual needs. The literature discussed death anxiety occurs on conscious and unconscious levels within each individual. The internal experience is a summary of all of the death-related and death anxiety-triggering events and evolutionary

predatory threat adaptations encoded on an individual. In the book “Death Anxiety and Clinical Practice” death anxiety is described as a uniquely human experience:

In addition to intensifying predatory death issues, language has created the basis for existential death anxieties — the universal human recognition and dread of eventual human demise. By facilitating the development of the human sense of identity and self, and the capacity to anticipate the future, language enabled the well-defined articulation of the beginning and end of human life. Evidence for the connection between language and existential death anxiety is found in the indications that the first human burial sites and religious rituals were developed about 150,000 years ago — at around the time that language first developed (p. 9, Langs, 1997).

Death anxiety is a human construct based on experience and biological reactions to predatory threat. The use of language and ritual shows the role spirituality and religion in end of life issues.

The Role of Spirituality and Religion

This theme dominated the literature. The role of spiritual beliefs, and by extension, religious beliefs, played a central role in the perception of a good death. The research showed a continuum of responses; from devout religious with little hesitancy about end of life due to their beliefs, to devout religious with increased death anxiety and increased request for medical intervention as death became inevitable, from atheists who believed in the spirituality of physical nature, self-acceptance and family and friends who were able to find peace to atheists who could be said to be rejecting death, and holding positive attitudes toward extending life (Cicirelli, 2011).

Since spirituality and religion are deeply personal, the interventions used in this project were related to expanding knowledge and providing a variety of viewpoints in which readers could identify. Spirituality was important to family and friends as well. One study (Balien, 2009) described both patients and partners as "being right with god" as very important to have a good death.

Concern for Family Members at End of Life and Quality of Relationships

This theme encompassed relationships between spouses, children, friends and the person facing death. Multiple studies described the person wanting to be able to say goodbye or have meaningful conversations (Balien, 2009, Pierson, Randall Curtis & Patrick, 2002, Heyland et al., 2006). The interventions addressed in the project centered around reaching out to estranged supports, writing letters to deceased loved ones, letting go of resentments and reaching out to loved ones as ways to increase positive relationships at end of life. This work can be done with help from a social worker, individual therapy or as a planned event. This increases satisfaction for the person dying as well as family members affected.

Legacy

The theme of legacy and reassurance of life purpose is described in the literature as a prime component of TMT. Death anxiety is mitigated when there is an awareness that the person has left a “mark” on their family and support system. The definition of legacy was defined in one study

An overriding finding was that legacy, on the most fundamental level, involved the transmission of one’s self or one’s beliefs and values. Making meaning of life in other words. Legacy is passed on to us from the past, developed and refined during our lives; and finally given to the next generation to begin the process all over again. The thread of legacy is what connects generations of people, not just family members, but friends, communities, institutions, cultures (Hunter, 2008).

This transmission of self is the motivation behind obituaries and eulogies. An intervention proposed in the project was to write an autobiographical life reflection and/or an ethical will. Alleviating death anxiety can be achieved through this action step.

Summary

In summary, the themes; sense of control in environment, fear (with subthemes fear of pain, fear of being alone, fear of death), spirituality, relationships and legacy that were developed in the literature review were explained in context of their application to the arts informed project. The themes were interconnected to each other. An arts informed action project was difficult to complete due in part to lack of exemplar papers to assist in structuring responses. The importance of integrity of product was outlined. Findings are based on interpretation of data and themes from literature review, disseminated into a writing project and then analyzed for method rigor and outcome.

The main finding in an action research project is the product developed. The branching plot style game book I created is as follows:

