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Hannah Myers
Caring for our Dead and
Dying: The Emotional
Outcomes of Providing
End of Life Care

ABSTRACT

The purpose of this study was to determine whether increased exposure to death through professional experiences relates to an individual's anxiety and perceptions of death and dying. It was hypothesized that increased exposure to death and dying through providing Hospice and/or funeral services would correlate with lower death anxiety and more positive attitudes about end of life concerns.

A quantitative measure, Thorson and Powell's Revised Death Anxiety Scale (RDAS), and qualitative open-response questions were distributed via an online survey program. 61 participants completed the online survey, 20 of whom had completed work in the fields of Hospice or funeral services, and 41 of whom had no experience in these arenas of professional experience.

Statistical analysis revealed that those participants with experience in end of life care had significantly lower RDAS scores than those without experience in these fields. Further, older participants and those with a religious affiliation scored significantly lower in terms of death anxiety. This researcher suggests that clinical social work students should have increased death education and be encouraged to reflect on their own experiences and belief systems surrounding death and loss, as death and dying are inevitable subject matter in the field of clinical social work.

Keywords: Death Anxiety, Hospice, Funeral, Death Attitudes

CARING FOR OUR DEAD AND DYING:
THE EMOTIONAL OUTCOMES OF PROVIDING END OF LIFE CARE

A project based upon an independent investigation,
submitted in partial fulfillment of the requirements
for the degree of Master of Social Work

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Chapter I: Introduction

Nature of the Problem

As Imber-Black (2004) states, “Increasingly our culture has allowed the funeral industry to shape mourning rituals, such that they express more about capitalism and the denial of death than about true authentic healing” (p. 342).

Many believe the United States of America has become a society that prefers to ignore and avoid the reality of our mortality, due to the “terror” we experience around the thought of non-existence (Neimeyer et al., 1994). Fear of death and death anxiety have become central features of American society, which some argue is most readily evidenced by denial of death, Nursing Homes, and the Funeral Home industry’s popularity (Imber-Black, 2004; Moller, 1996). When a loved one dies in America, it is increasingly occurring in Nursing Homes and Hospitals. Further, following the death, most family members and friends relinquish the body to the Funeral Director, who will likely embalm the body and prepare it for the funeral in a sterile Funeral Home basement away from those who knew and loved the deceased. Those who oppose this approach argue that the bereaved are left mourning their loss, detached from the body of the loved one, and often with limited control over the upcoming funeral process. Thus, it is argued that the “traditional” or “conventional” death and funeral in American society tends to be one of tremendous cost, controlled emotion, limited time frame, and minimal family and friend involvement (Imber-Black, 2004; Morgan, 1988; Bergen & Williams, 1981).

Although many believe that funeral rituals are essential in facilitating healthy grief resolve for the bereaved (Gamino, Esterling, & Stirman, 2000), others posit that this type of traditional funeral limits our ability to properly grieve the death of our loved ones (Bergen & Williams, 1981; Moller, 1996). Further, research has indicated that lack of education and self-reflection around our own perceptions and experiences with death within the social work profession relates to greater discomfort and fear when confronted with the realities of death and dying (Simons & Park-Lee, 2009).

Research Question and Hypothesis

Do these funeral rituals and avoidance of death-related experiences further contribute to distancing ourselves from the realities of death and further increasing the “death anxiety” which many claim runs rampant in our society?

Perhaps more direct contact with dead, through working with those who are dead or are dying and death education, would correlate with lower death anxiety. Research has found that students training to become funeral home providers have lower rates of death anxiety than do the general university student population (Bassett & Dabbs, 2003) - a finding that suggests that more experiences directly dealing with death may lower the level of anxiety associated with our mortality. When we confront a fear, it provides us an opportunity to resolve the distress we feel and grow to accept the reality of death. In contrast, avoiding death-related matters may serve to increase our anxiety and block our society from facing end-of-life scenarios which cause unpleasant emotions.

In more recent years, to combat the distance we place between ourselves and death, there has been a shift towards caring for our dead and dying in our homes or more personalized settings, such as Hospice Homes, or with Hospice care in the community. “Home funeral”

providers and funeral consumer movements have been established, to provide education and training for those who desire to care for the dead and dying in their own homes or through the use of alternative methods (such as green burial techniques, home funerals). These funerals are organized and carried out within the community, by the families and friends of the deceased, often in their homes, and with limited involvement of the funeral home industry (Bergen & Williams, 1981; Morgan, 1988). These alternative funerals are legal in almost all states, and organizations such as Passageways and Crossings have formed to educate the population of their options when choosing the funeral ritual to recognize the death of a loved one. The home funeral movement focuses on directly caring for the dead, and confronting the realities of death without makeup, embalming fluids, elaborate ceremonies, and thousands of dollars' worth of expenses.

Purpose of the Study

This study intends to compare the death anxiety scores between those who care for the dead/dying, such as alternative/home funeral providers, conventional/tradition funeral home providers, Hospice social workers, as compared to those who do not engage in this area of work. The research will explore whether we fear death less if we are exposed to it more, through caring for the dead and those who are dying.

In the field of clinical social work, many clients will present with difficulties regarding unresolved grief following the death of a loved one or difficulties confronting their own illnesses and end of life decisions. It is important that we understand the American culture around death, dying, and available death rituals. Specifically, it can be beneficial to understand what the available services are and who provides, these services. Of greatest importance, providers should reflect and be aware of their own perceptions and emotions which arise around death-related material. In a society which some claim is driven by death anxiety, it is important to be aware of

what funeral provider's attitudes are towards death, as well as our own, should we chose to work with those who are bereaved and those who are dying.

Traditional and alternative funeral providers and hospice workers are often a great source of support for the bereaved (Lensing, 2001). One can imagine that the provider's attitudes and emotional reactions to death will affect the experiences of the population that they serve. It is essential that we, as providers, explore our own attitudes about death in order to best serve our clients, as well as ourselves. It is the intent of this study to prove the effects that close work with the dead and dying has on one's death anxiety and perceptions of death, and to further assert that exposure to this arena of work, through self-exploration and education, would be beneficial in the social work professional's educational plan.

Chapter II: Literature Review

Introduction

The field of death studies encompasses a broad range of literature, including research on death anxiety, attitudes about death, hospice social work, funeral directors, customs and rituals observed in different societies, as well as grief and bereavement. As broad as the range of research is, many of the findings overlap, often supporting the view that more exposure to death correlates with greater comfort around death-related material (Bassett & Dabbs, 2003) and conversely that less exposure to death-related experiences and stimuli can relate to higher anxiety and discomfort with death (Kirchberg, Neimeyer, & James, 1998). These findings support this study's hypothesis that funeral home providers and hospice social workers would have lower death anxiety scores and greater comfort with death based on their intimate work with those who are dead and those who are dying. This finding could further indicate that involvement in funerals, death education and grief practices which directly address end of life issues, without disguise, could correlate with less distress and higher degrees of death acceptance.

Death Rituals: Costs and Customs

Much of the research in the field of death studies pertains to the relationship between funeral rituals, grief outcomes and perceptions of death. Death rituals, such as funerals, and hospice services have been found to be important elements in resolving grief and facing the realities of death and dying across many cultures throughout history (Matsunami, 1998;

Msimanga-Ramatebele, 2009; Romanoff & Terenzio, 1998). Research supports that hospice services, funerals and other death rituals facilitate healthy grieving processes in a variety of contexts and assist the bereaved in “making meaning” of their loss (Gamino, Easterling, & Stirman, 2000; Irion, 1990). Studies further suggest that death rituals confront the inevitability of death and those who work in the funeral and hospice industries tend to have lower intrinsic and extrinsic fear of death (Bassett & Dabbs, 2003; Payne, Dean, & Kalus, 1998; Pepitone-Arreola-Rockwell, 1981).

