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# Alternate Endings: Insight into Alternative End of Life Care Options

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Alternate Endings:  
Insight into Alternative End of Life Care Options

by

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MSW Clinical Research Paper

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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 publically present the findings of the study. This project is neither a master's thesis nor a dissertation.

### **Abstract**

Alternative end of life care options aim to serve people in their home to provide person-centered support at the end of life, but there is a dearth of research on the impacts of these emerging practices. The author of this study reviewed current literature regarding various alternative end of life options and interviewed eight alternative end of life practitioners from around the United States of America. Emerging practice include death doulas, death midwives, end of life guides, home funeral guides and green burial. Hospice and palliative care are recognized as current practices and current published literature examining what best serves people at the end of their life, as well as their caregivers, illuminates gaps in access to services that allow healing relationships with professionals at the end of life. This impacts the experience of dying and grieving. Historical perspectives and parallels on American death care highlighted. A qualitative Phenomenological Analysis approach was used to hone in on four themes that emerged from the interviews, including: practicing person-centered education and support, recognizing interconnectedness and the value of transition, impacts on dying person, caregivers and the living and empowering people to reclaim what was. Implications for social work include professional ethical duty to understand the range of options for end of life care and advocating for policy that supports people's access to these options. Future research is needed to explore the impact of alternative end of life options from the perspectives of the people utilizing these options.

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**Alternate Endings**

Medical advances have enabled people to live longer, changing the process of dying as well (Catania, et al., 2015). Most Americans will live the end of their life with five or more chronic and complex conditions, with death being a process as opposed to a sudden end (Institute of Medicine (IOM), 2015; Bensen & Aldrcih, 2012). As demographic changes reflect an older and more diverse population, more options for caring for people dying at home because most people die in the hospital and do not want to (Gomes, Calanzani, Gysels, Hall, & Higginson, 2013). Alternative end of life options present emerging models of caring for the dead and dying at home. They are not well researched or widely understood by professionals working with people at end of life or advance care planning.

Social workers play a critical role in the process of dying. The National Association of Social Workers (NASW) *NASW Standards for Social Work Practice in Palliative and End-of-Life Care* details guidelines to improve care and recognize the means in which social workers are skilled in contributing in this area (NASW, 2004). Social workers trained in providing mental health services and/or working with older adults have an important role in working with the loss, grief, and stress of adapting to chronic illness for the person as well as their caregiver (Gwyther, et al., 2005).

Hospice and palliative care are the mainstream options for end of life care, although the lack of utilization of these services makes them more in line with alternative options. While hospice serves 1.7 million people on Medicare at the end of life, the average time one spends in hospice is low as 35.5 percent die within seven days, not factoring in people who are in hospice

less than three days; however, 66.6 percent of people die at their own residence (National Hospice and Palliative Care Organization (NHPCO), 2015). Palliative care is growing service option; however it is underutilized due to lack of public understanding, inconsistent benefits, lack of services in the home, and cultural fears of death (IOM, 2015).

Alternative end of life options utilized in conjunction with the more mainstream options aim to benefit a person dying benefit the person dying a "good death" by empowering them to spend time with family, having their symptoms managed, and having a sense of dignity in their acceptance of death (Holdsworth, 2015). The movement has been cited as stemming from the same origins as hospice and home birth with the intent to regain the focus on the sacred power of the veils of these passages we all make (Hagerty, 2011, p. 60). It has been referred to as "The death positive movement" by some (Doughty, 2015, para. 1).

Medical experts define a "good death" as occurring when health care professionals coordinate care when settings change, ensure emotional support and physical comfort, actively share in decision making, and treat the person dying with respect (Teno, et al, 2004). Rather than relying on the physician, the health care administrator, the insurance company, the clergyperson, the lawmaker, or the scientist to determine what type of death is best, the most appropriate death is the one that a person would choose for him or herself if given the opportunity (Fine, 2004). Advance care planning is the means to do this, and the earlier people have these conversations the better their chances are of having their goals and wishes fulfilled (Benson & Aldrich, 2012).

Alternative end of life options offer a personalized, deinstitutionalized form of care for people dying and their caregivers. Some examples of this are death doulas, death midwives, home funerals and green burials. There are little consistencies in what the definition of and specific

services provided by alternative death providers at this time, and virtually no literature on the matter. However, there are groups and providers that have made efforts to find common terminology in order for these providers to be more widely recognized and deemed professional and not simply a fringe movement. Home death care and funerals are gaining interest, safe, and legal (National Home Funeral Alliance (NHFA), 2016). They provide an alternative for more personalized care and a deeper relationship with a skilled practitioner to guide the way. They can be vital in giving someone a good death and aide in supporting bereaved loved ones and caregivers (Wilson, 2009).

The aim of this research was to explore the phenomenon of alternative end of life options. This was accomplished by interviewing practitioners that provide alternative end of life services.



## **Literature Review**

This literature review will elucidate the research on end of life care practices and efforts to reclaim alternative end of life options. The impacts of current practices and programs, historical context and parallels, rituals, impact on caregivers, and emerging practices will be explored.

### **Current Practices and Programs**

As there is scant literature on alternative end of life practices, examining the impact of caring for people who are near the end of life at home from mainstream options offers insight into the need for people to have more options. Although hospice, palliative care and alternative end of life options are services that stand on their own, they can and are used together. This serves to fill in gaps in services to an extent, but little is known regarding the impact of alternative end of life options or their use. Hospice and palliative care theoretically serve to meet a person's needs in a holistic way. However there are many barriers to people getting the most from them and form healing therapeutic relationships.

### **Hospice**

Hospice is the model for quality, compassionate care at the end of life, with a team-oriented approach of expert medical care, pain management, and emotional and spiritual support in a way intended to meet to the persons' wishes (National Hospice and Palliative Care Organization (NHPCO), 2016). Emotional and spiritual support also is extended to the family and loved ones, typically in a person's home or in a home-like setting operated by a hospice program, and Medicare, private health insurance, and Medicaid in most states cover hospice care for people who meet the criteria (NHPCO, 2016). Hospice was originated to provide specialized care for people dying by nurse, social worker and physician Dame Cicely Saunders in suburban

London in 1948 and was introduced to the United States of America in the 1963 (NHPCO, 2016) .

While people consistently report a desire to die at home and increased focus in the United States and the United Kingdom on models of care that allow for home-based palliative and hospice care, trends in dying outside the home are shifting (Gomes, et al , 2013). In order to determine if the commonly accepted reason people end up dying in the hospital is due to people reconsidering their preferences as their disease progresses and explore variations in the literature, researchers conducted a systemic review of original data on just over 100,000 people's real life or hypothetical end of life care wishes if they were in the severe stages of a progressive disease in 33 countries (Gomes, et al , 2013). The researchers found that more than half of people want to die at home, and older people do not want to be moved around a the end of life, but people feared that their family would be burdened by their dependencies and not get adequate support to keep them at home; this echoed the fears of caregivers (Gomes, et al , 2013).

### **Caregivers**

Caregivers of a person with end-stage dementia who had moved their family member to a nursing home noted that they simply could not get enough support to care for the person and balance their own life; caregivers noted that they felt the person they cared for received better care in an institution when pain was uncontrolled, a fall or injury occurred, if there are safety issues in the home or due to increased dependency, but preferred to care for the person at home when assured supportive ongoing services (Gomes, et al , 2013). An increase in home services combined with a flexible and creative approach to care planning for the needs of the person dying has an impact of providing practical and emotional support on the caregiver's, improving their grieving process (Gomes, et al , 2013).

Family caregivers interviewed 1 to 2 years after their loss were asked what had been most valuable to them through the journey to the end of their loved one's life: their loved ones' wishes honored, and being included in decisions; support and assistance at home; practical help with transportation, medicines, and equipment; the ability to attend to personal care needs (bathing, feeding, toileting); honest information; continuous access to caregivers; a sense that they were being listened to; privacy; and continued contact after the death (Fine, 2004). Both patients and caregivers would prefer to be at home with strong practical and emotional support, and doing so has been found to support healthy grieving for the caregiver in their loss of role and of the person they cared for (Bausewein, et al., 2015; Gomes, et al, 2013; Holdsworth, 2015).

### **Palliative Care**

Palliative care was defined in 1990 by the World Health Organization to serve as a mode to address not only physical pain, but also emotional, social, and spiritual pain to achieve the best possible quality of life for people and their families earlier than hospice care so that more people could benefit from receiving this type of care earlier in their illness or disease process (NHPCO, 2016). As with hospice, interdisciplinary teams who specialize in hospice and palliative care work closely with staff and volunteers to address all the symptoms of illness, with the aim of promoting comfort and dignity (NHPCO, 2016).