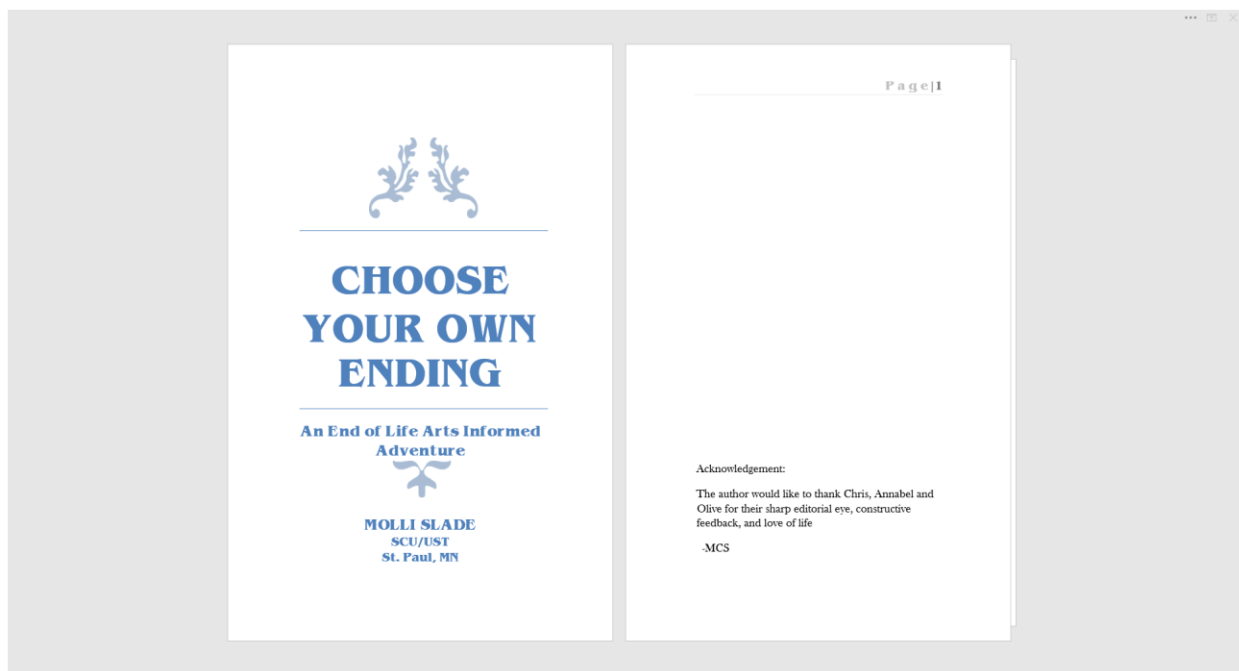
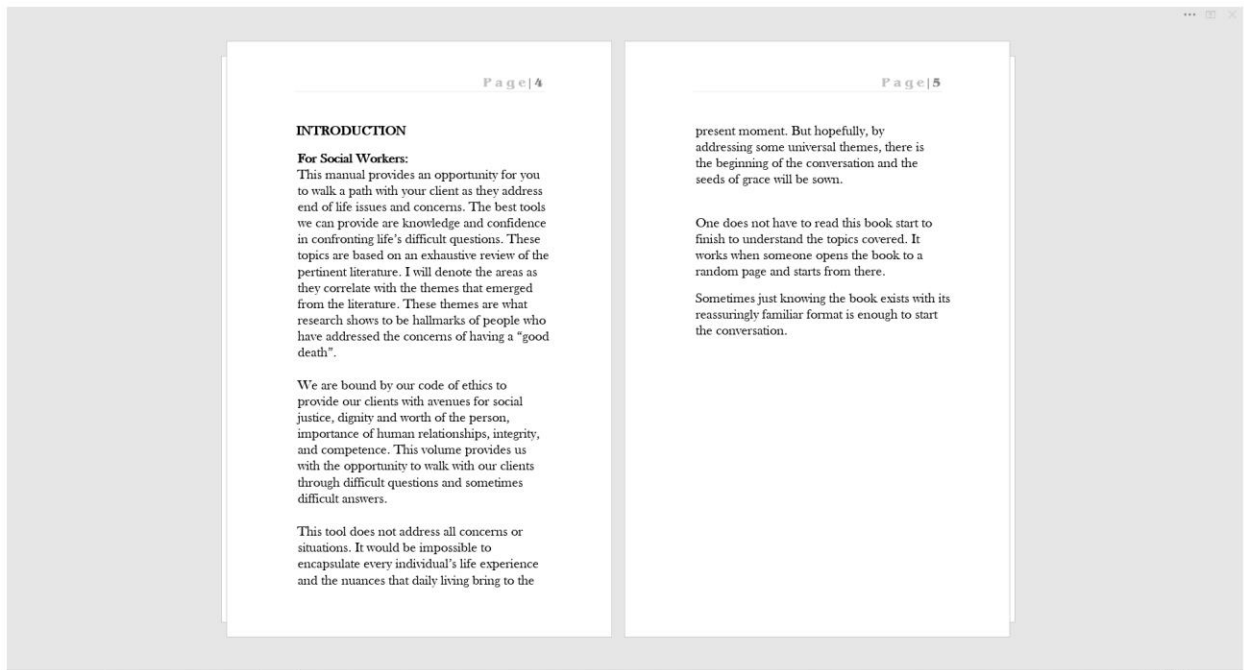
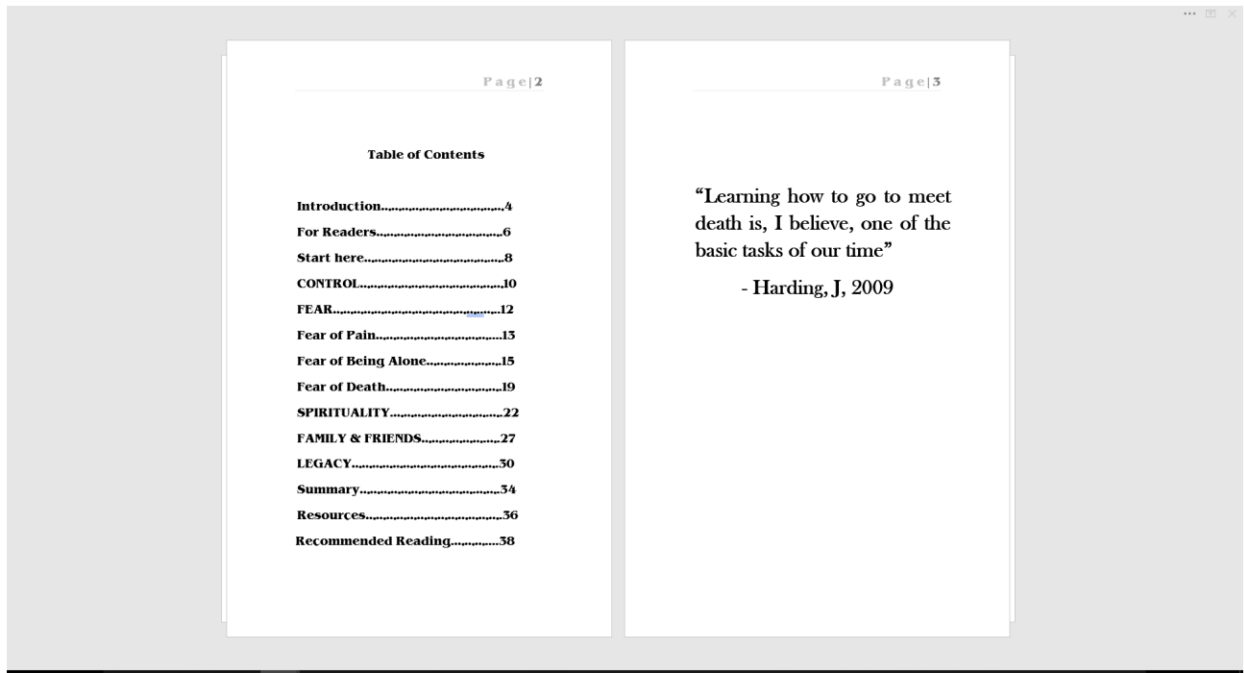
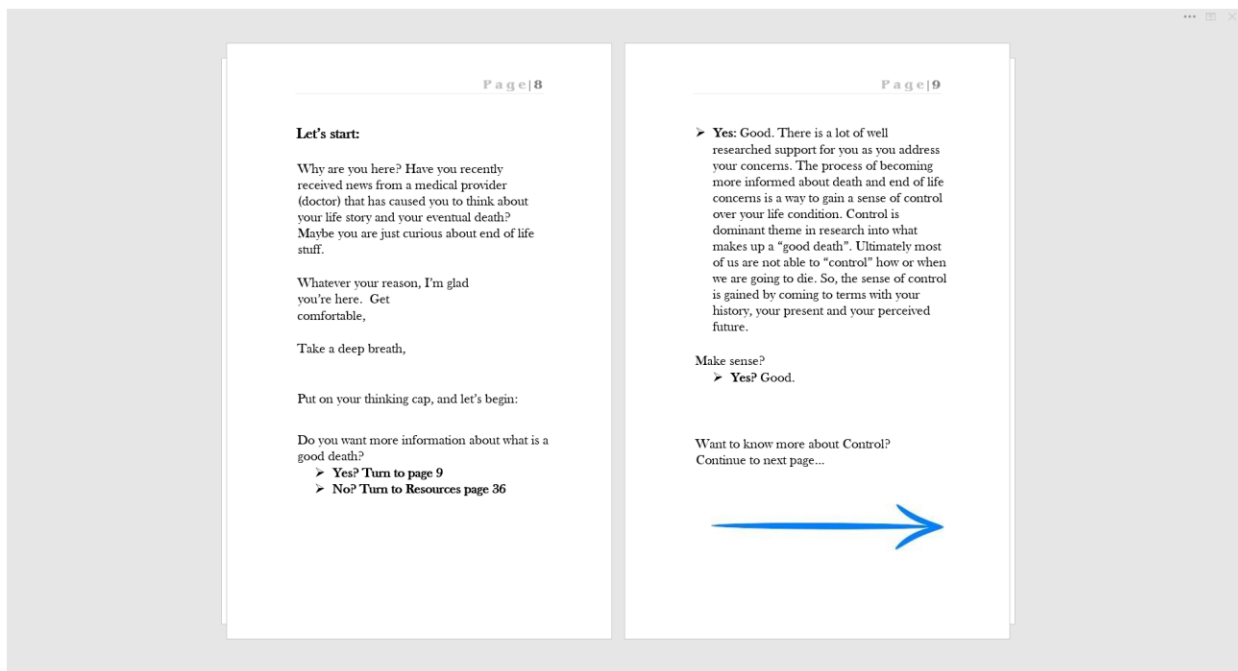
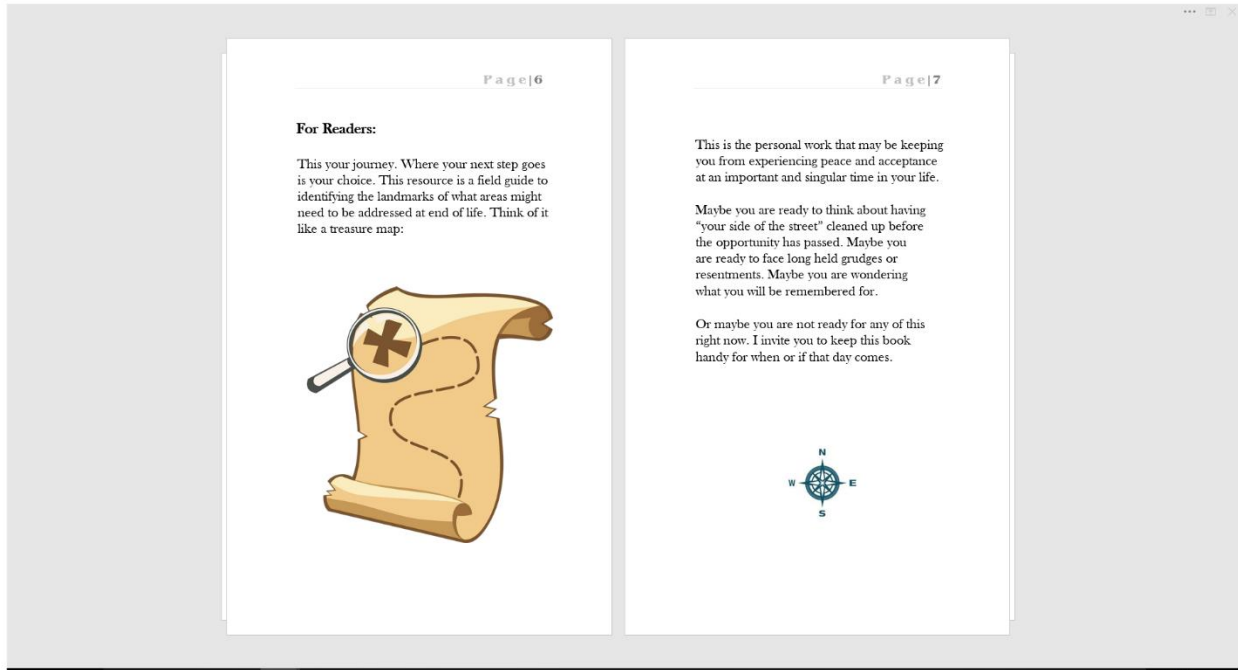