Throughout history and across the world, every society partakes in some form of observation of the death of a society member, whether through a large celebratory ceremony or an intimate gathering of mourners. In his book, *International Handbook of Funeral Customs*, Kodo Matsunami (1998) discusses the general perspectives on death held by the major world religions as well as the corresponding funeral practices in individual countries (organized by region: Asia, Oceania, Africa, Middle East, Europe, Commonwealth of Independent States, North and Central America, South America). Matsunami (1998) identifies several major trends which he predicts will continue to influence the funerals and rituals observed around the world. An excerpt from Matsunami (1998) predicts the following trends of the modern global funeral to conform to a standard of simplicity and distance from previous culturally held practices:

Following modern trends, [funerals] will develop in the direction of uniformity and coordination... The reason for this is that in the funeral customs prevalent in the industrialized and urban areas, regardless of the cultural or religious heritage they may retain, surprisingly common features and similarities can be seen. The traditional customs that have hitherto been practiced continue to be simplified, and sometimes under the

pressure of commercialism they are becoming mere formalities. Such a tendency is particularly noticeable in highly modernized countries. (p. 193)

In the last several decades, funeral traditions have shifted in the world, towards becoming more industrialized and less personal (Fulton, 1988; Park, 2010). Romanoff and Terenzio (1998) state that this shift away from intimate death rituals has resulted in “insufficient grieving and inadequate resolution of grief” (p.699). The most extreme of this trend can be evidenced in the phenomena of “drive through visitations” in which individuals can view the deceased through a drive-through window, without even leaving the comfort of their own car. Imber-Black (2004) states that these rushed funeral practices result in “incomplete mourning and unhealed loss” (p. 344). In addition, an increasing number of American deaths occur in long-term care facilities and hospitals away from loved ones, shielding survivors from the realities, emotions, sights, and smells of death (Moller, 1988).

Another trend over the past several decades has been the rising cost of the traditional funeral in the United States. According to the Federal Trade Commission (www.ftc.gov), “funerals rank among the most expensive purchases many consumers will ever make”. The modern day traditional American funeral costs anywhere from \$6,000 to over \$10,000. Many Americans feel pressure to purchase expensive flowers and hire a limousine , along with the costs of the casket, cemetery plot or urn, and the funeral service provider’s fee. The FTC outlines a consumer’s options for funeral, which include “full service” traditional funeral, direct burial and direct cremation, all of which include funeral home involvement. The website does not mention the less expensive and often more intimate alternative of a “home funeral”.

The “home funeral movement” challenges the tendency for Americans to distance themselves from death along with paying high costs to outside parties, and instead confronts

death and cares for the dead directly, in the home. Despite a growing wealth of public opinion pieces and documentaries, there are surprisingly few research studies exploring “alternative” funerals. Bergen and Williams (1981) conducted a study in which they interviewed 64 members of a congregation where alternative funerals were often the ritual of choice. In their research, Bergen and Williams (1981) discovered that 70% of the participants considered alternative funerals to offer “more strength, support, and sanctions for griefwork for the bereaved than conventional funerals offered” (p.75). The remaining 30% of participants preferred a combined conventional/alternative funeral approach. Not a single respondent believed that a purely conventional approach would provide the most support and opportunity for griefwork. Other than this study, it has been difficult to locate research conducted on alternative, or home, funeral practices.

Studies suggest that death rituals and direct reflection on death and dying may relate to lower death anxiety scores. Bassett & Dabbs (2003) posit that, “Greater exposure to death, which makes sustained denial more difficult, could result in a less threatening conceptualization of death” (p.356). This view could support that partaking in more alternative and “hands-on” home funeral practices, as well as working in the field of hospice social work, could correlate with lower death anxiety scores.

Death Anxiety and Occupation

The concept of “death anxiety” and fear of death have been widely debated and studied for decades. Put quite simply, death anxiety can be defined as a tremendous, often unconscious, fear of death that some believe is the central motivating force behind all that we accomplish in our lives (Bassett & Dabbs, 2003; Neimeyer, 1994). Since the inception of the death anxiety concept, numerous studies have explored the relationship between death anxiety and

characteristics of various populations: gender, age, marital status, religiosity, and of course, occupation. Various researchers have studied fear of death and death experiences among those who care for the dead and dying, namely healthcare professionals and funeral directors.

(Neimeyer, 1994)

In terms of research exploring the relationship between occupation and death anxiety levels, the hypotheses in many of these studies fall along two opposing poles. In much of the empirical literature, researchers hypothesize that more experiences with death and desire to work with the dead and dying would correlate with lower death anxiety scores (Payne et al., 1998). However, others assert that close proximity to death and being confronted with the reality of one's own mortality would raise an individual's death anxiety level (Pepitone-Arreola-Rockwell, 1981; Selby, 1977). Further, some researchers propose that individual's "preselect" their occupation based on their innate comfort with death and dying (Bassett & Dabbs, 2003).

Death anxiety is arguably the cause and result of the distance that we have put between ourselves and caring for our dead. In other words, we avoid death due to fear of our own mortality, and this avoidance leads to greater unconscious fear of our own inevitable deaths. This raises the question of whether proximity to death heightens or lowers death anxiety levels. Research suggests that students training to become funeral home providers have lower rates of death anxiety than do the general university student population (Bassett & Dabbs, 2003)- a finding that the authors propose has three plausible explanations. Either the findings suggest that more experiences directly dealing with death may lower the level of anxiety associated with our mortality; conversely, those with lower death anxiety may choose to work closely with the dead, dying and bereaved, as they are comfortable in these roles. Or, funeral home students may be

prone to under-report their death anxiety so as to justify their appropriateness for their chosen profession. (Bassett & Dabbs, 2003)

Findings generally suggest that healthcare professionals, funeral directors, and those who work closely with the dying score lower on death anxiety scales (Kootte, 2001; Payne et al., 1998; Pepitone-Arreola-Rockwell, 1981). However, Harrawood (2005) conducted a study in which 200 funeral home directors throughout the country were found to have higher than average death anxiety scores. The highest scores were found among older participants and those in “close personal romantic relationships”. These findings are in direct contrast with the aforementioned research suggesting that funeral home directors and hospice workers have lower death anxiety scores.

In studies comparing nurses and hospice nurses, findings support that those working in hospice settings report lower fear of death and discomfort associated with thoughts of death and dying. Payne, Dean and Kalus (1998) compared attitudes around death between hospice nurses and emergency nurses, using the Death Attitude Profile-Revised Questionnaire and a short interview. Their results suggest that hospice nurses have lower death anxiety scores and greater comfort around death and dying. Carr and Merriman (1996) conducted a similar study in which they found that hospital nurses had higher death anxiety than hospice nurses, and were more reluctant to spend time with dying patients. Kootte (2001) administered Thorson and Powell’s (1984) revised death anxiety scale (RDAS) to a sample of 87 hospice social workers, finding that this population scored “considerably lower” than the general nurse population.

Studies have found high death anxiety scores among those in the mental health professions compared to those working in the funeral home profession (Pepitone-Arreola-Rockwell, 1981). Kirchburg, Neimeyer, and James (1998) as well as Simons and Park-Lee

(2009) found that students in the mental health field generally reported high levels of death anxiety. However, both studies found that those who had personal experiences with death and a desire to work in hospice or grief counseling reported lower levels of death anxiety. Both studies suggested that beginning counselors explore their attitudes around death and dying as they will inevitably confront this topic throughout their careers.

Research has also been done to study “death orientation” among helping professionals, specifically comparing level of fear of death, proximity to death, and resulting attitudes and behaviors (Eggerman & Dustin, 1985; Neimeyer & Dingemans, 1980). Interestingly, Eggerman and Dustin (1985) found that higher levels of fear of death among physicians correlated with more consideration and deliberation around informing a patient of a terminal diagnosis. G.J. Neimeyer, Behnke, and Reiss (1984) found that physicians who had higher fear of death scores were more likely to employ avoidance techniques, such as becoming engulfed in their work and were less likely to attend patient’s funerals. As helping professionals, it seems that it is important to reflect on our own death anxiety and fear of death, as research seems to indicate that these factors will likely influence the way in which we relate to clients who are dying as well as the bereaved.