Palliative care is not widely used in home and community settings at this time, despite recommendations, therefore the primary place people have access to palliative care in most countries is in a long-term care facility (Hall, Davies, Gao & Higginson, 2014). People live an average of two years in long-term care facilities, and experience many sources of distress from multiple chronic diseases, grief about what they have lost and anticipated loss, concerns regarding being a burden to loved ones, and this manifests as suffering, hopelessness, spiritual

and existential crisis, loss of their sense of meaning in life and pleasure in things they once enjoyed, deeply impacting a person's quality of life (Hall, et al, 2014). Researchers used the reliable and validated Patient Dignity Inventory (PDI) measure to detail and compare sources of distress between people who have advanced cancer and people living in long-term care facilities to better inform interventions to manage this distress (Hall, et al, 2014). Overall, the PDI revealed that people were struggling with physical symptoms of their disease stage, not being able to maintain their usual routines, and not being able to carry out activities of daily living (ADLs), and not feeling that they had a sense of self as their disease and care needs all but eliminated their privacy (Hall, et al, 2014). The PDI can be a useful tool to identify what is causing a person distress, although the researchers clarify that these are not issues commonly measured in long-term care settings, where the focus is on physical distress (Hall, et al, 2014). This defies the intention and goals of palliative care by reducing it to pain management.

### **Home Based Palliative Care**

Palliative care is offered in some form in 85 percent of hospitals in the United States, but this extra layer of support is not consistently defined across systems and hospital-based palliative care may not be the most effective means of service delivery (Rabow, et al., 2013). Home based, "outpatient" palliative care is best implemented in routine care at the onset or diagnosis of a serious illness, as opposed to waiting until someone is hospitalized, however, despite strong evidence and support, home based palliative care is just beginning to emerge (Rabow, et al., 2013). Outpatient palliative care was found to provide people getting services and their families a higher quality of life for a longer time when compared to late referrals for hospice or hospital based palliative care programs due to improved efficacy of interventions, increased care coordination, and more input from people as to their preferences across care settings (Rabow, et

al., 2013). Decreased hospitalizations, emergency room and intensive care unit use and earlier hospice enrollment were noted to align the clinical benefits of earlier access to outpatient palliative care and the financial costs of providing such services (Rabow, et al., 2013). Four controlled studies detailed in the review found in-home palliative care accessed earlier in the disease process increased patient satisfaction, improved the person's symptoms and quality of life, lengthened survival, reduced health care costs and decreased caregiver burden with caregiver's reporting fewer unmet needs (Rabow, et al., 2013).

The ultimate goal of palliative care is to align what a person wants and needs with the services they get, and home based palliative care fills a gap for people who want to stay home and manage their illness (Rabow, et al., 2013, p. 1545). This is not because people are not allowed to go to the hospital or use aggressive treatments, but rather that they are better educated about their options and support to manage whatever choice they make. Unfortunately, the need for home based palliative care is outpacing the capacity to meet the needs of people aging and living with chronic illnesses (Rabow, et al., 2013).

There is a drive to standardize and measure a person who is dying's quality of life as a gauge of success in palliative care and hospice over time as circumstances and context change, but there is no standard instrument (Catania, et al., 2015). The tools that are being used show that palliative care interventions are being utilized too far into the disease progress, as opposed to more proactively when symptoms can be better managed and have a greater impact on improving a person's quality of life (Catania, et al., 2015, p.6). Quality of life assessments are seen as a part of the goal of holistic outcomes, and can be used to determine if people getting palliative care are struggling with psychological and social needs so these can be addressed (Catania, et al., 2015, p. 6). Similar to Holdsworth's findings, Catania, et al., recommend 11 essential principles

to consider, including working with people to help them understand the trajectory of their illness and being proactive in anticipation of what they may need; having treatments and supports available and professionals trained to deliver (2015; 2015). The research team conducted a systematic review of complex interventions, or activities that contain a multitude of parts with the potential for each to interact and result in a range of outcomes in a target population, in palliative care and to determine the impact they have on a person's quality of life (Catania, et al., 2015).

Overall, the interventions focusing on quality of life had a moderate improvement in the person's depressive symptoms, frequency of unmet needs, as well as distress from pain, fatigue and insomnia; however, these interventions were only measured two to seven days and it was unclear if they were ongoing supports or on-time interventions (Catania, et al, 2015). In conclusion, Catania, et al., found that these results may be the contribution of close relationships between the person getting palliative care, their caregiver(s) and the professionals providing the services (Catania, et al., 2015). The current models of care do not allow for these types of relationships to develop, and it is costly.

People who in the most ill five percent of patients in the hospital account for over 50 percent of health care spending in the US, primarily due to inpatient hospital stays, despite a decade of evidence that hospital-based palliative care programs demonstrating improved outcomes and decreased costs (Lustbader, et al., 2016).

As there is little literature regarding home-based palliative care programs (HBPC), innovative models of HBPC programs were evaluated to determine if it is more cost effective to provide care for people in their homes, where they want it, without needing to meet the Medicare hospice criteria (Lustbader, et al., 2016).

The HBPC programs were offered in the context of an Accountable Care Organization (ACO), where the ACO provider can bill Medicare the same rates as other providers, but any savings that are created go back to the ACO, so long as Medicare quality indicators are upheld (Lustbader, et al., 2016, p.2). The HBPC program offered two weekly in-person visits from an interdisciplinary team and a one hour weekly one-to-one with a social worker, nurse and palliative care doctor, access to 24/7 telephone support, and visits with volunteers trained by the social worker who offer Reiki energy therapy, play music, or just listening (Lustbader, et al., 2016). The outcomes for the 82 people on Medicare compared to the 569 who received the usual care in three New York counties found that those getting the HBPC program intervention had an average of \$12,000 lower health care cost in the last three months of life due to decreases in ER visits, hospital admissions, and increased use of hospice (Lustbader, et al., 2016). These programs are not typical practice, despite the cost savings and satisfaction evidence. The reality of service options available at the end of life is there are still many barriers to getting quality care at home.

### **Barriers and Facilitators**

Most people do not die at home with supports, as they would prefer, despite national level strategies, policy frameworks, and the World Health Organization (WHO) calling for honoring people's preferences (Klinger, Howell, Zakus & Deber, 2014). Barriers and facilitators to terminally ill adults accessing palliative and hospice care were evaluated in a cross-country case comparison between England, Canada, the United States and Germany to inform policy and health care systems (Klinger, et al, 2014). These four countries were selected because they have active end of life care movements, highly developed health care systems, and standards of care for palliative care and hospice and efforts to integrate end of life care into their systems; they

varied in their health care laws, financing and regulation, models of service, resource use and service expenditures (Klinger, et al, 2014). In 77 semi-structured interviews with people working in provider organizations, academia, national hospice and palliative care associations, legislatures and health insurance, they found that palliative care and hospice utilization rates for adults with terminal illness was 16-30 percent in Canada, 23 percent in England, 12 percent in Germany, and 41 percent in the United States (Klinger, et al, 2014). The barriers identified were lack of integration into the health systems; lack of education and training for professionals and volunteers; the need for prognostication as criteria for Medicare hospice benefits and the Gold Standard Framework in England limit access to already limited services, and lack of public knowledge of the benefits of palliative and hospice care in cultures where death is denied and institutionalized (Klinger, et al, 2014). Standards of care that address physical, psychosocial and spiritual needs through an interdisciplinary team available 24 hours a day, seven days a week and stable funding were seen as facilitators to access, although there were variations in access due to legislative and regulatory requirements (Klinger, et al, 2014). The researchers concluded that there is a need to shift perceptions of palliative care and hospice as “giving up hope,” a lack of coordination of services, restricted access in rural areas, and the need for a shift in focus away from the medical model to a model that intervenes earlier and more holistically to be more in line with recommended best practices (Klinger, et al, 2014). Alternative end of life options offer a means of person centered and holistic models of care that work with people, their care teams and medical professionals.

### **Historical Practices and Parallels**

Caring for the dying and dead outside the home is a relatively new concept, as is giving birth outside the home. Although it may seem countercultural and radical to practice or utilize



alternative end of life care options, it is an attempt to rebalance typical life practices that have become institutionalized and empower people to through these experiences.