Figure 3. Choose your own ending template, Mollie Slade, 2017





CONTROL:

The format of this book, based on the "Choose Your Own Adventure" books, is your first example of **control**. You made a choice to read this far. You get to choose what section to read. You get to choose what areas of having a "good death" are important to you. This is the basis of maintaining some control over how you react to this singular time in your life. Your choices and your voice are ultimately the only ones that matter in your dying process.

We are unable to affect the ultimate outcome when dying. We can **control** how we react to the feelings the process of death engenders and the behaviors that may come as the inevitable approaches.

There is strong evidence and research that Cognitive Behavioral Therapy (CBT) is effective for anxiety and depression related to end of life concerns. This short-term therapy involves learning to recognize and challenge unhelpful thoughts, while examining resulting behavior. It aims to build on strengths and develop new ways of coping. It is unlikely that you will feel completely in **control** of

troubling thoughts and feelings through CBT, but you will learn new coping skills that will help alleviate the duration of the negativity.

To maintain some **control** in the end of life process, don't give up your regular routines. You may have to adapt them for any developing disabilities, but make it a point to do them. Continue to get out of the house, connect with friends and family, read the Sunday funnies, eat ice cream at 10:00 AM, choose your outfit every day, whatever defined your day to day life. By maintaining your routines, you are maintaining **control** over your interactions in your environment.