This literature review supports that research conducted on funeral providers, hospice social workers and death anxiety suggests that there exists a correlation between the amount of experience/direct contact with death and lower death anxiety scores (Bassett & Dabbs, 2003; Kootte, 2001; Simons & Park-Lee, 2009). Although Harrawood (2005) reports higher death anxiety scores among funeral home professionals, this is the only study located by this researcher which supports that finding. Research suggests that when the bereaved have more control in planning and carrying out the funeral, their grief outcome tends to be positively influenced

(Bergen & Williams, 1981; Gamino et al., 2000). There are also research studies which assert that avoidance of death is linked with higher death anxiety scores (G.J. Neimeyer et al., 1984). These findings support the hypothesis of this study and suggest that perhaps more direct and honest views of death may be associated with lower death anxiety and more positive attitudes about death. This study comparing death anxiety scores and death attitudes between hospice social workers, conventional and alternative funeral providers will build upon these findings and continue to assess whether direct contact with death correlates with lower death anxiety scores and greater comfort with death.

Chapter III: Methodology

This study was designed to answer the research question of whether professional experience working intimately with death would have any effect on an individual's anxiety and beliefs regarding death. In addition, demographics and open responses were collected to account for other factors which may influence experiences with death, fear of death, and exposure to end-of-life issues. The researcher hypothesized that more exposure to death through professional experiences would relate to lower death anxiety scores, as measured by Thorson and Powell's 1994 Revised Death Anxiety Scale (RDAS), and more positive beliefs and attitudes towards death, as measured through responses to an online survey.

Design

This experimental, qualitative and quantitative, study explored whether professional exposure to death, through involvement in Hospice or funeral work, correlated with lower death anxiety scores (DAS) and more positive attitudes towards death than those who had not participated in these areas of work. Participants were divided into two groups. The first group was composed of those who had worked professionally with at least one client either in the Hospice-related field or conducting funerals, whether alternative or traditional style funerals. The second group was composed of those who had not engaged in this type of work with the dead and/or dying. The survey developed by the researcher and inclusive of Thorson and Powell's 1994 RDAS (Neimeyer, 1994), was administered to participants through SurveyMonkey. (See

Appendix E for complete questionnaire). RDAS used with permission granted by the researchers on page 43 of Neimeyer's 1994 Death Anxiety Handbook.

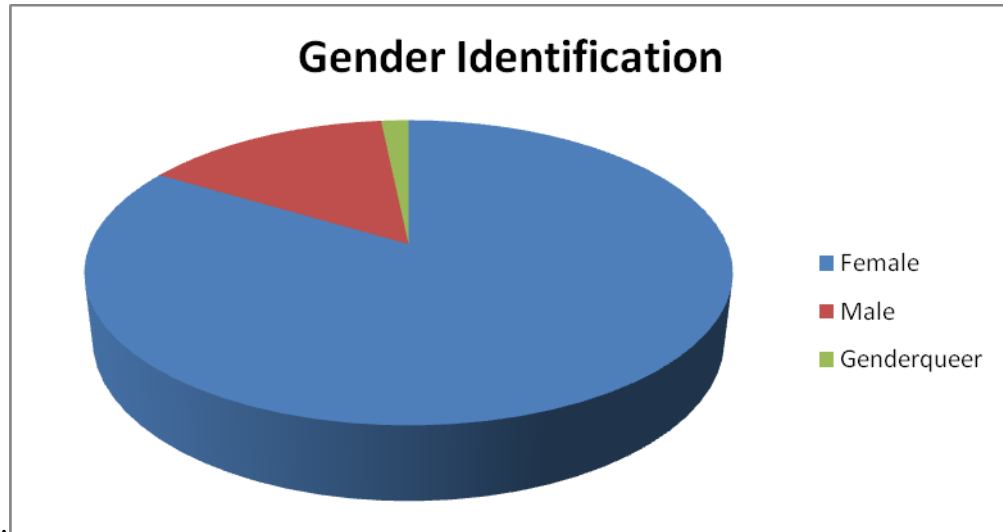
Sample.

A total of 61 participants completed the survey sufficiently enough to be included in the study (N=61). All participants met the eligibility criteria of being greater than 18 years of age, English speaking, residing in the United States, and being comfortable and willing to answer questions regarding death. Of the 61 respondents, 20 had completed work in the Hospice or funeral field (n=20) and 41 had not completed work in either of those fields (n=41).

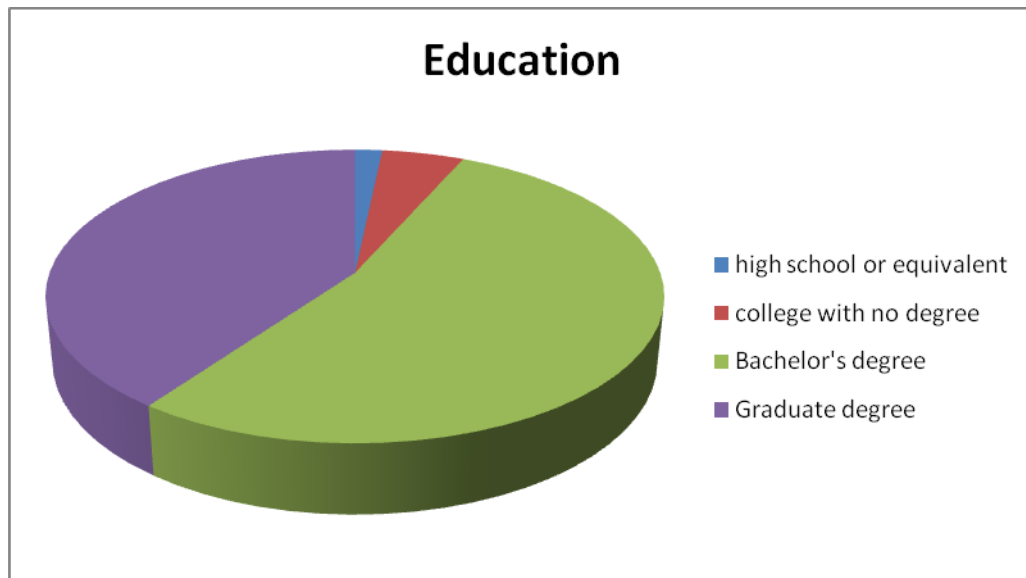
The method of sample selection was non-probability, using a technique of availability/convenience sampling. Participants were recruited through email distribution of a recruitment email (See Appendix D) with a link to access the SurveyMonkey survey. This email was sent out to Smith colleagues which wielded a high response rate. In addition, the email was sent to contacts in the field, and using a snowball sampling technique, they forwarded the email on to other potential participants. Surveys were completed anonymously and voluntarily. The process outlined in the Human Subjects Review Application (See Appendix A) was followed to ensure confidentiality of participants, while minimizing harm and maximizing benefit.

Participant's demographics are illustrated in the following visual representations.

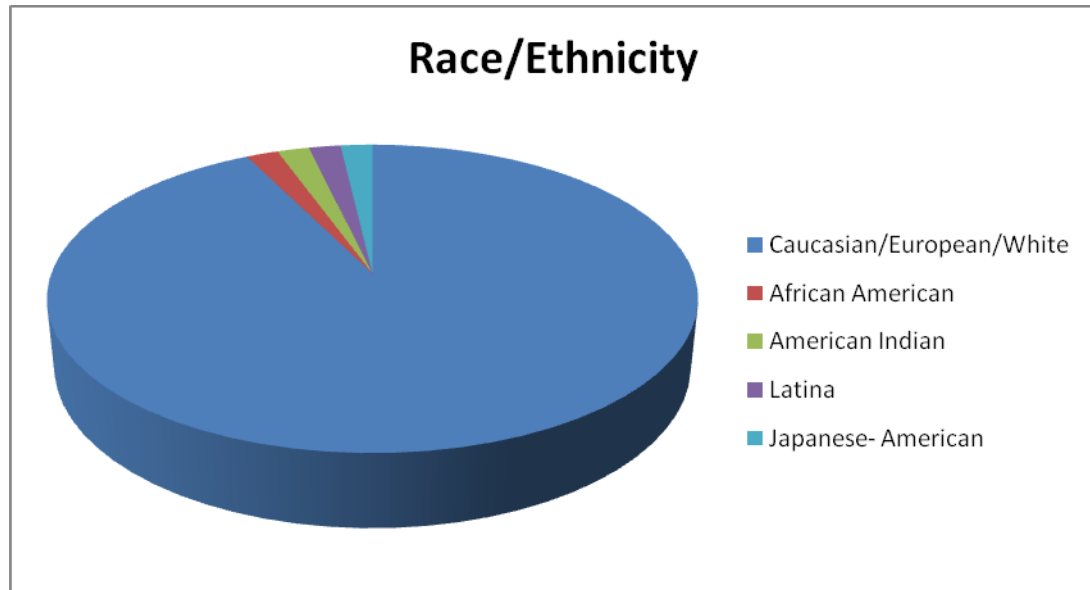
Age: Participants ranged in age from 21-83 with a mean age of 42.1



83.6% of respondents identified as female (n=51) while 14.8 % identified as male (n=9), and 1 participant identified as genderqueer.