While no exact statistics are known regarding the rate of people reclaiming home death care practices, one can parallel the home birth movement born of similar intentions to reclaim natural life processes by working with midwives and doulas that are skilled, knowledgeable and have the time to develop relationships. The CDC reports that births at home began to increase by 29 percent between 2004 and 2012 from 0.87 percent to 1.36 percent, and is low-risk for most women (MacDorman, Mathews, & Declercq, 2014). A home birth gives women and families an option to reduce non-evidence based invasive interventions, such as electronic fetal heart monitoring that interferes with the physiological birth process and has been consistently found to have no impact of infant outcomes, and increases maternal death and caesarean sections rates (Loithian, 2014). Hagerty, an anthropologist and death midwife, observes that the home funeral movement is increasingly being utilized by urban immigrants but primarily by people who are white and middle class, similar to trends in home births (2011; MacDorman, et al., 2014).

Care for the dead and dying at home began to change when two major events occurred during the Civil War; the increasing availability of embalming and the creation of the National Funeral Directors Association, which promoted embalming as necessary for the safety of public health, a rampant myth until this day (Wilson, 2009).

The social changes of women going to work outside the home, families moving further apart, and house getting smaller with no parlor to host a parlor vigil, and an increase in societies wish to distance from nature and be sanitized and commercialized even in death have nearly eliminated home death care as it became institutionalized by funeral homes (Wilson, 2009.) In

the 1920s, hospitals became the places people went to die, with a small shift in this when hospice was created in the 1970s to bring death and dying back home (INELDA, 2016).

### **Emerging Practices**

There are little consistencies in what the definition of and specific services provided by alternative death providers at this time, and virtually no literature on the matter. However, there are groups and providers that have made efforts to find common terminology in order for these providers to be more widely recognized and deemed professional and not simply a fringe movement. For instance, the Death Positive Movement and Let's Have Dinner and Talk about Death aim to get people of all ages talking about end of life wishes to normalize death and dying in our culture. The Canadian Integrative Network on Death Education and Alternatives (CINDEA), The National Home Funeral Alliance (NHFA), and the International End of Life Doula Association (INELDA) are examples of groups working to educate, promote and advocate for awareness of alternative end of life options.

### **Cultural Shifts**

The Death Positive Movement aims to challenge the notion that death is something to patently avoid and be fearful of, and that by gaining a more realistic perspective through conversation and education one can live better. The term was coined by mortician Caitlin Doughty, author of a 2015 memoir, *When Smoke Gets in Your Eyes*, creator of a YouTube series, "Ask a Mortician," and originator of The Order of the Good Death in 2011. The Order of the Good Death, a group made up of funeral industry professionals, artists and more, is working to find ways to challenge people to evaluate their own fear of death through death salons and cafes, and Undertaking LA, an alternative funeral home where people are encouraged to participate in the final preparations of their loved one (Doughty, 2015). A 2016 *Marie Claire*

article highlights the events of a death cafe, including DJ's spinning music, taxidermy, and more critically, the fact that this movement is being led by women and inspiring millennials to friends and family about their end of life wishes and live life a new way, many in the face of loss (Ortiz, 2016).

In partnership with the Elisabeth Kubler Ross Foundation, The National Hospice and Palliative Care Association, "Let's Have Dinner and Talk About Death" was developed by Michal Hebb and launched as a simple concept to give people tools to have the conversations too few people are having by simply filling out an online form as to who will be at dinner, what the intention is for the dinner, and reading, watching or listening homework in preparation for the dinner (2013). Hebb originated the project from a Master of Communication in Digital Media class at The University of Washington as the final project requirement was to raise community conversations around death, healthcare and human life, support universal discourse, and bring a revolution of life (Let's Have Dinner and Talk about Death, 2013). He also has TED Talk, *What happens when death is what's for dinner?*

These are examples of cultural shift occurring that is long overdue and not the first of its kind. The Death Positive Movement as the third wave, the first occurring in the 1970s in the USA and the UK, and a second surge in interest during the AIDS epidemic in the 1980s in light of changes in a more secular culture where people have more options and recognize the denial of death has contributed to the lack of policy to provide support to people seriously ill and at the end of their life (2015). Research had found that people who think about death and recognize the fear of it have a greater sense of self-esteem, self-concept, locus of control, self-realization and existential well-being because they have a healthier *actual-self*, as opposed to a *symbolic-self* defined by and entrenched in extrinsic expectations and social systems (Cozzolino, Blackie, &

Meyers, 2014). One goal of the death positive movement and alternative end of life practitioner's is to increase people discussing their wishes and beliefs, normalizing these conversations and creating advance care plans to formalize their wishes.

### **Alternative End of Life Care Options**

There is no state or federal certification for alternative end of life practitioners, who go by various titles and have the ability to shape their roles as they choose. Approximately 30 training programs, ranging from a course for \$200 to a yearlong program for thousands of dollars are available in the United States and Canada (Canadian Integrative Network for Death Education and Alternatives (CINDEA), 2014). There is a range of people who go through these trainings, some seeking tools for caring for their own dying loved one, some who are professionals with various backgrounds, so the range of options supports this (CINDEA, 2014).

CINDEA uses the term "pan-death" to acknowledge that alternative end of life practitioner's work across the spectrum before, during, and after death in a holistic, ecologically-minded, natural model of care (2014). While this term is not seen in American resources, it clearly articulates the differences between segmented and disjointed models of palliative and hospice care that are consistently found as barriers to good care and satisfaction of people dying and their caregiver (Fine, 2004; Holdsworth, 2015; IOM, 2014; Klinger, et al, 2014).

The National Home Funeral Alliance (NHFA) is a Washington based 503(c6) in 2010 the formed as a grassroots organization in 1997 with an intention to offer training and courses on end of life care at home around the county (2016). The group is comprised of health care professionals, spiritual and mental health professionals, education sector professionals, business professionals, and volunteers (2016). After conducting a survey with the intention to solidify

terminology with the group's intention to find common ground in terms people understand that are not off-putting, they came to the following definitions:

End-of-Life Transition Guide: Accompanies a dying person and/or family and friends through a personal, intentional and conscious dying process to realize a good death.

(Other terms used include: *Conscious Dying Guide*, *Death Doula*, *Death Midwife*, *Death Transition Guide*, *End-of-Life Doula*, *End-of-Life Guide*, *Midwife to the Dying*, *Midwife to the Soul*, *Pre-Death Guide*, *Psychopomp*, *Soul Midwife*, *Sacred Crossings Guide* and *Thanadoula*.)

Home Funeral Guide: One who empowers families and/or friends to care for their own dead, including educating, consulting, and guiding them through after-death care

Celebrant: One who works with family and/or friends to co-create a highly customized ceremony (for funeral, memorial, celebration of life)" (2016).

Depending on how a practitioner offers their services, they are likely to guide people through the needed paperwork and legal requirements after a person dies, and advocate for a family's rights to provide home death care (CINDEA, 2014). It is currently seen as a grassroots, community-based model of care by some, and an emerging profession with regulations and reimbursement to come in the near future, similar to the differing perspectives in birth midwifery and doulas (Bareham, 2015).

### **Advance Care Planning**

A sub-set of Millennial's engaging in end life discussions is a hopeful sign of change for this generation, but this has not been the case the aging Baby Boomers and the Greatest Generation. While most people want to die at home, few would get that option because they likely have not had a conversation with their family and only about one-third of people under 60

have advanced directives and half of people over age 60 (Benson & Aldrich, 2012). Effective January 1, 2016, physicians and non-physicians can bill Medicare for Advanced Care Planning Services so that more people will have access these important conversations (The Lancet, 2015).

Medicare reimbursement offers more opportunity for people on Medicare to have these conversations with health care professionals. However, alternative end of life practitioners and the movement behind them views advance care planning as an ongoing process that should be done sooner rather than later to ensure people are aware of the full spectrum of their options and their wishes are upheld, offering support along the way (CINELA, 2014).

### **Home Funerals and Green Burials**

American people are also making the choice not have any type of funeral or memorial service, often due to a lack of any connection to a religious or spiritual belief that prescribes a ritual in this. Nearly 23 percent of American's claim no religious affiliation (The Pew Research Center, 2014). Social workers have the education and skills to provide person-centered, holistic spiritual care at the end-of-life, as they are equipped to listen to the person and their loved ones, support varying cultural beliefs, and support people in making their own decisions by partnering and offering choices, something that has been found integral to providing spiritual care but also lacking in the training of other disciplines (Edwards et al., 2010). Home death care and funerals allows people to have a person centered means of letting go, with no rules regarding funeral home timelines and rules (Wilson, 2009). People may also choose alternative end of life options for economic reasons, if they are aware of the options.