Completing your advanced health care directives can also help with communicating your wishes to providers, family, and friends in the event of an emergency and you are unable to speak for yourself. Please see the Resources page for more information

What about our emotions?



FEAR:

One of the first emotions that comes up for folks when thinking about our own death is often fear. It is a completely natural reaction. This fear comes in multiple forms. What are you most afraid of?

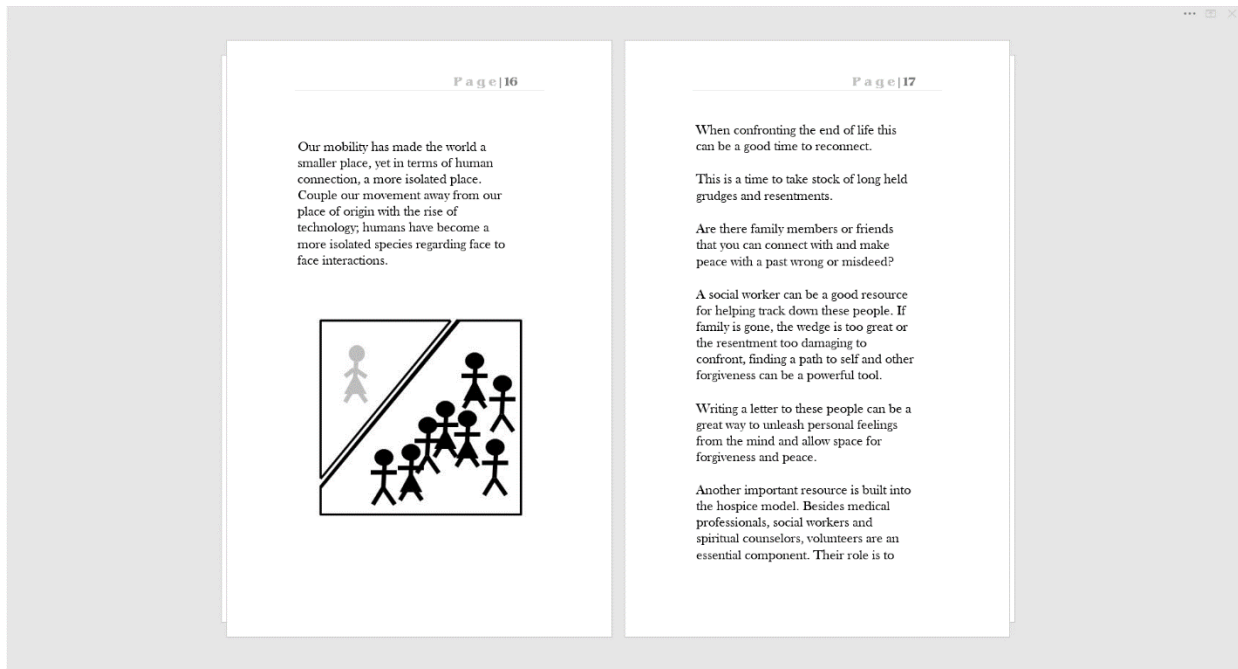
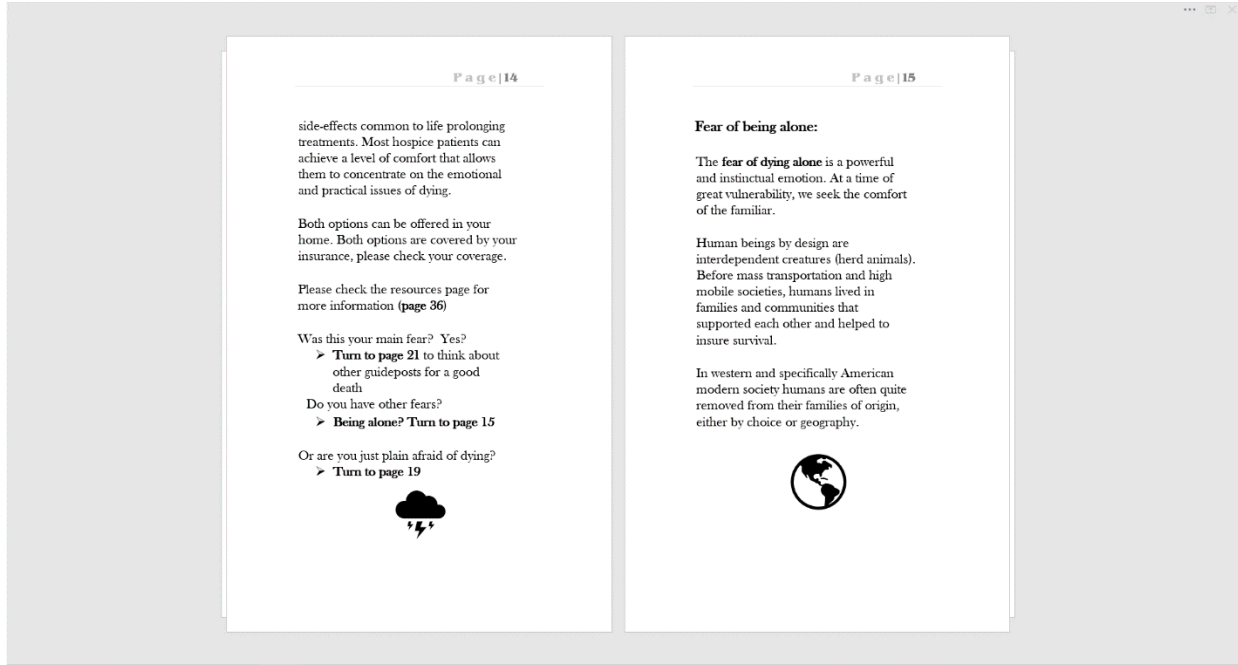
- Pain? Turn to page 13
- Being alone? Turn to page 15
- Death? Turn to page 17



Fear of Pain:

Are you afraid of the anticipated pain at the end of life? While this is common, there are numerous techniques and options available to combat pain. Palliative care is prescribed at the discretion of the physician and patient at any time, at any stage of illness, terminal or not. Palliative care is specialized medical care for people with life limiting diagnoses. It focuses on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Hospice eligibility requires that two physicians certify that the patient has less than six months to live if the disease follows its usual course. Hospice programs concentrate on comfort rather than recovery. By choosing to forego extensive life prolonging treatment, hospice patients can concentrate on getting the most out of the time they have left, without some of the negative



Page | 18

make sure no one dies **alone**. They stay by you as you are "actively dying". This is a biological set of steps your body goes through as it prepares to shut down.