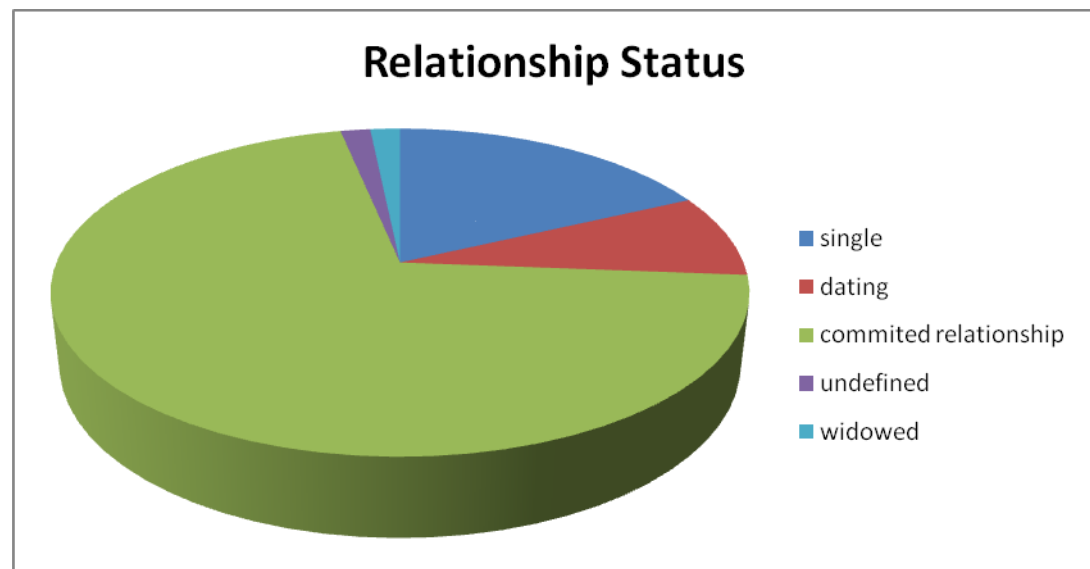
Most respondents had completed higher education degrees. 1 participant had a high school degree or equivalent, 3 had completed some college with no degree, 32 had their bachelor's degrees, and 24 had completed a graduate degree.



In terms of race, 50 identified as Caucasian/-European/-White. Of these 50, 4 also identified as Jewish. 1 identified as African American, 1 identified as American Indian, 1 identified as Latina, and 1 identified as Japanese-American.

A wide range of religions were reported.

Relationship Status was reported as follows:



11 participants reported being single, 5 dating, 43 in a committed relationship (inclusive of marriage), 1 undefined, and 1 widowed.

All participants met the eligibility criteria of being greater than 18 years of age, fluent in English, residing in the United States, and all reported being comfortable and able to answer a questionnaire concerning their attitudes around death.

Procedures/ Data Collection.

All participants were recruited through email distribution of a recruitment letter (Appendix D) with the Informed Consent form (Appendix B) attached as a reference. They were given the option to follow a link to complete the online survey. The survey, included in full in Appendix E, begins with eligibility screening questions, then the Informed Consent, followed by the RDAS, and finishes with a few short-answer questions. All participants had to meet all eligibility criteria, read the Informed Consent and then check a box indicating that they understood and agreed to the Informed Consent form in order to proceed with the survey. Due to the voluntary nature of this study, all participants were able to decline answering any particular question on the questionnaires or to stop the survey at any time.

The RDAS was administered as it is a reliable measure which has been used to conduct much research in the death studies field over the past two decades (Neimeyer, 1994). The researcher felt that having a structured, reliable scale would assist with ensuring more substantial and generalizable findings. Open-ended questions were also included to allow participants to express their viewpoints and experiences with more freedom. Online distribution and collection of survey responses was chosen for ease of collection as well as in an attempt to limit the effects of researcher bias and social desirability.

Data analysis.

The data collected through this survey was analyzed with the assistance of Marjorie Postal, Smith's data analyst. Using t-tests and a Pearson correlation, relationships were examined

between death anxiety scores and various variables, including work experiences with death/dying, relationship status, gender, religion and age. Open-response answers to the question “What does death mean to you?” were coded and a t-test was run to determine whether there was a correlation between negative versus positive-toned meanings of death and death anxiety score.

The other open-response questions were coded based on content, patterns are identified.

The findings are outlined in the following section.

Chapter IV: Findings

Purpose of the Study

This study was designed to explore whether there exists a relationship between an individual's death anxiety level and their experiences working intimately in a professional context with the dead and/or those who are in the process of dying. Demographics, such as age, gender identification, relationship status, religious/spiritual affiliation, and ethnic/-racial identity were also collected. Responses were gathered through the online survey program, SurveyMonkey. Death anxiety was measured using the Revised Death Anxiety Scale (RDAS) and attitudes regarding death were measured with several open-response short-answer questions. The data was entered into SPSS and analyzed with the assistance of Marjorie Postal.

The major findings of this study indicate that there was a significant difference between the RDAS scores of those who have worked in Hospice and/or funeral work, versus the scores of those who have not been involved in this manner of work. There were no significant differences found in terms of RDAS and gender or relationship status. Significant differences were found between RDAS scores based on age and religious/spiritual identification, as well as the meaning attributed to death.

Quantitative Findings

Revised death anxiety scale (RDAS).

While analyzing the data, Cronbach's alpha, a test of internal reliability, was run to score the RDAS scores of the participants. The total number of participants who sufficiently completed

the 25-item scale was 60 (N=60). The alpha was determined to be .87, which indicates strong internal reliability.

The RDAS contains 25 statements which participants are asked to respond to on a 5-point Likert scale, with 0 given to statements which indicate least anxiety and 4 given to statements which indicate highest anxiety. The possible range of the participant's final score is 0 (as the lowest possible score) and 100 (as the highest possible score). Any questions left blank are assigned a value of 2, for neutral. 8 items are scored negatively with reverse scoring, but otherwise item's values are added up to get the overall RDAS score. (Neimeyer, ed., 1994, p.43)

In this study, 60 respondents completed the RDAS, with the following statistical outcomes:

	Mean	Median	Std. Deviation	Minimum	Maximum
RDAS	40.05	40.00	13.88	13.00	71.00

Death anxiety and professional experience with death.

A significant difference was found between the Death Anxiety scores of those with experience working with the dead and/or dying through Hospice or funeral work and those who self-reported not working in those capacities. The study participants were divided into two groups: those who had clinically worked in a Hospice or performed funeral ceremonies (N=33), and those who had not performed this type of work (N=25). The following table illustrates the mean and standard deviation between these samples.

	Professional Experience with Death	N	Mean	Std. Deviation	Std. Error Mean
RDAS	None	25	44.60	13.88	2.44
	Funeral or Hospice work	33	37.30	14.52	2.52

To determine whether the lower mean of RDAS scores among funeral and Hospice workers was significant, an Independent Samples t-test was run. A significant difference was found, $t(56)=2.025$, $p=.048$, two-tailed. This indicates that those respondents who had professional experience with death, either through funeral or Hospice work, scored significantly lower on the RDAS than those who had not engaged with death in these capacities.

Death anxiety and age.

A Pearson correlation determined that there was a significant, weak, negative correlation between death anxiety and age ($r=-.389$, $p=.003$). This finding suggests that as age increases, death anxiety scores decrease.