The average funeral in the United States is \$8-10,000, with the funeral industry being a \$20.7 billion market serving 2.4 million people a year, and in a time of shifting demographics

with a boom in people aged 60 and older reaching an estimate 76 million by 2020, and people are looking for other options (PBS POV, 2013).

Home funerals and green burials offer people options that feel more personal with less environmental damage from toxins through a direct return to the earth (Kelly, 2012). The research into end-of-life options has shown a dissatisfaction with the traditional American funeral options and costs over last half of the twentieth century, and while the immediate rituals of a traditional funeral provide structure in a time of shock, they do not serve to promote meaningful grieving in the ways alternative end of life practices aim to reclaim (Hunter, 2007).

### **Death Midwife**

Typically, after an initial in-home consultation, the death midwife works with the person dying and their caregivers to create a plan that meets their emotional, spiritual and physical needs; visits may be monthly, weekly or even daily depending on the needs of the family (Bareham, 2015). Working in conjunction with hospice, doctors, out-of-town family members, and religious or spiritual officials, the following list of services is what one death midwife offers:

- In-home, hospital, or nursing home visits with you and your loved-one
- Detailed reporting to next-of-kin unable to visit
- Emergency room support after unexpected death
- Holding space while life-support is discontinued (includes sacred singing, spiritual guidance, after-death rituals and body preparation if required)
- Finding a local, reputable hospice to meet your loved-ones needs
- Assistance with completing advance directives for health care and death care
- Assistance with fulfilling final wishes / healing relationships / putting things in order

- Spiritual support including guided imagery, meditations and exercises to help alleviate anxiety and suffering
- Guidance with completing the life-review
- Help with writing an autobiography or creating a video-biography as a legacy to loved one
- Guidance with after death care of the body (if required)
- Coordinating with funeral home
- Assistance with funeral planning including the home vigil and funeral (Bareham, 2016).

### **Death Doula**

Birth doulas have been supporting women through childbirth since for countless years, and have been professionally certified and trained since the 1980s (International End of Life Doula Association (INELDA), 2016). One example of a death doula program is INELDA, co-founded by social worker Henry Fersko-Weiss in 2013, adapting the philosophy, tools, and approaches used by birth doulas to create a program for an end of life doula, to support and guide people through the dying process to bring deeper meaning and greater comfort to dying people and their loved ones (2106). INELDA is an international nonprofit that provides direct training for end of life doulas in the US and through the Institute of Traditional Medicine in Toronto, Canada, and provides consultation to hospice organizations who want to include this model in their services (2016). INELDA and its president, Henry Fersko-Weiss, continue to provide community trainings and workshops with the goal of creating a change in how society approaches and faces death – rather than arriving in fear, if we talk and prepare, the patient and loved ones can reflect and honor the life. Fersko-Weiss encourages people to embrace death as a “transition” and he explained the suffering stems when the focus is on the medical and not on the “sacred nature



of the process" (INELDA, 2016). This transition and having support through it are valuable not just to the person dying, but to their caregivers as well.

Caregivers, or carers, who were interviewed six to 10 months after the death of a relative, were asked about the role that formal health and social care providers, "care providers," shaped their perception as to whether or not the person they were caring for had a good death (Holdsworth, 2015). Holdsworth found that the majority of the caregiver's saw the end of life as a period of time of days or months, not as much the moment of death, and that guidance and support in six areas were key to feeling their relative had a good death, no matter the location (2015). These six themes were: social engagement; maintaining relationships and connection to identity; caregiver's felt isolated in their roles, losing contact with family and friends and felt disconnected from their own self, and having support to be a partner or relative and not just a caregiver was important (Holdsworth, 2015). This was possible with the second theme, working with care providers who were proactive and empathetic caring, and could educate the carer about what to expect while providing continuous support from the same team members in order to build relationships and trust (Holdsworth, 2015).

Carer's ability; confidence in caring and the understanding of the carer's role in 'professional caring' was the third theme, in that the caregiver felt that they had met their relative's needs and felt supported and included by the caring professional, as opposed to those who were treated as if they were health care professionals who should know exactly what to do in a given situation or not included in decision making by the team (Holdsworth, 2015). Care providers who contributed to the person dying and/or the carer's preparation and awareness in accepting death was critical in that it was a supportive and well-timed process, and not something that they were informed of as if someone was simply checking off

a box (Holdsworth, 2015). The perceptions of the carer's ability for the support team to preserve the presentation of the patient at death; control of the dying body through balancing pain relief and sedation, because carer's wanted their relative to be able to communicate as much as they could but to also be comfortable and gave caregiver's the sense that their relative had a dignified and peaceful death (Holdsworth, 2015). Finally, the sixth theme was that the carer felt that they had enough support with end of life arrangements, returning medical equipment, and necessary paperwork to have their grief protected from the bureaucracy, and that care provider's also followed up with them after their loss (Holdsworth, 2015).

Holdsworth's findings echo those of Teno, et al, in that simply having access to support through hospice is not enough and the relationship between the person dying, the carer, and the professional care providers shapes the way caregiver perceive their relative having a good death and that perceptions of quality care are based on those relationships (2013; 2004).

Alternative end of life options are an option for people to work with skilled professionals who take time to build relationships and spend time understanding the person dying and their caregivers through the entire dying process, if that is what a person chooses. Providers can serve to fill gaps in access to home based palliative care and supportive home services, but what is the impact of alternative end of options on the person dying and their caregiver?

### **Conceptual Framework**

Alternative end of life options allow one to disconnect from medicalization and depersonalize of what is simply a part of life. That is not to minimize the process and event of loss; on the contrary, the alternative end of life movement recognizes the value of grieving and returning a body to the earth through ecological means harmonious with nature. Transpersonal Theory recognizes the impact of transpersonal experiences that come from common experiences, such as creating a piece of art, feeling creative inspiration, birth and death (Boucouvalas, 2016; Kaspro & Scotton, 1999). The power of these individual experiences in turn effects all of humanity and beyond, and as does the loss.

Alternative end of life services are not a requirement for a good death or the only option for grieving, but they are an underutilized option that can serve all involved. They allow a time of transition and ritual vital to allow both the newly dead and the newly bereaved a time to adjust to their new roles while still engaged in an transpersonal relationship in which the dead and the living are caring for one another (Hagerty, 2011). Considering the spiritual connection that Transpersonal Theory framework strives for, alternative end of life practices encourage and support this transition to play out as a process as opposed to the common North-American, middle-class conception of death that has been created and dictates grief as something we are to “get over” as opposed to nurture (Hagerty, 2011, p. 60).

## **Methods**

### **Research Design**

Qualitative research methodology with Phenomenological Analysis technique was used to explore the phenomenon of alternative end of life options. Qualitative research methodology was selected to obtain rich narratives to regarding the small but growing alternative end of life options movement. Qualitative research allows the complex phenomenon in regard to alternative end of life care to emerge that is not possible to capture in quantitative research. The approach of Phenomenological Analysis serves to explore the experiences of participants as well as the circumstances and conditions of those experiences.

### **Sample**

Participants were chosen from National Home Funeral Alliance (NHFA) publicly available contact list via email. Participants have had training on and experience with a range of alternative end of life options. The goal was to interview 8-10 practitioners, and the sample size for this qualitative research is eight practitioners, all female and ranging in age from mid-30s to 73 years. Participants have a range of backgrounds, including journalism, psychology, nursing, philosophy/ethics and neuroscience, holistic therapist, education and theology.

Two participants live in the South; two participants live in the East; three participants live in the Midwest; one participant lives in the West. Participant one has over 30 years of practice with home funerals through her faith background and has called herself a Home Funeral Guide for five years. Participant two has been a Death Midwife for over 10 years and also teaches others. Participant three is an End of Life Specialist with four years' experience. Participant four has nearly 20 years' experience as a Death Consultant/Guide. Participant five is a Funeral/Memorial Specialist Home Funeral Guide with over 10 years' experience. Participant six

is has been a Death Doula for three years. Participant seven works with a hospice agency and has been providing support and education about alternative end of life options for seven years.

Participant eight is a Home Funeral Guide and owns a green cemetery and has eight years of planning and training.

### **Protection of Human Subjects**

St. Catherine University Institutional Review Board (IRB) approval was secured before any research was conducted. All interviews were conducted in a private location convenient to the participants to maintain privacy and to accommodate their needs or via phone. No personal information is included in the results that could identify the individuals participating in this research study. Furthermore, all data collected from the interviews are stored in a locked desk drawer and will be destroyed by June 30, 2017. Participants were given the National Alliance on Mental Health's Helpline phone number and web address as a resource in the event they experience any emotional stress as a result of their participation. The Letter of Consent was reviewed with each participant before they signed on to the study (see Appendix A for Letter of Consent). Informed consent is essential to upholding the ethics the research process. This research was approved by the University of St. Catherine IRB, as it is a required for this research.