- -If you would like to connect/reconnect with family or friends **please turn to page 27**
- -If you would like to know more about hospice please refer to the **Resources page 36**
- -If you are concerned about **your fear of pain turn to page 13**
- -If you are just terrified of dying **please turn to page 19**

Page | 19

Fear of Death:

Fear of death is also known as death anxiety. When the fear of death interrupts one's ability to function effectively in the world and may not even be in reaction to evidence of impending death, it is called Thanatophobia.

There are many theories around death anxiety. Sigmund Freud believed that people who express death-related fears, are trying to deal with unresolved childhood conflicts that they cannot come to terms with or express emotion towards. The anxiety was a disguise for a deeper source of concern. It was not actually death that people feared, because in Freud's view nobody believes in their own death.

Developmental psychologist, Erik Erikson described the final life stage as ego integrity vs despair. He states that:

Page | 20

"When one can find meaning or purpose in their life, they have reached the integrity stage. In opposition, when an individual views their life as a series of failed and missed opportunities, they do not reach the ego integrity stage.

Those that have attained this stage of ego integrity are believed to exhibit less of an influence from death anxiety"


This is an important point. Part of being able to reduce the "fear of death" anxiety is to come to terms with your life journey.

All theories and research points to finding peace with where you are at as essential to life satisfaction.

Find your unique successes and accomplishments during your time in this world! (This is a good place for a social worker to help as they

are trained to help find your strengths and contributions)

Spirituality is another important area that helps address **fear of death**.



-Have you thought about the role of spirituality?

- Turn to page 22

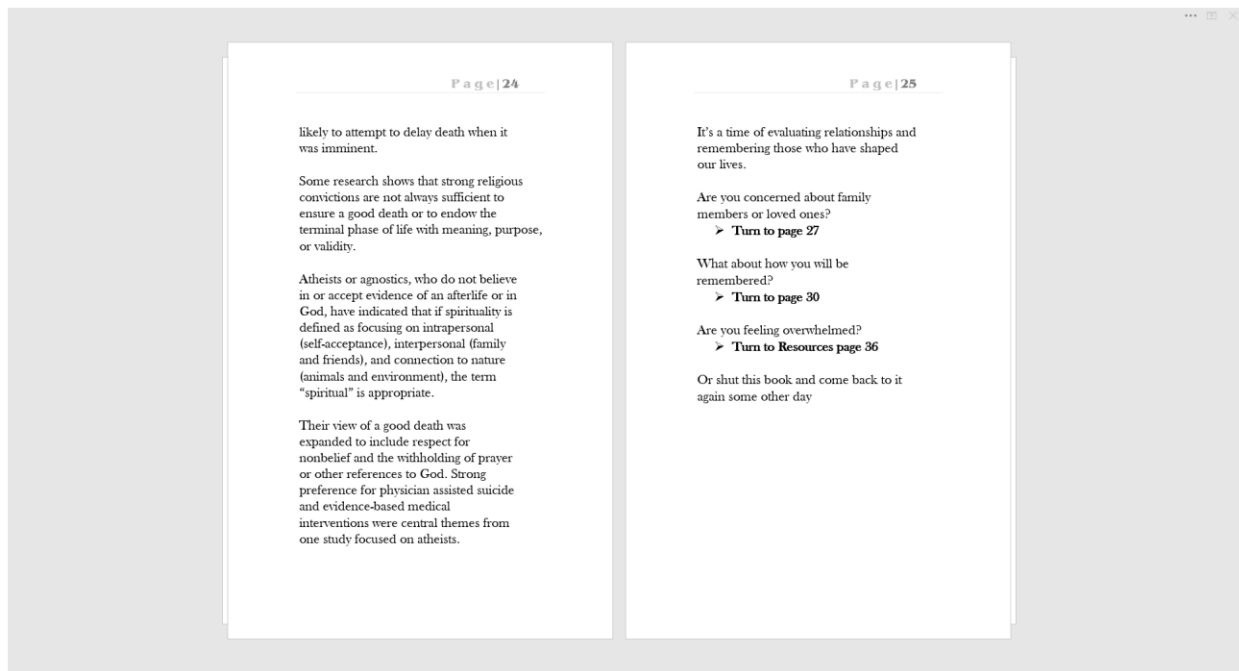
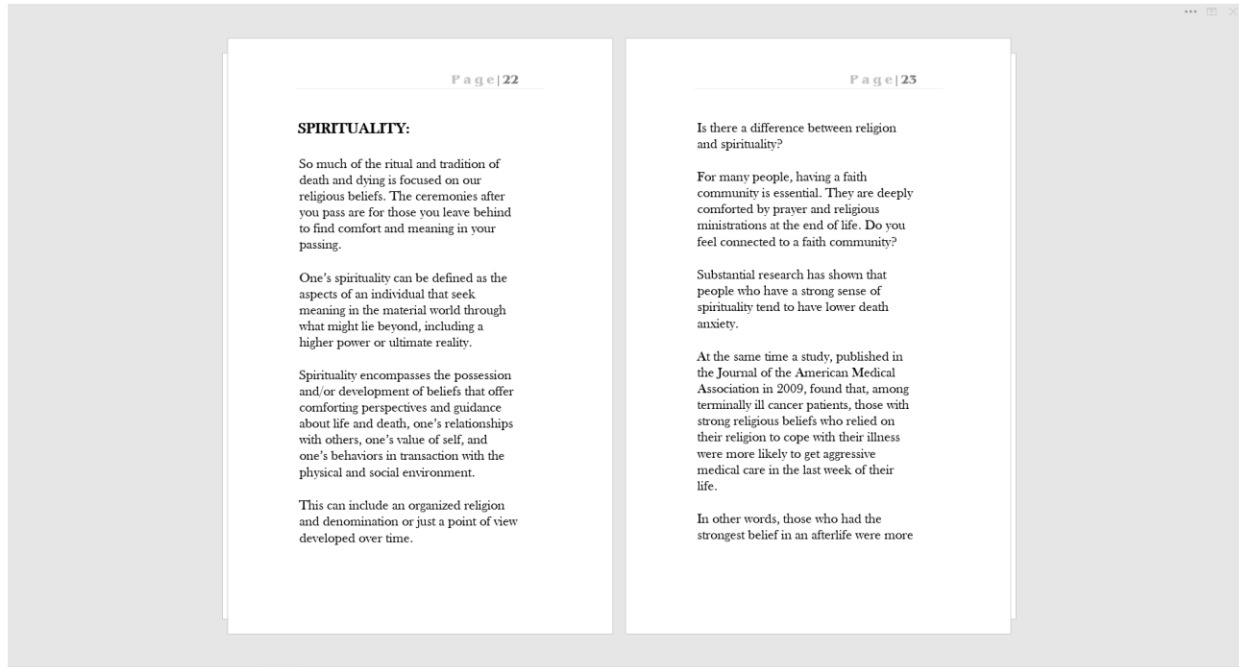
Spirituality isn't really a big concern? What about friends and family?