Death anxiety and gender identity, relationship status, and education.

No significant differences were found in terms of the relationships among the RDAS scores and gender identification, relationship status, or highest education level completed.

Death anxiety and religious/ spiritual identity.

Study respondents reported a wide range of religious/ spiritual identifications, including Christianity, Catholicism, Judaism, Algonquin Wabanaki, Ridhwan School, Quaker, Unitarian, eclectic Tantra, and several others. Many respondents identified as Atheist, Agnostic, or as having no spiritual or religious affiliation. For the purposes of statistical analysis, participants were coded into two groups: those with a spiritual/religious identification and those who either have none or identified as atheist/ agnostic.

A t-test revealed that there was a significant difference between the two groups, $t(56) = -2.382$, $p = .021$, two-tailed). Those who identified a spiritual or religious affiliation had a lower

average RDAS score ($M=33.95$) than those who had no affiliation or affiliated as atheist/agnostic ($M=42.51$).

Death anxiety and racial/ ethnic identity.

Based on the fact that the majority of respondents were White/Caucasian and very few people of color were represented in the sample, no tests were run to compare RDAS based on race or ethnic identification.

Qualitative Findings

Death anxiety and meaning of death.

Participants were asked to respond to the question, “What does death mean to you?” Responses tended to fit into four different groupings: death as the end, death as a continuation of life/transition to the next type of existence, death as both an end and a beginning, and death as an unknown. Responses were coded into those preceding four categories (1=end, 2=continuation, 3=both, 4=unsure). For example, responses such as death means “a next stage of existence”, “moving on to a better place”, and “the beginning of something else” were all coded 2 for continuation. Examples of death as the end include responses which stated that death meant the end, as well as responses such as “the cessation of relative consciousness in a physical body” and “my spirit leaving a physical body which can longer support its existence”. Some responses fell into both categories, such as: “ Separation from my ‘earthly family’. And going to be with God.”

The following statistics were found for the RDAS scores for each of the 4 groups.

Meaning of Death	N	Mean of RDAS	Std. Deviation	Std. Error Mean
End	20	34.60	12.89	2.88
continuation	12	38.66	11.62	3.35
Both	10	46.5	11.84	3.74
Unsure	16	45.31	15.77	3.94

A one-way ANOVA was run to determine if participant's RDAS were different based on the meanings they had attributed to death. The researcher hypothesized that more positive attitudes towards death, i.e., death as a continuation of life, would go along with lower death anxiety scores. A significant difference was found ($f(3.54)=2.741, p=.052$). The significant difference was found to be between those who indicated death as end, versus those who indicated death as either "both" or "unsure". Interestingly, those who reported death representing "the end" had lower average RDAS scores ($M=34.6$) than those who viewed death as both a beginning and an end ($M=46.5$) and those who were unsure of death's meaning ($M=45.31$).

Meaning of death and professional experience with death.

It was hypothesized that those who work with death may have more positive meanings associated with death and the dying process. In reviewing the statistics, it appears that those participants who have had experience working with death have a higher percentage of viewing death as end (47.4%) versus those who do not work with death or dying (28.2%). Otherwise, the two groups fell rather equally into the four categories of responses.

Experiences with death and/or dying.

Participants responded to the question, "What in your life has informed your feelings and beliefs about death and dying?" These responses were coded into six categories, as follows: personal experience, work/volunteer experience, church/religion, study/education, family, and other. Multiple respondents indicated more than one influence out of the preceding list. 24 respondents indicated that personal life experience, such as the loss of a loved one or a personal illness, influenced and informed their feelings surrounding death and dying. 16 referenced work/volunteer experience, 21 indicated the influence of church/religion, 17 referred to study

and education on the topics, 10 referenced family, and 4 responses did not seem appropriately coded into any of the five categories.

Examples of responses are as follows:

What in your life has informed your feelings and beliefs about death and dying?

Seeing others including my father die. Singing at the bedside of dying people.

I have cancer myself, so I have had to live with the very real possibility that I will die before expected. As well, I don't believe in hell, so I'm not worried that death might bring everlasting torture. It might be relieving is someone has had a particularly challenging life. And I believe that death is just another inevitable part of the human condition.

I have had a lot of loss in my life and many miraculous experiences that have proven that death and loss are nothing but mere illusions.

Exposure to Christian teachings as a young child. Buddhist beliefs in my own family. My own personal ideas and opinions.

Church. Being around death in church. I am married to a clergy person as well so death is part of our life.

Parental influences, such as lack of fear of death. Beliefs in life after death, and that when someone dies I will see them once again.

Not being religious or spiritual. Having somewhat existential beliefs.
Acknowledging the level of injustice and pain involved in living.

Due to the number of responses which fit into multiple categories of coding, statistical analysis was not conducted on these responses. When reviewing the responses alongside their corresponding Death Anxiety Scores, no trends or patterns were apparent.

Providers who responded to the survey were also asked to describe the services they provide to the bereaved and what attracted them to the field of end of life care. Responses to these questions varied, though often, it was indicated that personal loss and an inclination

towards helping others were cited as reasons behind the interest in their chosen field. One respondent bluntly stated, “It is part of my job, I have no choice.”

Examples of services provided are as follows:

- comforting , listening, arrangements for services after death
- casket bearer
- traditional wake/funeral service and burial
- I work with patients and families from the time they enter hospice services, providing support, case management, companionship and counseling. I have provided bereavement support to families and friends of the deceased and have assisted in preparing bodies for the families' good-byes at home before the body is removed. I have participated in several bed-side prayers/ceremonies during active dying and immediately after death.
- Providing a safe, calm holding environment for those who are dying and their families so they can access and express their feelings, concerns and have support and education re the dying process. Also helping people to access their inner strengths as they approach the end of their lives.
- My experience was only in setting up for and directing the funeral service. “Like a wedding” my boss told me “a funeral is an important ceremony. It provides closure, marks a change of things.”

No statistical analysis was conducted given the range and complexities of these responses. As previously stated, providers did have significantly lower Death Anxiety Scores.

The significance of these findings and how they relate to previously conducted studies will be explored in the forthcoming section.

Chapter V: Discussion

Purpose of the Study

The purpose of this study was to address whether working intimately with those who are dead and/or dying would correlate with lower death anxiety scores and more positive perceptions of death. The study specifically compared those who work closely with death, i.e., funeral providers and Hospice workers, versus those who do not engage in this area of work. Attitudes and perceptions of death were collected and analyzed through the completion of the Revised Death Anxiety Scale (RDAS) and a series of open-ended questions.

Major Findings

The major findings of this study indicate that there was a significant difference between the RDAS scores of those who have worked in Hospice and/or funeral work, versus the scores of those who have not been involved in this manner of work. There were no significant differences found in terms of RDAS and gender or relationship status. Significant differences were found between RDAS scores based on age and religious/spiritual identification, as well as the meaning attributed to death.

Review of the Findings

Death anxiety and professional experience with death.

A significant difference was found between the Death Anxiety scores of those with experience working with the dead and/or dying through Hospice or funeral work and those who self-reported not working in those capacities. The significantly lower death anxiety scores found

among end-of-life care professionals are consistent with several other studies in the field (Bassett & Dabbs, 2003; Kootte, 2001; Payne et al., 1998; Pepitone--Arreola-Rockwell, 1981). These researchers all conducted studies in which those working closely with the dead and/or dying endorsed lower fear of death and generally more positive constructions of the meaning of death. The researchers suggested several hypotheses as to why professionals in the field would report lower death anxiety. Bassett & Dabbs (2003) posit that while exposure to death may lower death anxiety and force one to develop a comfort with death and the dying process, individuals who innately have lower death anxiety may also pre-select into this profession, or may under-report their death anxiety due to pressures from justifying their appropriateness in their profession.

This research study further explores findings in the literature which suggest that mental health professionals and students tend to score higher on the RDAS than the general population, though those with personal experiences with death and a desire to work in end-of-life care tend to score lower (Kirchburg, Neimeyer, & James, 1998; Simons & Park-Lee, 2009). Similarly, this study's findings suggest that mental health professionals who engage in the role of Hospice social work have lower RDAS scores and more positive meanings of death than those who may not pursue this type of work. This finding supports the study's hypothesis that increased exposure to death will correlate with lower RDAS scores.