Utilizing the National Home Funeral Association (NHFA) providers list that is publicly available, participants were contacted via email addresses available on the NHFA website (see email solicitation Appendix B). The initial plan was to contact participants via phone in the event email was not available, but all participants were contact via email.

Personal information obtained in connection with this research study that can be identified with results has been kept confidential. In adhering to the ethical standards of any

written reports or publications, no one will be identified or identifiable. Research results and digital voice recorder data and field notes will be secured locked desk drawer. Data with any identifying information will be destroyed by June 30, 2017.

### **Data Collection and Instrument Process**

A semi-structured 45-60-minute interview was conducted at a private location convenient to the participant. One interview was conducted in-person and seven were conducted over the phone. Ten interview open-ended questions were created by the researcher to explore the participant's perceptions of the impact of alternative end of life options (see Appendix C for interview questions). The interviews were recorded with a digital voice recorder. Field notes were taken at the time of the interview in a notebook to capture nonverbal reactions, researcher reactions and other observations in the face-to-face interview. Data with any identifying information will be destroyed by June 30, 2017.

### **Data Analysis Plan**

The researcher utilized a content analysis approach by conducting coding to discover themes and document them using a master coding log notebook. Transcripts were read entirely and then again to code emerging themes line by line. Codes and themes were organized using a spreadsheet. Themes were grouped into sub-categories as they develop from the analysis. Phenomenological Analysis results are presented as frequencies of emblematic themes that frame the findings (Padgett, 2008).

## **Findings**

This research study was designed to explore the phenomenon of alternative end of life options from the perspective of the practitioners. Data analysis of sub-themes generated four themes by the researcher: Practicing person-centered education and support, reclaiming what was, recognizing interconnectedness and the value of transition, and the impacts on the person dying, caregivers and the living.

### **Practicing person-centered education and support**

Practicing person-centered education and support means that the participants expressed that their role was to empower and educate people to be as active in end of life care as they can be, although there is variation in the ways this is done. Participants all use different titles and have a variety of training experiences. Some charge fees for their services and some do not. Similarities and differences will be highlighted. Competing advance care plans, providing education, offering direct support or guidance in the process, recognizing the spiritual transition are part of the roles of the participants are detailed.

### **Training, experience and fees**

All participants had a variety of training experience for home funerals and on the laws that support people's choice to do so. Participants had training on advance care planning, the dying process, caring for the dead body. Some participants follow up with the families to provide after-death grief support. Four of the eight participants have service fees, with one offering home funeral guide service as an extension of a green cemetery she owns. The three other participants offered services for a fee, with one reporting she work with a sliding scale and has worked for barter and would not turn anyone down. All participants' reported that

they have had experience with death and loss that has deeply impacted them and their decision to be an alternative end of life practitioner.

All participants reported that they have a base of what needs to be done, as far as caring for a body at home or when discussing advance care plans with people. They also all emphasized the importance of personalizing their work for each person and family, and had a range of experience as to how active they are due to that variance. One participant explained,

It's walking him through what he wants his ideal death to look like and coaching his family member and his friend and loved one through caring for him at the end of life, and what that is going to look like. So empowering them to care for their dead, which is their friend who is going through this (...), so what can we do to create this ideal vision for you? It's always different and it's always beautiful and it's always powerful.

#### **Importance of completing advance care plans and honoring wishes**

All participants work with people to create advance care plans, some using standard forms as well as using documents to enhance conversations regarding end of life care and after death wishes. One participant noted:

I try to get people comfortable with the fact that they do need to talk about these things. I think the push to have everyone have a form is great, but unfortunately it still leaves so many questions and there are so many things that can come up where people are still asking, 'Well, we don't know what they would want.'

This sentiment was echoed by seven other participants, who valued the recent uptick in people completing forms. Another participant stated, "Making a plan for the end is a big burden, but it is so helpful if the person can be a part of that."



All participants agreed that if someone explicitly expressed other wishes, those wishes should be followed as much as possible. To have a home funeral requires support, from the family and/or community, and it is not uncommon per these participants experience that family dynamics may prohibit all from agreeing as to what happens to a person. However, as one participant expressed, “If it is too tense between siblings about not being totally mainstream, find a compromise.” Another stated that a family may take time for ritual in the nursing home, or a more intimate experience at a funeral home. One participant shared the experience of helping coordinate a virtual vigil when family strife kept a partner out of the end of life service:

Someone had a situation where they lost someone long distance, and they weren’t married yet, so it was a partner to that person, so that person wasn’t family and couldn’t be in on some of the things that happened. So we had a virtual vigil. We met in my home, brought pictures of the person and we supported that person who had lost her beloved in a way that she couldn’t do somewhere else.

All participants reported that they are active in providing training and education in their community regarding alternative end of life options. This could be in the form of multi-day intensive experiential classes, to speaking to social workers at hospitals and hospice agencies, community education classes, death cafes facilitating discussion groups aimed at normalizing death, doing interviews and writing articles for local newspapers. All participants worked with people to complete advance care directives, from the basic Five Wishes form to three day in-depth conversations with facilitated and coached that include health care proxies and wishes for want they want after they die.

### **Offering hands-on support and/or education**

Three of the eight participants reported their role as end of life guides were typically limited to educating people on preparing for what death tends to look like, how to care for the body after death, discussing rituals that a family could create, and advising on final disposition options. They may or may not be present at the time of death, and tended to feel their role was to empower families to care for their loved one and not disrupt the process:

I really try to stress that this is something anyone can do if they want, without a third party directing it. That's where a lot of the healing comes from because when we insert ourselves in this experience, they naturally default to the person in the room who actually knows something about the experience, so it can derail them from realizing that they can actually handle it on their own.

Two of those three participants shared that they have had home vigils for people they barely knew or didn't know at all. One situation was a person who had wanted a funeral in a church but had died at Easter time and there was no time for the funeral. Another was a situation where a person who lived in another state had called a practitioner after a parent died in her area. The adult child wanted to provide a home vigil, so the practitioner brought the person to her house to do just that. They also provided more support to families where a person who was dying wanted a home funeral, but their family was uncomfortable with caring for the body. One participant shared an experience of a woman who wanted a home funeral, but her daughter was not comfortable caring for the body. With support, the daughter was able to honor her mother's wishes, which, "completely changed her way of thinking and it had changed her grieving."

One participant reported that she has had training to do home funerals and offers that support in her community where she has opened a green cemetery in her retirement. She reported that she not done one so far and she does not charge for the service. This is due to restrictions in her state's law that this can be seen as practicing as a funeral director without a license, and as long as she does not charge for the service, she is within the law.

### **Recognizing interconnectedness and the value of transition**

Recognizing interconnectedness and the value of transition means participants shared the experience that end of life care and after death care choices impact the earth and the experience of the living in profound ways that are not easily measured. All participants spoke to value of allowing time for the spirit or soul or energy to transition. This included the perception that a home funeral is a natural extension of hospice care, the value in facing death, and impacts on the environment. They also spoke to the impact alternative end of life options on the living in a holistic and interconnected manner to support a conscious death:

“These movements of returning to the most natural place [death care at home, green burials], they're all a part of it. It's physical, its emotional, its social, its cultural, its spiritual, so every little piece is a part of that process.”

### **Giving the soul “A leg-up”**

All participants talked about the belief by different spiritual backgrounds regarding the time for the soul to transition out of the body and the possibility of interrupting that process. In the first interview conducted, the participant stated:

Not many home funeral guides might say this, but many us feel that it is really for the living after death, but also for the transition of the soul to the spiritual world and we're

giving the a leg up, so to speak, by giving some grounding and assistance in preparing the person who has passed in experiencing that love after their death.

While one participant specified her faith background understands this as 72 hours, other participants spoke of the concept in a less esoteric manner. The participants all expressed the belief that there is time of transition, when the threshold is open. One participant shared:

I personally believe that there is an interruption of the spirit, the soul, that there is a karmic interruption or glitch that can happen. To interrupt the death process when the body is whisked away (...) Some say it takes up to 72 hours for the soul to leave the body. What if? What if there is a disruption? Would we make different choices? Humanity and the earth need all the help we can get!

Another participant noted, "This time is not like the time before death and it's not like the time later. Having gone through this, in those days there is something that is palpably present that help us make that transition."