- Turn to page 27

Are you not sure?

- Turn to the Resources page 36

Page | 21



Page | 26



Page | 27

Family Members and Loved Ones:

Are you worried about how your family and friends will cope as you pass out of this world? Research shows that communication between the person addressing their mortality and their family members and their support network is vital in finding a sense of peace for all involved.

Family members have a greater sense of their loved one having a "good death" when they have been an active part of the end of life proceedings.

Advanced care directives are a good way to start the conversation about how you want to be treated if you become unable to advocate on your own behalf. These documents come in many forms and are effective tools to communicate your wishes. They range from very technical and medical to more spiritual and personal. Please refer to the resource section for some of these options.

Page | 28

A study of homeless individuals who were dying showed that they were most concerned that the alienation many of them had from their families would negatively affect the emotional support they received at end of life. (more on **fear of dying** alone please turn to page 15)

This is the time to come to peace about long held grudges and resentments.

Is that "beef" you had with your brother when you were 20 years old *really* that important now?

Can you apologize for the hurt your actions caused a loved one? Are you able to forgive someone who was abusive to you? Whether they apologize or not? Whether they are alive or not?

Page | 29

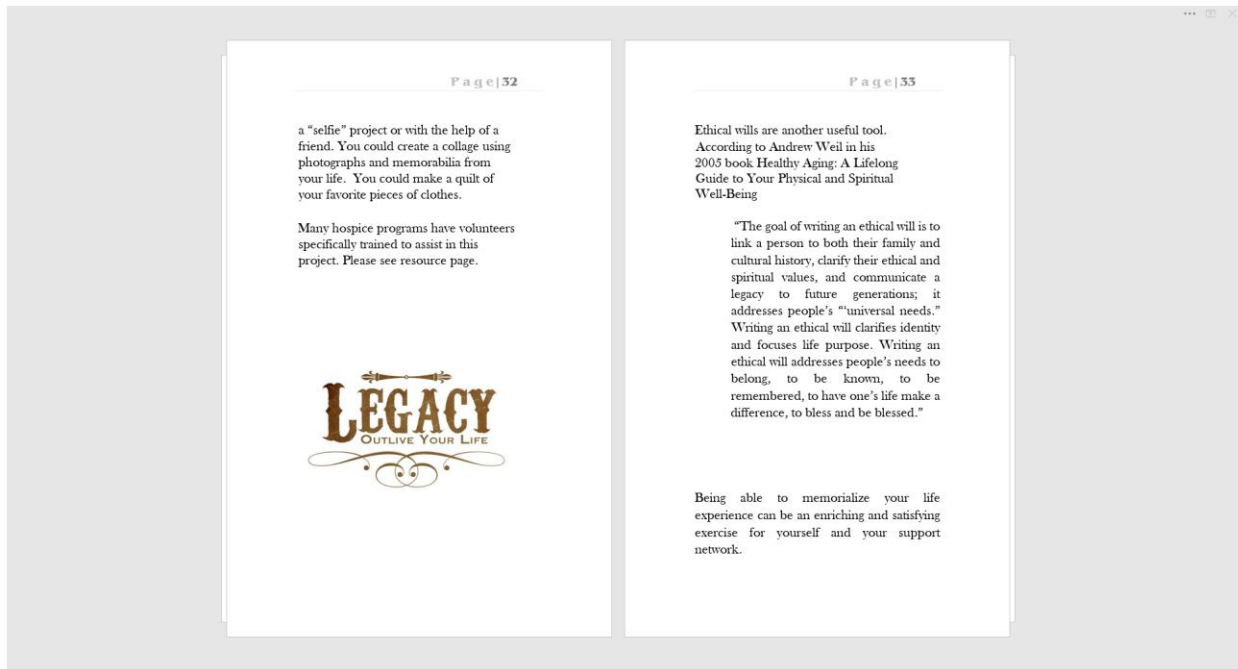
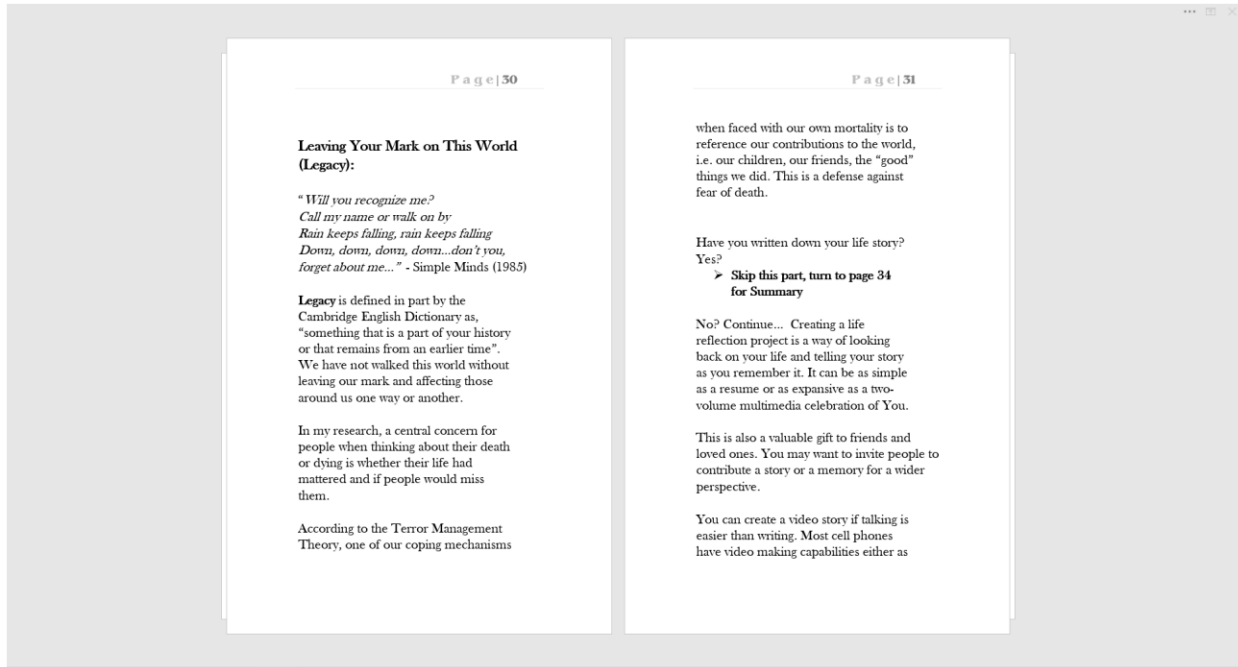
These actions taken sincerely and in good faith, can lead to a sense of peace and closure. This is also a time to reach out to those who are and were important to you and let them know what they meant to you. If the person is no longer alive, write a letter.