Avoidance of death has been found to correlate with higher fear of death and anxiety about the dying process (G.J. Neimeyer et al., 1984). This study supports this finding, in that those who have sought out careers working closely with terminal illness and death are clearly not avoiding the reality of our own mortalities. Avoiding this anxiety-provoking topic seems to ultimately arouse more anxiety.

Death anxiety and age.

There was a weak correlation between increased age and lower death anxiety. This finding can perhaps be considered consistent with the hypothesis, if we assume that as age increases, personal experiences with death and loss also increase, as does personal reflection about the meanings of death. However, this study did not directly explore exposure to death and loss in personal life, and therefore we are left to simply hypothesize as to the meaning of this study.

Limited research has directly reported on any relationship between age and death anxiety. However, Harrawood (2005) found elevated death anxiety scores among older funeral home directors. This study also found higher death anxiety scores in general for funeral home directors, findings that directly disagree with much of the other literature, which found lower fear of death among those who work in the funeral industry (Pepitone-Arreola-Rockwell, 1981).

Death anxiety and gender identity, relationship status, and education.

No significant differences were found in terms of the relationships among the RDAS scores and gender identification, relationship status, or highest education level completed. Harrawood (2005) had found high death anxiety scores among funeral directors in “close personal romantic relationships”. Although some studies have shown significant differences based on gender and level of education, this study did not reveal any such trend.

Death anxiety and religious/ spiritual identity.

Those who endorsed having a religious or spiritual practice tended to have lower RDAS scores than those who were either atheist, agnostic, or uncertain of their religious affiliation. This tends to be an area of interest which is often left out of the research in this field. The finding suggests that having a religious or spiritual belief system may provide more meaning and

understanding of death, and result in more comfort when confronted with the realities of death and dying. However, further research in this area would be indicated to explore the meaning of this finding.

Death anxiety and racial/ ethnic identity.

Based on the fact that the majority of respondents were White/Caucasian and very few people of color were represented in the sample, no tests were run to compare RDAS based on race or ethnic identification. No existing study was located which compared attitudes towards death and racial/ethnic identity.

Death anxiety and meaning of death.

As in this study, other research also supports the finding that “making meaning” of death and loss through involvement in the dying process, funeral services and/or the act of grieving relate to lower fear of death and more positive interpretations of the dying process (Gamino, Easterling, & Stirman, 2000; Irion, 1990). Those who have explored their beliefs and reflected more fully on the meanings of death may have obtained greater comfort in regards to death. Similar to having a religious or spiritual affiliation, some form of system to help “explain” the mystery of death and dying may provide comfort to those confronted with loss. This finding suggests that greater reflection and education around end of life issues may benefit individuals in reducing stress and unpleasantness often associated with death.

Experiences with death and/or dying.

The majority of participants indicated that personal life experience, such as death of a loved one or personal illness, had informed their beliefs and feelings around death and dying. Due to the open nature of the responses, there were several factors to consider in each response, so no statistical analysis was conducted on this finding. However, this finding suggests that it is

of importance in future studies to consider the effect that death of a loved one or personal illness would likely have on an individual's death anxiety. In keeping with this finding, many providers in the end of life care fields further indicated that they entered the field due to personal experiences with deaths of loved ones. In future studies, exploring the "chicken and the egg" phenomenon is indicated to clarify whether those who enter the field are innately more comfortable with death, or their comfort springs from exposure, or, as seems most likely, it is a combination of the two.

Strengths of the Study

This study's strengths include the use of a reliable measure (RDAS), a good response rate (N=60), a focused research question and quantitative data collection. Findings were significant. The sample was representative of both populations, inclusive of those who work with the dead/dying and those who do not have experience in this area of work. Collecting data using SurveyMonkey, an online tool, ensured the confidentiality of participants and ease of data collection and analysis.

The research question was explored through the design and execution of this project. The RDAS served as an already well-established and reliable measure of death anxiety, facilitating comparisons between study groups. However, the open-response questions could have been better developed and more consistent with the research question, regarding exactly how exposure to death professionally may have affected an individual's thoughts, feelings, and beliefs about death and/or dying.

Limitations of the Study

The study sample was not representative of the overall population. Of great concern is the underrepresentation of people of color in the sample. Funeral service providers were also under-

represented due to inadequate recruitment efforts. Furthermore, the study design was rigid and at the same time a little ambiguous in terms of population groups. While this researcher attempted to place respondents into two separate categories, it became apparent that although an individual may not work professionally with death, they may have been present during the dying process of a loved one and assisted in a loved one's funeral. Furthermore, there were professionals who work with the dead/dying and yet were not included in the study criteria, such as bereavement counselors and coroners. Future studies should be mindful of who should be included in the study sample and whether more stringent or flexible criteria would be appropriate.

No distinction was made in the study between personal and professional exposure to death. Further research could explore the impact of personal as well as professional experiences with death as these experiences relate to perceptions and emotional reactions to death.

Implications of the Study

The findings of this study imply that those with more exposure to death tend to have lower death anxiety scores, and thus be more effective in approaching versus avoiding death-related scenarios. Given the limited education that social work students receive in graduate school regarding death and end-of-life care, one could argue that schools should consider death study courses, as death and dying will inevitably be encountered in the work social work in which clinicians engage. Graduate level social work students should be encouraged to partake in formal and informal death education, as an opportunity to reflect on individual perceptions and belief systems about death and dying, to best serve their clients in their future careers.

Concluding Paragraph

This study explored the relationship between death anxiety and professional exposure to death through Hospice and funeral service providing. The study found that those who have more

professional exposure to death also scored lower on the RDAS. In addition, older adults and those with more positive meanings of death endorsed lower death anxiety. This researcher suggests that increased reflection, education, and direct exposure to death may benefit social work clinicians in better assisting their clients.

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Appendix A

Human Subjects Review Application

November 27, 2011

Revisions completed: March 12, 2012

Applicant's Name: Hannah Myers

Project Title: Caring for our Dead and Dying:
A Comparative Study of Providers' Attitudes about Death

Project Purpose and Design:

Do we fear death less if we are exposed to it more, through caring for the dead and those who are dying? This research project intends to explore whether there exists a significant difference between death anxiety scores among those who work with the dying and deceased, such as traditional funeral home directors, alternative funeral providers, and Hospice social workers, and those who do not engage in this kind of work. This topic will be explored through the collection of demographic data, the distribution of one online survey, and open-ended questions regarding professional experiences and attitudes towards death. The proposed survey is the Revised Death Anxiety Scale (RDAS, Thorson & Powell, 1994). Permission has been obtained to use this survey, as it is stated in Neimeyer's (1994) *Death Anxiety Handbook* that this scale can be used for research purposes as long as the source is cited (p.54).

Research studies exploring the relationship between professional experiences and fear of death have resulted in fascinating, at times contradictory, findings. Bassett & Dabbs (2003) conducted a study in which the data suggests that there are lower death anxiety scores among funeral service and mortuary science students as opposed to the general undergraduate student population. Other findings generally suggest that healthcare professionals, funeral directors, and those who work closely with the dying score lower on death anxiety scales (Kootte, 2011; Payne, Dean & Kalus, 1998; Pepitone-Arreola-Rockwell, 1981). However, Harrawood (2005) conducted a study in which 200 traditional funeral home directors throughout the country were found to have higher than average death anxiety scores. In studies comparing nurses and hospice nurses, findings support that those working in hospice settings report lower fear of death and discomfort associated with thoughts of death and dying than the general nurse participants (Kootte, 2011; Payne, Dean and Kalus, 1998). Limited research explores the use of alternative, or home, funeral practices in which families and communities arrange the funeral with limited funeral home use (Bergen & Williams, 1981; Morgan, 1988).

This study will explore any relationship which may exist between funeral providers, Hospice social workers, those who have not cared for the dying or dead, and their subsequent attitudes, as well as anxiety, around death. Additionally, this study is designed to further the existing body of research to include the current growing practice of home funerals and to explore whether there is a measurable difference in anxiety among providers of this newer, alternative funeral option.