#### **Natural extension of hospice model of care at home for a conscious death**

All participants viewed a home funeral as a natural extension of hospice care, as the concept of death is a normal part of life. "Most people are on hospice and they're already at home and they know when they die they don't want the funeral director to come in and whisk away the body. They've done their research; they're conscious people who make the choice for religious or cultural beliefs." The concept that, "everything is slowed down and their in their own environment." One participant is a hospice nurse, and four others have been hospice volunteers. Two participants noted that they felt limited in the context of hospice, one stating, "I realized that

there was some I so far I could go with how much I was able to work with the dying patient and how much I was able to offer because there's a lot of red tape in hospice. It helps have a better sense of, control, of being connected to themselves and what they want." Another participant noted that she does not fault hospice, but recognizes the constraints of resources and reality of their payment models. "What can you do to make this situation easier because that's not hospices role, they are there for a very circumscribed role, and it's not because they don't care it's because they don't have the funds."

### **Value in facing death**

All participants spoke to the value for caregivers and other people to shift from the cultural norm of fearing death, and that can be in the form of a significant shift to a more complete awareness that serves grieving. One participant stated, "We become more available to a kind of ability to cope with grief and to heal."

All participants also spoke to the reality of the funeral industry and medical systems being self-serving in keeping death taboo. "The funeral industry has turned it into this thing to be afraid of and fear and that the more money you spend the more you loved your deceased. It's just ridiculous." They spoke of this movement being as giving a chance for people to open up the perspectives of death and dying, "and within the medical system there's also this need to shield a patient a client from the impending."

All participants shared antidotes about people who were not comfortable with a family member having a home funeral or working with an end of life guide, but as one participant phrased it, "when they take this emotional leap, I have never heard anyone regret it." Another said:

There is something that is much deeper that happens when you are helping that person, not only for them and in helping the soul move through the stages of leaving the earthly plane, but also for those who are left behind. It enhances our humanity. It's more tender. It helps us address our fear of death, which is so destructive to our experience here on earth.

### **Environmental impacts**

All participants noted the environmental impacts of customary burial traditions, including embalming fluid, wood or metal caskets, and metal or concrete vaults required by many cemeteries for maintenance and upkeep of park-like grass. One participant stated she explains to people that there is a distinction between “conventional” and “traditional” funeral practices, “traditional is that of people taking care of their loved ones on their own. Conventional is getting the funeral home involved.” One participant commented the many people in their 20s are interested in alternative end of life options because of environmental concerns.

Four participants spoke to the health risks created by embalming fluid to the funeral home directors, and that they wear protection not from the dead body, but from the fumes from the fluid. One participant stated:

It's also that everything is more conscious, so we consciously decide not to be buried in a vault, or maybe look at water cremation, people are wanting to do what is more natural for the earth, and each other.

Two participants noted that embalming is not a requirement, but it can be helpful if someone has to come from a long distance. All participants noted that there may be concerns

regarding certain disease processes, if someone had actively been receiving chemo or had a highly infectious disease, with the clarification that a body itself does not pose a health risk to others, even without embalming

### **Impacts on dying person, caregivers and the living**

Impacts on the person dying, caregivers and the living mean the participant's perceptions on what led to a good death for the person dying as well as the experience for the living caregivers or family. These include witnessing a person being filled with love at the end of life, access to care supports to fill in the gaps, saving money that eases the burden for all, changes to the grieving process, and people sharing common experiences when they open up to alternative end of life options.

#### **Being filled with love**

All participants shared the experience that a person being filled with love is a common perception of an ideal death for many people:

For the person who has seen the beauty in the intimate touch, the value of creating their own ritual, people coming around the body, singing and sharing stories, for someone who wants that, it is definitely a help in dying peacefully.

However, it was also noted by one participant that a "good death" may not be a peaceful death, as "sometimes people have to go out dying on their own terms, you know, kicking and screaming and I think that this is what that family needed."

Four participants reported they have more active roles in supporting a person dying and their family, but they all do educate and empower a family to do as much as they are comfortable with. From advance directives and planning, to being available to support families

facing a loved one being taken off life support in hospital after a car accident, to creating rituals and funeral ceremony with the family, including living funerals where a person dying partakes in the celebration:

If you're dying, how nice it is to hear and see all your friends and relatives and say goodbye personally, have a big celebration and a feast. It's intense, but for those who are ready for it and can embrace it, you can see how they are just so filled up with love. What a better way to die.

### **Improving care/filling in gaps**

Four of the eight participants shared that they have been or are hospice volunteers, and one currently works as a nurse in hospice. These four participants were inspired in part by to the role as an alternative end of life practitioner to offer what they see as an opportunity to fill in the gaps and complement the role of hospice to improve the process for all involved:

I want the system to be better for everyone, especially when we look at the gaps in the places people are really let down. Families get overwhelmed and exhausted, and changes need to happen on the systems level.

These four participants spoke to professional and personal experience with the realities of the limitations hospice providers have and that this is not always clear to people:

I think people have a lot of misconceptions about hospice, that hospice will come in and do everything. Unfortunately, hospice comes in and teaches you how to do everything and you have to figure it out how to do the everything. And they'll be as supportive as they can be but they can't be there 24/7 so can you afford around the clock nursing care or can you afford someone like me who will work on sliding scale or even take barter?



**Saves money and eases burden**

All participants felt strongly that alternative end of life options such as death midwife or doula, end of life guide, home funeral and green burial offer a substantial cost savings for families. One participant noted that her father's funeral had cost \$12,000 nearly a decade ago, but that was something he had money for and had planned. The plots at her green cemetery are \$1065 for a Veteran to be buried and \$2700-\$2900 for a single plot, depending on the location. All participants noted that families should not have to face the burden of debt in the face of loss, and that alternative end of life care options offer a space for transforming grief, if they are presented with the option. A participant gave this example:

If there has been a car accident and life support is being pulled at eleven o'clock, "Well, we better call the funeral home then." And the hospital gives you a list of funeral homes and you're just randomly picking one because you don't know and they tell you how it's going to be. I think the social workers have an obligation to let the family know they can spend time with the person, wash the body, make a shroud, anoint her with oil, put flowers around her. If a mother can't afford a \$7000 funeral, she can bring her son home, and she has something to do. She can bring her son home for two more nights and that's huge, in terms of the healing process for her.

**Changes grieving process**

All participants reported that "something" during a home funeral or green burial that shifts the grieving process. This was noted as three things: one being that it allows space for the person to grieve in their own time:

Part of what happens with a home funeral is that the life goes on in the house around the dead person and that's a really important part of how people restructure their relationship with the person who's missing and the other who are now left without them because they're all living in and around the person.

Second, there was that there is a shift of energy that can be experienced that is lost if the body is not there:

From my own experience as the caregiver, one of the real benefits for me was that first night after my grandfather died when I had been caring for him for four years, twenty four/ seven. That first night that he was in the house and he no longer alive was a real shift in the energy of our relationship, and because he was still there in our home, I could sit with him and really absorb the fact that there was no longer tending of his physical body that I needed to do and I could just be with still love of our relationship and feel that with the grief.

Third is that it allows the space for people to more spontaneous and personal in their grief, as opposed to having to work with the schedule of the funeral home and cemetery:

People ask, 'Can I do this? Can I do that?' I say, 'You can do anything you want as long as it's not disrespectful or disrespectful to anyone else's grave. If your buddy died and you buried him and you drank beer together, if you want to stand there and drink a beer together, I don't care! You can't have a keg party out here, but if that's your ritual. If your ritual is you want to sit out there all night by the grave, you're more than welcome to.' Just taking away any thought of what you 'HAVE' to do when someone dies. That

you ‘have’ to be embalmed, that you ‘have’ to have a vault that you have to do this, that or the other.

Three participants specifically stated that families do not always know what to ask or feel comfortable, “but if they don’t ask, it won’t happen.” One participant shared that after her grandfather who had been a Holocaust survivor died at home, and during the home funeral, the family created an impromptu memorial to family and friends he had lost at that time by writing their names on his plain wooden casket.

**People who open up to these options share common experiences.**

Six of the eight participants who had experience educating or supporting someone through a home funeral all share this basic sentiment:

If somebody has had a home funeral they often will make contact with me and want to share how the experience was and they seem they're always the same themes and it's really interesting to hear that. I can always predict they're going to say. They always say, “I can't imagine doing this any other way now that I had this experience. I was really surprised by how natural it felt and I had some anxiety about what it was like to take care of a dead body, and it was so fine. Not only fine, but it felt really good to be able to do something and have this really sacred special time”. Like everybody said it without prompting.