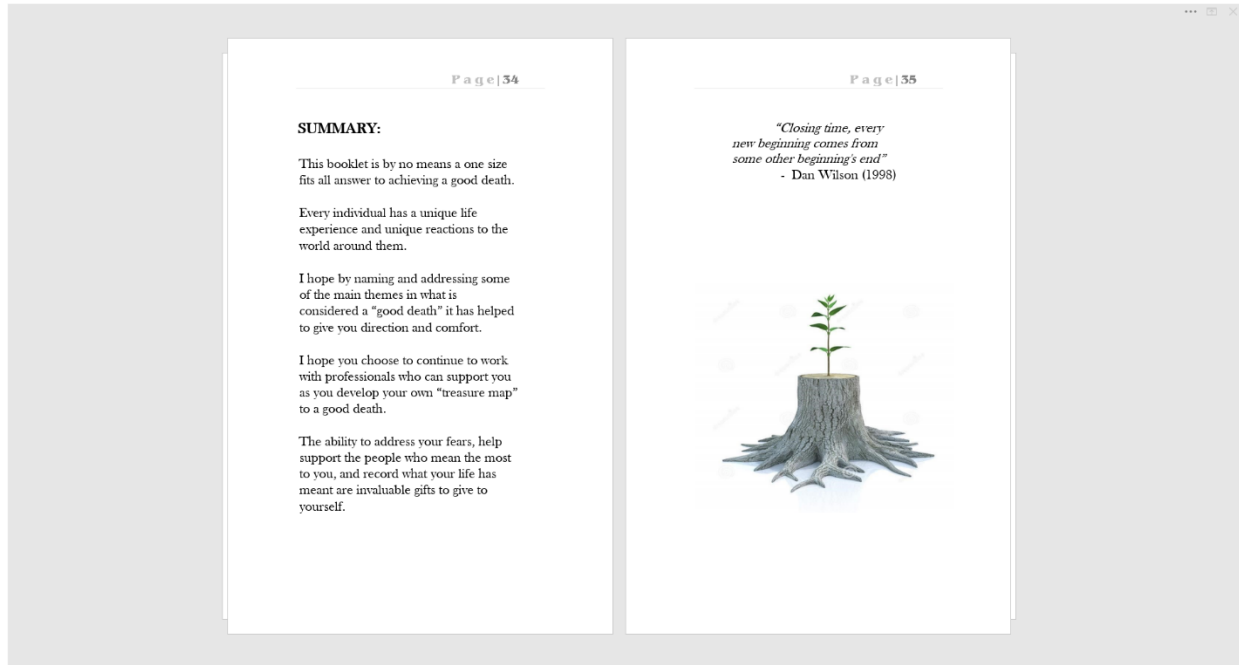
Many hospice providers encourage people to write an ethical will or a life reflection. This is a way to address the legacy you want to leave for those in your world.

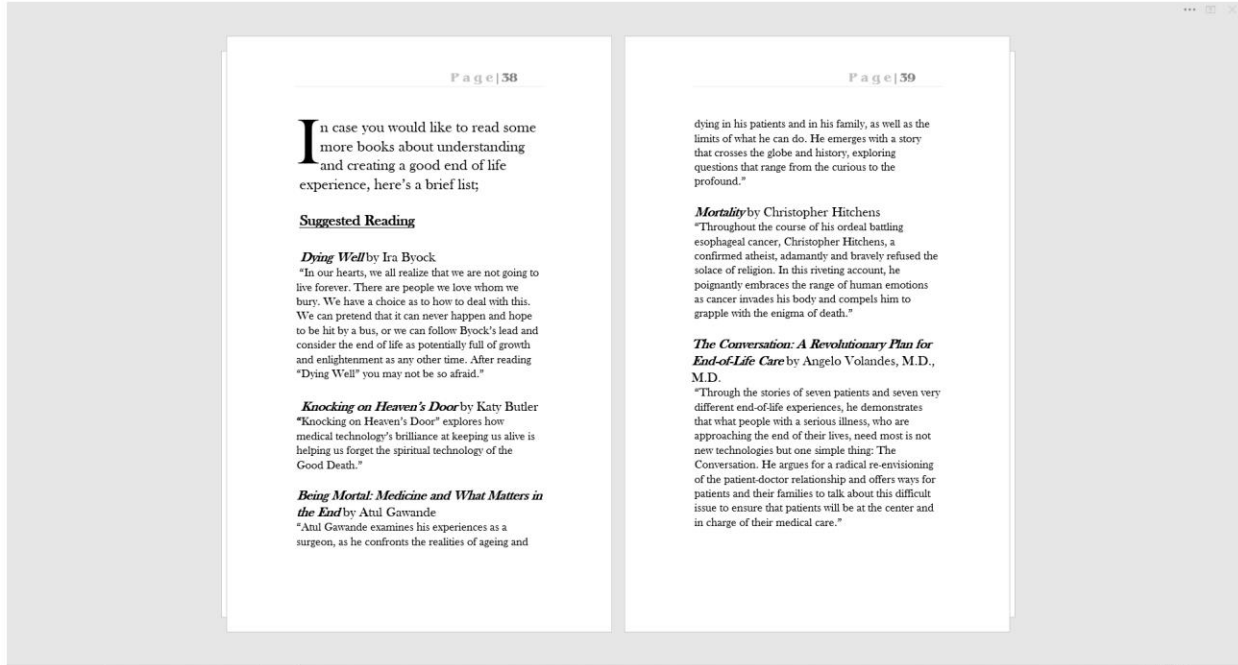
If you want to know more about legacies and leaving your mark in this world
➤ **turn to page 30**