These findings may further our understanding around fear of death and dying and the effect that intimate exposure may have on those who assist the dead, dying and bereaved. As we build our

understanding of the relationship between providers and death anxiety, we can become more aware of ways to address our own potential anxiety and fears regarding end of life issues. This study could possibly assist in building social work curriculum and personal life practices which serve to lower our fear of death so that we are available to better serve clients confronting end of life situations. Furthermore, the study will provide information regarding available services that are provided for the terminally ill and grieving populations. Data from this study will be used to fulfill MSW Thesis requirements for the Smith School for Social Work. The data may also be used for possible publication and presentation.

Characteristics of the Participants

Participants must be willing, voluntary and fully informed of the nature of the study. Participants must be over the age of eighteen, able to read and respond in English, and reside within the United States. Participants must be capable of completing an online survey and be comfortable answering questions regarding their thoughts and experiences with death without becoming overly distressed.

There will be two groups of participants:

One group will consist of those who work in the fields of funeral services or Hospice social work. This population will include alternative funeral providers, also known as Death Midwives or Home Funeral Guides. These individuals assist and conduct funerals in the home or community for and organized by the survivors of the deceased. There are no degree requirements, but completion of some training is necessary, such as completing a certificate, attending a training, being an apprentice to a licensed professional, or completing a degree in Mortuary Science. Participants must have assisted in at least one funeral or had at least one client in Hospice-related work.

The second group of participants will be those who have not engaged in this area of work.

Participants are voluntary and anonymous and can withdraw from the study at any time, prior to submitting their survey responses.

The desired sample size will be fifty participants: ten in each category of providers, and twenty participants who are not providers in these fields.

Recruitment Process

Recruitment will take place through email with contacts in the field and personal correspondents. Using a convenience sampling method, most participants will be recruited through snowball sampling, in which contacts I have in the home funeral, traditional funeral, and Hospice industries will forward the online survey information along to potential participants. No recruiting will be done through agencies such as hospitals or other formal organizations. Efforts will be made to achieve diversity among participants through recruiting in various areas and through a wide range of contacts in the field.

Please refer to the attached recruitment email which will be sent to contacts along with a link to the online survey.

Screening will be completed on the first page of the survey, to ensure that all eligibility criteria are met. Participants will respond to a series of “yes” and “no” questions. If they do not meet criteria for participation, they will be brought to a screen which thanks them for their interest in

the study, but informs them that they are not eligible to participate. If they meet criteria, they continue to the next page, which will contain the Informed Consent form. Please refer to attached survey to review the screening materials.

Nature of Participation

Participants will be asked to access the survey online. They will be asked to read through the screening criteria to assess their eligibility to participate in the survey. If eligible, they will proceed to the informed consent form, and click the “I accept” button in order to proceed to the online survey. Subject anonymity will be obtained as data collected goes to an excel spreadsheet and is not linked with client identifying information.

Demographic data such as age, gender identity, racial/ethnic identity, religious/spiritual affiliation and specifics about experience in the field will be obtained. Participants will also be asked to describe the services they provide, if applicable, and answer two short questions regarding their beliefs about death.

Participants will complete one survey: the Revised Death Anxiety Scale (RDAS, Thorson & Powell, 1994). This survey is comprised of 25 statements which participants rate using a 5-point Likert scale which ranges from strongly agree to strongly disagree, with neutral in the middle.

The total time to complete the survey should not exceed 30 minutes. Responses will be collected through SurveyMonkey. All materials will be password protected. Identifying information used during recruitment will be kept confidential and not attached to any data collected. All measures to ensure participant privacy will be taken.

Risks of Participation

As this study deals with the issue of death, there is a risk of intense emotional reactions when responding to questions regarding personal attitudes towards death. One assumes that funeral providers and Hospice social workers have likely reflected on, and been confronted with, their own death anxiety in their line of work. Those who do not engage in this type of work may not have explored their feelings regarding death as thoroughly. Measures will be taken to seek to reduce harm to all study participants. As previously stated, participation is entirely voluntary and participants are under no obligation to participate or to complete the survey should the content be too emotionally charged. Furthermore, for all participants, a list of several resources will be included at the end of the informed consent. Please refer to the informed consent to review the resources.

Benefits of Participation

Researchers in the field of death studies have indicated that many participants have found it personally rewarding to share and reflect upon their experiences with death (Cook & Bosley, 1995). Having an opportunity to share and reflect on experiences with death can be a healthy way to further process the emotions death may provoke. Further, participants can add to future understanding regarding death anxiety and proximity to death work, which can improve our understanding of death anxiety and factors which affect it.

Informed Consent Procedures

Participants will access the informed consent form through the online survey. Before proceeding to the survey, participants will read through the form and be fully informed of the nature of the questions they will be responding to, the voluntary nature of their participation, and their right to withdraw from the study at any time prior to completing the survey. In order to access the online survey, participants must first check a box to indicate that they have read the above information and wish to proceed with the survey.

Precautions Taken to Safeguard Confidentiality

Participants will complete the survey in an anonymous manner, in which no name or identifying information will be linked with their responses. Although some identifying information will be received during the recruitment process, none of this information will be linked with final survey responses. A coding system will be used to keep track of various participants. Efforts will be made to ensure anonymity and confidentiality, as participants will not be required to identify themselves by name and further, the identifying information that may be collected during the recruitment process will not be shared with any outside party. Data will be scrubbed of all identifying information prior to being shared with the data analyst and my research advisor.

All data collected online will be password protected and collected through software which ensures anonymity. This data will be password protected for three years, after which it will be systematically destroyed.

The Voluntary Nature of Participation

Participation is entirely voluntary, and participants are able to decline to answer questions, except for the screening questions, and to withdraw at any point prior to submitting the online survey. Participants can withdraw at any point while actively participating in the study, simply by not completing the survey. However, if participants decide after they have submitted their materials that they would then want to withdraw, their information can no longer be withdrawn as they were anonymous and thus their data is unidentifiable.

Participants may contact me at the email or phone listed on the consent form with questions or concerns, before or after completing the survey.

Investigator's Signature: _____ Date: _____

Advisor's Signature: _____ Date: _____

Appendix B Informed Consent Form

Dear Study Participant,

I am a student at Smith College School for Social Work conducting a research project regarding funeral providers, Hospice social workers, those not involved in this work, and their attitudes about death. Many researchers have found a correlation between less fear of death among those who work closely with the dead and dying (Kootte, 2001; Payne, Dean & Kalus, 1998; Pepitone-Arreola-Rockwell, 1981) This study specifically will be looking at the relationship between the death anxiety scores among those who work intimately with the dead and dying, i.e. traditional and alternative funeral providers and Hospice social workers, compared to those scores of individuals who are not engaged in this kind of work. The data from this study will be used towards completion of a Masters of Social Work thesis and may be used for possible publication and presentation.

Nature of Participation

You are being asked to participate in this study on an entirely voluntary and anonymous basis. In order to participate, you must be over the age of 18, able to complete an online questionnaire in English, and comfortable responding to questions about death and dying.

You must have either

- a.) conducted at least one funeral ritual or clinically worked with one dying patient in a Hospice setting, and completed some training/ certification/ apprenticeship in this work
OR:
- b.) not be involved in this work at all.

The study involves completion of one survey, which will ask demographic information, statements regarding your personal feelings about death, and a few short answer questions. The survey will be available through an online survey program. The survey should take no longer than 30 minutes to complete. After the submission of your responses electronically, no identifying information will be connected with your responses.

Risks and Benefits

Given the sensitive nature of people's emotional responses to death, participants may potentially experience discomfort when responding to questions regarding their attitudes about death. If you believe that this emotional discomfort will be overwhelming, you may decline to participate or you may withdraw from the study at any time, prior to submitting the survey. You will be provided with a list of resources for national support and referral networks at the end of this informed consent form.

In terms of benefits, some find it personally beneficial to share their experiences with and impressions of death. In addition, there are gains to the field of social work education, as grief counseling and Hospice social work can be greatly informed by understanding attitudes towards death as influenced by various funeral ritual practices and proximity to work with the dead and dying.

No compensation will be provided for participation in this research study.