**Empowering people to reclaim what was**

Empowering people to reclaim what was means all participant’s expressed that historically, people cared for their own dead, and there is value to that process and impacts from the institutionalization of death care. All participants shared the perspective that the aim

of the home funeral movement is to empower families to once again care for their own dead at home; recognizing that “home” may be a nursing home and “family” is not simply blood-relatives. This movement has been shaped by women, through education, and advocating for legislation. The participants insights for shaping the role and responsibilities of social workers will also be examined, as well as their perceptions of the funeral industry.

### **Women’s roles**

All participants noted that this movement to reclaim alternative end of life options is being led by women. They all view it in parallel to the institutionalization and professionalization of birth, with one participant noting that women were also fighting to be more involved in politics and for the right to vote at this time. The role of women in this movement is also seen as reclamation similar to that of the home birth movement:

Not long ago, women did not need to take course on natural birthing or end of life care; these roles have been shifted to professionals People need to be supporting this and it’s a movement to returning to what was.

Four of the eight participants are in their 60s or 70s. This work gives them much needed sense of purpose at this time in their life, this reclamation of their role in caring for the dead:

I've been politically active my whole life, and this is the perfect beautiful thing to have my day be touched by something I believe in every way; environmentally, economically, socially, spiritually, culturally, for the future of humanity.

### **Education**

Participants agreed that public education was the key to making alternative end of life options more available to people. Every participant is a member of the National Home Funeral

Alliance that works to provide education and support. Participants were involved in local state chapters, as well as with the Funeral Consumer Alliance and the Green Burial Association. Two of the participants offer experiential training on becoming more comfortable with death through writing and/or meditation. Five other participants regularly host Death Cafes in their community. Two participants work with groups that have throughout websites where a person can learn what is needed for a home funeral on their own. However, they also recognize that this is not the case yet, so there is a need for providing the service while empowering people to do as much as they want with the process:

The more we spread this knowledge the more accessible it makes this to the masses. Yes, this is possible to do this, it's within the realm of our rights, and actually it just makes sense. I mean, when you boil it down it just makes more sense.

### **Advocating for legislation**

Seven out of eight participants were active with legislation to ensure people have access to home funerals and green burials. "We educate people on what's legal and we also worked to change the laws when they got more constricted in 2010." One participant worked in her state to improve people's access to end of life supplies by challenging laws that require people purchase these items from state licensed funeral directors. Another worked to change burial depth requirements that were unnecessary and burdensome for people seeking green burial. This participant also noted the importance of challenging hospitals and nursing homes that may not have changed their policies to be in line with laws that support people in having a home funeral or green burial. These seven participants noted the support of national level

organizations such as the Green Burial Council, the National Home Funeral Alliance, and the Funeral Consumers Alliance.

### **Shaping social worker's role and responsibilities**

Participants recognized the value of social workers having a firm knowledge base regarding alternative end of life options, as they are on the front lines and there with families when difficult decisions need to be made. Social workers also complete advance care directives with people, which ideally would also include a person's wishes for final disposition. One participant said, "Social workers should not be afraid of telling people about the options after death, we need to talk about death. Advance directives are great, but take it one more step, because the hospice people leave and then the funeral people come, because people don't know there is an option here." Joining in online discussion groups, attending community trainings, death cafes, hosting a death over dinner talk, using prompts from, "The Conversation Project" are all ways participants identified for social workers to learn more about alternative end of life options.

Another noted Atul Gawande's 2014 book, "Being Mortal" and using the principles laid out by the author to approach a person as someone to engage in their care, not just someone to fix, "because people want to be home when they die and they might want to be home after they die." The value of vigil for the living in the grief process was noted by all participants, and one added that social workers consider, "The greatest gift we can give anyone is to add to the peace and ease of a person crossing over and their loved ones." Three others noted that social workers should explore their own feelings and perceptions of death, as well as be open to spiritual and religious practices and end of life rituals, because, "It's really great to have more

tools!” Furthermore, five participants spoke to the value of working with the person and their family to understand what will support the person in their next phase of life. One participant sums this up as:

Be patient led and never be afraid to ask, because it’s really ok to not know everything, it’s impossible in fact! Everyone is so different, you could be doing this for a lifetime and you’re not going to know it all.

### **Funeral Industry Perceptions**

All participants shared their perception that the local funeral home was not seen as an enemy, but that the commercialized funeral industry has a way of capitalizing on people’s unfamiliarity, lack of planning, and shock. There was also consensus on the idea that the industry sanitizes and shields the public from death. One participant phrased it as:

People don’t have experience making these choices and they're making them under duress and it’s a perfect recipe for people really getting confused, or somewhere along the continuum of being confused or absolutely hoodwinked, to spend more money.

Five out of the eight participants noted that there is no need for embalming a body, but state laws in seven states still require a state licensed funeral director for transporting a body and getting a death certificate. Three participants reported being in states where this is the case, and even in a major city in the Midwest, there are only two funeral homes that are supportive of people who chose home funerals. Another participant noted that a local funeral director in her area stated that he could, “just charge people more for something else” in response to changes in that state’s law that allow families to make or bring their own casket. Despite that experience, the participant does have local funeral home directors who she has

found to be supportive. Two other participants expressed the desire to work more closely with funeral home schools and cemeteries, to educate them and combine forces:

We are trying to convince the cemeteries that they don't need the cement vault and the metal caskets, because people want to be returned to the earth. So these movements of returning to the most natural place, there all a part of it. It's physical, its emotional, its social, its cultural, its spiritual, so every little piece is a part of that process.



### **Discussion and Implications**

The findings of this research suggest that the experiences of alternative end of life practitioners validates the dearth of literature that these options are a solution for filling in the gaps in for person-entered end of life care. Alternative end of life practitioners have the flexibility to meet non-medical spiritual, emotional and practical needs in a person-centered way, thereby supporting caregivers as well as the person dying. Palliative care literature examining quality of life found that unmet needs and relief from pain, fatigue and insomnia were eased by close relationships, and noted that current models of care do not allow for these types of relationships to develop due to cost constraints (Catania, et al., 2015).

This research validates the literature regarding people's wish to die at home. While the alternative end of life practitioners will work wherever a person calls home, they do aim to keep people from succumbing to unwanted medical procedures through their advocacy and deliberately intentional approach to Advance Care Planning. While the impact of alternative end of life care practitioners have on cost savings is not a known factor, their impact on shaping the cultural perceptions about death is happening incrementally, and especially more recently, according to the participants experience. This shift aligns what people want with potential cost savings and better care outcomes.

In-home palliative care program models with high levels of flexible supports (including 24/7 support, social workers, volunteer's to talk with, reiki energy therapy) were found to significantly reduce costs by \$12,000 a year per person, but these are small pilot studies and not accessible to most people (Lustbader, et al., 2016). With both people dying and their caregivers wanting to be at home with support for practical and emotional support through this part of their journey, the results of the current study suggest that alternative end of life options offer a cost

effective means for them to achieve that goal (Bausewein, et al., 2015; Gomes, et al., 2013; Holdsworth, 2015). When family caregiver's were interviewed 12-24 months following their loss were asked what had been most important to them through this process, they reported that their loved ones' wishes honored, and being included in decisions; support and assistance at home; practical help with transportation, medicines, and equipment; the ability to attend to personal care needs (bathing, feeding, toileting); honest information; continuous access to caregivers; a sense that they were being listened to; privacy; and continued contact after the death (Fine, 2004). This falls in line with the findings of this study in that participants who offered these types of supports are a vast source of support for people at this time and impact their healing and grief process.

While the scope of this research limits an adequate exploration of ritual, grief and spiritual transitions, the conceptual framework of transpersonal theory speaks to the value of reclaiming natural life processes to impact society on multiple levels. Alternative end of life options offer a means of person-centered support that allows time for the grieving process to unfold more on their own time and spontaneous use of ritual to support a more complete grief process (Hunter, 2007). These findings validate research that speaks to the impact of embracing this time of transition as a natural and sacred part of life allows people to experience death without fear, so they can die better and live better (Cozzolino, Blackie, & Meyers, 2014;. INEDLA, 2016). The results of this current research suggest that alternative end of life options offer means for people to allow time for transition, for the person dying as well as those around them. Supporting people in their home is seen by these participants as a natural extension of hospice; however the role of alternative end of life practitioners is not limited by the highly regulated hospice requirements and aims to fill in gaps, if a person choses.