If you feel like you've got a handle on this
➤ **turn to page 34 for Summary**

If you would like resources please refer to page 36







Discussion

"What is a good death?" is an inherently individualized question. The aim of this project was to synthesize the information into an applicable and accessible tool that illustrated the themes revealed in the literature. Using an arts-informed action research method was an effective way to communicate the data and present it in an unexpected format that challenged readers to engage with the material. The viability of the tool created is validated by the research.

Discussion of the results covers the findings and interventions supported by the literature, unexpected findings of arts-informed action research, and implications for future research and clinical social work applications on the subject of how one can navigate a good death.

Findings Supported by the Literature

Creating this tool is consistently supported in the literature as a tool to increase positive end of life experiences. The literature showed that the more patients and their families are involved in end of life decisions, the more they report having had a good death experience. This was supported by studies of family's perception of care post death. The literature described the concept of being in control in a variety of ways. Examples of patient perception of control included Advanced Healthcare Directives, communication with providers and family members, feeling heard by providers, ability to say goodbye to family and friends, and the ability to leave a legacy. Fear was a major concern for dying patients in the literature. Fear was addressed through spirituality, education about the palliative and hospice model, knowledge of dying process and being engaged in the medical decisions and process. Spirituality was a consistent theme. The role of a belief or no belief in a higher power did not determine one's readiness for end of life. The literature showed there was a continuum of responses to spirituality and religion for both the

patient and their families. One possible explanation is that everyone has an individualized relationship to their spirituality. Another explanation was that for a very religious person to give up and die was to let down their god.

The breadth of response to religion, atheism, and spirituality was a surprise to me. I guessed that the people who had a strong faith in god would have less fear and anxiety at the end of life. Multiple studies showed that people who reported a strong faith were the ones who wanted the most medical interventions at the end. I was intrigued by the atheist response to spirituality. They identified nature, being at peace with their death, and loving relationships as their form of spirituality. Spirituality is an important part of many people's identities. It has implications for future practice as to how we address this area at end of life.

Implications

The findings of this arts informed action research project has considerable implications for social work practice including communication, resilience, and empowerment (for both clinician and client). It is vital for an experienced clinician to have an array of skills to communicate with clients. The use of the branching plot style book, an accessible, somewhat light-hearted and familiar format to many people is a benefit for practitioners. It is a straightforward but non-threatening way to start a difficult conversation. It could be used as a part of group discussions about end of life concerns or in a one on one setting. This tool builds resilience by providing the client with an opportunity to address the concerns they have about end of life in a structured and engaged manner. Most importantly, this tool is empowering. A person who is confronting their own mortality often feels vulnerable, frightened, overwhelmed and at the mercy of the medical

establishment. This tool provides an intervention through self-direction, knowledge and simple interventions to help them understand what end of life encompasses.

Implications for Social Work Education

This is an important area. The opportunity was almost missed to create this tool by an academic structure that values expediency and familiar over innovation and process. The institution of social work academia in the United States has become a brisk check list of "to do"s. I was not aware of alternative research methods and had to be guided in the direction that suited my particular point of view and learning style. I had a lot of difficulties finding pertinent information on how to conduct arts informed action research. Most of the direction I received came from universities in Scotland, Australia, and Canada.

Social work could be considered an arts-informed calling. We are constantly asked to "think outside the box" and to creatively meet our clients "where they are at" in our practice. If we are not given permission or even encouraged, to stretch our thinking beyond traditional quantitative and qualitative research when we are in the perfect environment to investigate an issue from all angles, what kind of professionals are we creating? What makes social workers different than other behavioral health professionals is our ability to look at the whole picture and how all the parts and players interact. We are tasked with understanding a situation from as many angles as we can find.

The implications for clinical social work students is that we are becoming automatons to the 50-minute insurance covered hour. We have lost the magic of relationship and innovation that is the hallmark of our field. Our field thrives in the intersection of art and science. The arts

informed action research findings I found were only possible because I was given permission by my chair to look beyond the binary approach of quantitative or qualitative research methods.

Future research should take this tool and field test it on multiple populations and adjust as needed. The limitations based on lack of diverse research results could be ameliorated by this process. The perspective of this book was informed by the literature and much of the research in the literature was based on white, Christian Americans. Future research should be considered for other ethnic, cultural, and religious backgrounds. These varying perspectives will effect the themes and the intervention developed.

Action research is never really done. This tool can and should be adjusted as more insight and information about end of life care is made known to social work students, patients, and professionals. This is a living document that can be edited and applied for years to come.

Conclusion

This arts informed action research project produced a tool that can be very beneficial to clinicians and clients confronting end of life issues. This research method, while not supported in many academic settings is a rewarding and difficult process to navigate. The literature reviewed supported clear themes of control, fear, relationships, and legacy for addressing the concerns many face as they confront their own mortality and impending death. This project has strong implications for the changing paradigm for how death is discussed between a patient and their families, and their providers, including social workers. We as social workers have a duty to address our clients concerns and issues using every available perspective and intervention. This research project is an excellent example of an arts-informed action research method that can provide knowledge and comfort to our clients and their families at one of the most difficult times in their lives. As social workers, that is in our code of ethics and our reason for being.

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