Confidentiality

All measures will be taken to ensure confidentiality in this study. Surveys will be completed electronically, in an anonymous fashion, so that participant identifying information will not be attached to the data collected. Though some participant identifying information will be obtained during the recruitment process, it will not be linked with actual participant responses.

Besides myself, my research advisor and data analyst will also have access to respondent data, however no identifying information will be attached with this data.

All data will be kept in a secure, password protected database for a period of three years as mandated by Federal guidelines. The online data will be password protected and only accessible to me, the principle investigator. After the period of three years, all data will be destroyed.

Voluntary Nature of the Participation

Your participation in this study is voluntary. You may withdraw from the study at any time while completing the survey and may decline answering any question that you do not wish to answer, with the exception of screening questions to assess eligibility. If you withdraw before completing the survey, your data will be destroyed and not included in the study. However, if you choose to withdraw after you have submitted your survey responses, as the study is anonymous, it will not be possible to locate your survey responses, and the data will be included in the study. You may contact me at the email or phone listed below with any questions or concerns about this study, before or after completing the survey. You may also contact the Chair of the Smith School for Social Work Human Subjects Review Committee at (413)585-7974.

Thank you for your participation and may I suggest that you retain a copy of this form for your records.

BY CHECKING THIS BOX, YOU INDICATE THAT YOU HAVE READ AND UNDERSTAND THE ABOVE INFORMATION AND THAT YOU HAVE HAD THE OPPORTUNITY TO ASK QUESTIONS ABOUT THE STUDY, YOUR PARTICIPATION, AND YOUR RIGHTS AND THAT YOU AGREE TO PARTICIPATE IN THE STUDY.

Date: _____

Researcher's Contact:

Hannah Myers
MSW Candidate
Smith College School for Social Work
Northampton, MA 01063

In case of any distress or discomfort resulting from participation in this study, please make use of any of the following national support networks:

- I. www.griefnet.org: an online community grief support group
- II. www.compassionatefriends.org: a support network with local chapters, providing support for the bereaved
- III. www.hospicefoundation.org: provides support for those personally and professionally affected by death, with many resources and suggestions for coping with loss
- IV. www.adec.org: several resources listed, including a "find a specialist" database, which allows individuals to search for local, licensed providers.
- V. www.TherapyMatchers.org: Social Work Therapy Referral Service offered through the Massachusetts NASW chapter, to receive assistance by phone, dial 617-720-2828 or 800-242-9794

Appendix C
HSR Approval Letter



School for Social Work

Smith College
Northampton, Massachusetts 01063
T (413) 585-7950 F (413) 585-7994

March 12, 2012

Hannah Myers

Dear Hannah,

Very nice job with your revisions! Thank you for your professional correspondence and your detailed work. Your project is now approved by the Human Subjects Review Committee.

Please note the following requirements:

Consent Forms: All subjects should be given a copy of the consent form.

Maintaining Data: You must retain all data and other documents for at least three (3) years past completion of the research activity.

In addition, these requirements may also be applicable:

Amendments: If you wish to change any aspect of the study (such as design, procedures, consent forms or subject population), please submit these changes to the Committee.

Renewal: You are required to apply for renewal of approval every year for as long as the study is active.

Completion: You are required to notify the Chair of the Human Subjects Review Committee when your study is completed (data collection finished). This requirement is met by completion of the thesis project during the Third Summer.

Good luck with your research.

Sincerely,

A handwritten signature in black ink, appearing to read 'David L. Burton', with a long horizontal flourish extending to the right.

David L. Burton, M.S.W., Ph.D.
Chair, Human Subjects Review Committee

CC: Alexandra Graham, Research Advisor

Appendix D
Recruitment Email

Greetings Possible Study Participant,

I am a Master's student at Smith College School for Social Work conducting research on attitudes towards death among end-of-life care providers, funeral providers, and those who are not providers in this area of work.

If you are eighteen or over, comfortable answering questions about death and dying, and able and willing to complete an online survey which will take no more than 30 minutes of your time, please follow the link attached to my survey. Also, please forward this email along to any one else who might be interested in participating.

I have attached the Informed Consent form to provide you with more information regarding the survey and including my contact information should any questions arise.

Thank you.

Sincerely,
Hannah Myers
hmyers@smith.edu

Appendix E Complete Questionnaire

Welcome to my "Attitudes regarding Death" survey.

To begin, please respond to the following screening questions:

1. I am eighteen years old or older.

Yes.

No.

2. I am capable of reading and responding to an online survey in English.

Yes.

No.

3. I reside in the United States.

Yes.

No.

4. I am willing and comfortable completing surveys regarding my attitudes and experiences relating to death and dying.

Yes.

No.

5. I fit into one of the following categories:

I am a traditional or alternative funeral provider who has completed training or certification or an apprenticeship in the field, and assisted in at least one funeral.

I have done the work of a Hospice social worker, I have completed some training, education, or a certificate in this work, and have clinically worked with at least one client in a Hospice setting.

I have NOT completed any work in the above mentioned fields.

Please provide the following optional demographic information:

7. Please state your age:

8. Please indicate your gender identification:

- Male
- Female
- Transgendered
- Prefer not to Specify

Other (please specify)

9. What is the highest level of school you have completed or the highest degree you have received?

- Less than high school degree
- High school degree or equivalent (e.g., GED)
- Some college but no degree
- Associate degree
- Bachelor degree
- Graduate degree

10. What is your racial and/or ethnic identity?

11. What is your religious/spiritual affiliation?

12. What is your current partnership status?

- single
- dating
- in a committed long-term relationship

Other (please specify)

Thorson & Powell's Revised Death Anxiety Scale

13. Please indicate on a scale from 0 to 4 whether you strongly disagree (0), disagree (1), neutral (2), agree (3), or strongly agree (4) with the following statements:

	0- strongly disagree	1- disagree	2- neutral	3- agree	4- strongly agree
1. I fear dying a painful death.		<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
2. Not knowing what the next world is like troubles me.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
3. The idea of never thinking again after I die frightens me.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
4. I am not at all anxious about what happens to the body after burial.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
5. Coffins make me anxious.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
6. I hate to think about losing control of my affairs after I am gone.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
7. Being totally immobile after death bothers me.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
8. I dread to think about having an operation.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
9. The subject of life after death troubles me greatly.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
10. I am not afraid of long, slow dying.	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>

14. Please respond to the following statements using the same scale as above:

	0- strongly disagree	1- disagree	2- neutral	3- agree	4- strongly agree
11. I do not mind the idea of being shut into a coffin after I die.		<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I hate the idea that I will be helpless	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	0- strongly disagree	1- disagree	2- neutral	3- agree	4- strongly agree
after I die.					
13. I am not at all concerned over whether or not there is an afterlife.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Never feeling anything again after I die upsets me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. The pain involved in dying frightens me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I am looking forward to a new life after I die.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I am not worried about ever being helpless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I am troubled by the thought that my body will decompose in the grave.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. The feeling that I will be missing out on so much after I die disturbs me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I am worried about what happens to us after we die.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I am not at all concerned with being in control of things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. The total isolation of death is frightening to me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I am not particularly afraid of getting cancer.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I will leave detailed instructions about how things should be done after I am gone.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	0- strongly disagree	1- disagree	2- neutral	3- agree	4- strongly agree
25. What happens to my body after I die does not bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please answer the following questions:

15. What does death mean to you?

16. What in your life has informed your feelings and beliefs about death and dying?

17. What statement (or statements) below describe your prior experience working professionally with the deceased and/or terminally ill?

- I have assisted with at least one traditional funeral.
- I have assisted with at least one alternative funeral.
- I have clinically worked with at least one dying individual in a Hospice setting.
- I have done none of the above.

18. Please estimate the number of clients that you have served either in performing their funeral rituals or during Hospice related work with terminally ill clients:

- not applicable
- 1-10
- 11-25
- 26-50
- 51 or more

19. Please describe the services that you provide for the dead, the bereaved, and/or those who are dying: (please write N/A if you do not provide these services)

20. What attracted you to be a provider in the field of end-of-life care/ funeral services? (please write N/A if you do not provide these services)

Thank you for completing this survey!