### **Implications for Social Work Practice**

Social work as a profession has a commitment to have a multidimensional role as clinicians, educators, researchers, advocates, community leaders, and policy analysts, and the values, skills and training of social work are needed to in palliative and end of life care (Gwyther, et al., 2005). This multidimensional approach enables the social worker to plan biopsychosocial spiritual interventions with the person and their support network in collaboration with care providers and/or the interdisciplinary team with consideration of the diverse background and needs of people getting services (Gwyther, et al., 2005). Social workers have an ethical responsibility to the profession and the people they serve to understand and present the full range of options for end of life care and disposition, including home funeral guides, green burial, death midwives and doulas. This alternative end of life options are in line with the recommendations of the Institute of Medicine's 2014 report, "Dying in America."

Social workers have specific training and education regarding group dynamics, family systems and developmental needs of each family member, making them a vital member of the palliative care team because they recognize that advance care planning is a personal and complex process and more than simply filling out a form (Wallace, 2016). Social workers understand that there are multilevel interacting systems that have an influence on a person and their families' feelings about advance care planning and can support them in having conversations in line with their culture, values and options. Social workers and health providers all have a responsibility to educate people about misinformation that abounds in regards to advance care planning, illness, disability, death and dying (IOM, 2016). Social workers must be supporting people's options for alternative end of life options, and can do so by ensuring the laws support this. They can also ensure people are aware of these options by connecting to local or national organizations such as

the National Home Funeral Alliance, the Funeral Consumer Alliance, and the Green Burial Council.

### **Implications for Policy**

The aim of the Institute of Medicine (IOM) is to, “provide independent, objective, evidence-based advice to policy makers, health professionals, the private sector, and the public” (2014). The expert committee implores those working at every level of health care and health care policy to improve access to high quality medical and social services to people and their families, as evidence shows this improves quality of life and creates a health care system that is more sustainable (IOM, 2014). The recommendations include: ensuring delivery of person-centered, family-oriented care; improving clinician-patient communication and advance care planning; expanding professional education and development; specific changes to fee-for-service payment models and policies that support payment systems that reward excess care; public education and engagement to normalize death and dying (IOM, 2014).

Improving funding for people to access home based palliative care and other home and community-based care would help people living with chronic illness, disability and allow people to have more options to get their support needs met as they age. The Commonwealth Fund surveyed nearly 11,000 Medicare beneficiaries over 14 years, and found that people were often moved to nursing homes, sometimes temporarily, but usually permanently, and needed to use Medicaid funds to get this paid for (2016). The report offers two options that would allow Medicare to intervene earlier and offset savings in Medicaid and Medicare; an optional supplemental benefit for home and community based services (HCBS) and an expansion of the Medicaid Community First Choice program to people with incomes up to 200 percent of

poverty, as most state programs have high copays or “spenddowns” for HCBS that are inaccessible to people (The Commonwealth Fund, 2016).

While most alternative end of life practitioners will not likely see Medicare or insurance reimbursement in the near future, allowing more flexibility for people to pay for supports using HCBS at the end of life would be a significant step in recognizing value the of alternative practices. For example, people with disabilities living in Minnesota can utilize waiver budgets through the Consumer Directed Community Support (CDCS) option where approval to use funds for alternative healing supports such as aromatherapy or massage therapy (Minnesota Department of Human Services, 2010).

### **Implications for Research**

Future research could evaluate the impacts of alternative end of life options on a larger scale from the perspective of the practitioners. Research focused on the experiences of the person who has made advance care plans and would like to utilize alternative end of life options to further explore their perceptions of person-centered care at the end of life. The relationship between alternative end of life practitioners and hospice professionals and volunteers is an area to be explored. The impact of alternative end of life options person-centered care at the end of life and how this affects the experience of caregivers and/or family member’s grief process is another area to consider for future research.

### **Strengths and Limitations**

The small sample size of the study limits the ability to generalize results. Qualitative research requires a sample of participants who have knowledge of the subject to gather information for conceptual and theoretical purposes, and not intended to be a representative sample (Padgett, 2008). The impacts of alternative end of life options are described from the

perspective of the practitioners, and not from the perspective of the people using the services. Furthermore, multiple interviews are recommended in Phenomenological Analysis, but not within the scope of this research. The majority of the interviews were conducted over the phone, so the value of Naturalistic Observation was diminished in this research (Padgett, 2008).

Qualitative research using personal interviews with alternative end of life practitioners offers a unique insight into these little known options from the perspectives of the research participants. It allows the complex phenomenon in regards to alternative end of life care that is not possible to capture in quantitative research. The person-centered nature of these options is not best captured by standardized measurements (Padgett, 2008).

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## Appendix A

**ST CATHERINE UNIVERSITY****Informed Consent for a Research Study**

**Study Title:** Alternate Endings: Insight into Alternative End of Life Care Options

**Researcher(s):** Rachelle Henkel, LSW

You are invited to participate in a research study. This study is called Alternate Endings: Insight into Alternative End of Life Care Options. The study is being done by Rachelle Henkel, LSW, a Master's of Social Work student at St. Catherine University in St. Paul, MN. The faculty advisor for this study is Rajean Moone, Ph.D, LNHA at St. Catherine University.

The purpose of this study is to gain insight into the impacts of alternative end of life options from the point of view of the people providing these services. This study is important because this growing movement is little researched and not very well known to people. Approximately 8-10 people are expected to participate in this research. Below, you will find answers to the most commonly asked questions about participating in a research study. Please read this entire document and ask questions you have before you agree to be in the study.

**Why have I been asked to be in this study?**

You were selected based on your membership with the National Home Funeral Alliance, where providers of alternative end of life services have listed contact information, or as a person working or volunteering with metro area hospice organizations.

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

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

- Participate in a one hour interview in person or via telephone
- Agree to allow the interview to be recorded
- In total, this study will take approximately one hour over one session.

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

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

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

Participation in the interviewing process and sharing your experiences and perceptions about working with people at the end of life may be emotional and is a potential psychological risk. Participants are urged to contact the National Alliance on Mental Illness for support at 1-800-950-NAMI (6264) or [info@nami.org](mailto:info@nami.org).

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

Participation in this study may not offer direct benefits to you, but increasing the awareness and research on alternative end of life options offers the opportunity for more people to access these services and include this in their advance care planning.

**Will I receive any compensation for participating in this study?**

You will not be compensated for participating in this study.

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

The information that you provide in this study will be transcribed from the recordings and information from each interview will be evaluated and presented as to the themes that are found. Quotes and specific stories will be used, but information will be presented in a confidential manner using no names. I will keep the research results in a locked in a desk drawer and only the research advisor and I will have access to the records while I work on this project. I will finish analyzing the data by June 30, 2017. I will then destroy all original reports, audio recordings and identifying information that can be linked back to you.

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

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

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

**How can I get more information?**

If you have any questions, you can ask them before you sign this form. You can also feel free to contact me at 715-220-8743 or henk3910@stthomas.edu. If you have any additional questions later and would like to talk to the faculty advisor, please contact Rajean Moone at 651-235-0346 or moon9451@stthomas.edu. If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or jsschmitt@stkate.edu.

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

**Statement of Consent:**

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

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Signature of Participant

Date

---

Signature of Researcher

Date

## Appendix B

**Email Solicitation**

Hello,

My name is Rachelle Henkel, and I am conducting research on alternative end of life options titled, *Alternate Endings: Insights into Alternative End of Life Options*. This research is a part of the degree requirements for the University of St. Thomas and St. Catherine University Master of Social Work program in St. Paul, MN, and is being done under the supervision of faculty member Rajean Moone, PhD., LNHA. I began this journey researching home funerals and hospice, and I have found your contact information from the National Home Funeral Association's website. I am reaching out to you to ask that you participate in one 45-60 minute interview regarding your training and experience as a practitioner of alternative end of life services.

The interview will be conducted in a private location convenient to you and will be recorded and transcribed as part of the research process. There is a letter of informed consent detailing protections to and rights of participants that I will email you and review when we meet.

Please email me or call me at 715-220-8743 if you are interested in participating in this research project or have any questions. The interviews must be conducted by March 20, 2017.

Thank you for considering sharing your experience,

Rachelle Henkel, LSW



Appendix C

**Interview Questions**

1. Can you tell me about what brought you to this field?
2. How long have you been doing this work?
3. What is your background?
4. What alternative end of life options do you use?
5. How do you see alternative end of life options complementing mainstream options?
6. Describe a situation where alternative end of life options enhanced a good death.
7. Can you talk about situations where you would not recommend alternative end of life options?
8. How do you see alternative end of life options impacting the living and/or caregivers?
9. If you could influence the education of social workers interested in alternative end of life options, what advice would you give them?
10. What thoughts do you have in regards to making alternative end of life options more widely available?