

**CONSTRUCTION AND INITIAL VALIDATION OF THE DESCRIPTIVE  
DEATH SCALE**

by

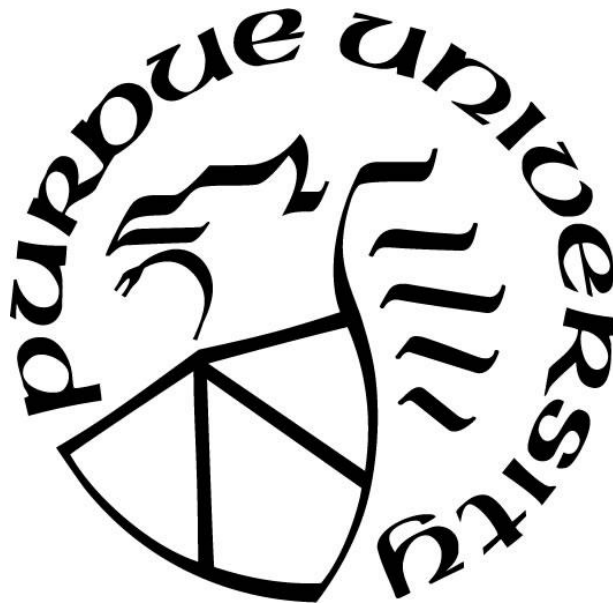
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*But as you left us, there broke upon this stage  
a glimpse of reality, shown through the slight  
opening through which you disappeared: green,  
evergreen, bathed in sunlight, actual woods.*

*We keep on playing, still anxious, our difficult roles  
declaiming, accompanied by matching gestures  
as required. But your presence so suddenly  
removed from our midst and from our play, at times*

*overcomes us like a sense of that other  
reality: yours, that we are so overwhelmed  
and play our actual lives instead of the performance,  
forgetting altogether the applause.*

*-Rainer Maria Rilke*

For Terri Lane Shemwell

For Kent George Luzader

This world *continues* to be shaped by you

## **ACKNOWLEDGMENTS**

I never expected to get a PhD but through high school and college the sense of direction and purpose developed. Even though I had a compass and map, I meandered, sometimes intentionally but mostly without knowing. My family and friends have been patient and sheperded my journey.

Thank you for accepting the challenge Dr. SS. You looked for me, helped me read the map, revised the map and waited as I made my way here.

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## ABSTRACT

The purpose of the present study was to develop the Descriptive Death Scale (DDS), a brief, descriptive and multidimensional measure that assesses individual perceptions of single death experiences. The DDS has the potential to expand how death experiences are understood in the literature because it can serve as a tool for griever to quantitatively contextualize their single death experiences instead of indicating only the mode of death. From a constructivist perspective, the adjectives included in the DDS are parcels of meaning that symbolically contextualize griever's subjective understanding. Drawing from qualitative research, I compiled a broad list of 65 adjectives that griever and terminally ill patients have used to describe past and impending deaths. My online recruitment process resulted in a sample of respondents ( $N = 572$ ) who identified primarily as White/European American, cisgender female and heterosexual (83%, 85%, and 83%, respectively). Their ages ranged from 18 to 80 ( $M = 43.13$ ,  $SD = 13.40$ ). The results of the EFA indicated a 5-factor structure; however, the CFA analysis/ESEM indicated that a 4-factor model better fit the data. The DDS subscales (i.e., Incomprehensible, Warm, Withering, Ostracized) include a total of 27-items and scores on each subscale displayed good internal consistency and convergent and discriminant validity. The results from the regression analysis indicated that the Incomprehensible, Warm and Withering death subscales contributed significantly and positively to grief distress, beyond closeness to the deceased and age of the deceased. The DDS assesses the nuanced and unique profiles of griever's perceptions of single deaths. It can serve as an important and novel tool for researchers and clinicians to capture griever multidimensional and subjective understanding of their death experiences. With single word items, it is brief, easy to use, and versatile across domains.

## CHAPTER 1: INTRODUCTION

### Overview of Problem

The way specific deaths are examined and measured by grief-related researchers is often discordant with how these deaths are described by griever, and the consequences may affect griever in a number of ways. Specifically, there is little consistency in the application and operationalization of descriptive terms, and there has been a narrow focus on circumstances and descriptors that exacerbate grieving. For example, the words “sudden” and “violent” are frequently used to describe deaths, but researchers use these words as *a priori* categories to classify deaths based on whether certain causes of death (e.g., accidents, illnesses, suicide) may or may not fit into these categories. Researchers regularly use the same griever (i.e., bereaved by suicide, homicide, accidental) in both sudden and violent death categories. In essence, researchers have narrowly and consistently, for example, judged suicide to be a “sudden” death, despite suicidally bereaved griever regularly indicating that their loved ones’ death was in some ways predictable (Armour, 2006). In addition, some illness-related deaths (e.g., heart attack) may be sudden whereas others (e.g., cancer) may not be. In addition, some deaths associated with cancer may be perceived as sudden whereas others would not. Griever have unique ways of perceiving and describing the deaths they experience; ways that go beyond a unidimensional focus on the specific *cause* of death.

To understand unique views of specific deaths, a descriptive measure of death must be constructed to allow for the appropriate assessment of the complex and idiosyncratic nature inherent in griever’s perceptions of specific deaths. My review of the literature did not uncover any existing measures that allow griever to retrospectively consider their subjective understanding or description of specific death losses they have experienced. Although measures

of “good death” exist, their purpose has been to capture dying individuals’ prospective sense of their own dying process. The scope of these measures is limited and they cannot be easily or even effectively be used to study how griever perceive and describe their experience of the deaths of others.

In addition, to attend to the dynamic nature of individual grievers’ descriptions of specific death losses, my focus is also on the possible discrepancy between how individuals make sense of deaths and how these same deaths may be viewed or perceived by their culture or society. Grievers and their societies often describe deaths in discrepant ways because grievers’ descriptions are grounded in the intimate details connected to a specific death loss whereas cultural and societal descriptions are often more general definitions associated with the labels given to specific causes of death. For example, grievers may experience miscarriage as a traumatic and jarring death, whereas their society may not even view miscarriage as a death (McCreight, 2004). In addition, deaths connected with suicide may be viewed as unpreventable by grievers, but preventable by members of their society, a discrepancy that could have far reaching impact on how grievers are treated (Armour, 2006). More specifically, a society that views suicide as preventable may blame grievers for suicide deaths resulting in added distress and burden for grievers.

The purpose of the present study was to develop a measure that not only allows for the multidimensional retrospective description of specific deaths, but also provides a structure for assessing the potential discrepancies between grievers’ perceptions of deaths and their sense of societal perceptions of the same specific deaths.

Historically, grief theories were primarily stage-based models with a focus on identifying universal processes and experiences. Kubler-Ross’s (1969) stage theory (i.e., denial, anger,

bargaining, depression, and acceptance) became globally popular. Through her qualitative investigation of people close to death, she provided a five-step description and argued for it *not* to be rigidly applied. Whereas her theory has been applied far beyond her intention, it was a key catalyst in the emergence of the field of thanatology (i.e., study of death and dying). Worden (2009) theorized four tasks of mourning (i.e., accept the reality of the death, process through grief, adjust to the world absent of deceased, form continued connection to deceased integrated with new life). He believed griever would process their grief by working through these tasks and doing their “grief work,” (p. 90, Worden, 2009). Although Worden (2009) began moving away from a seemingly linear approach toward a process-based orientation, contemporary grief theory has moved even further to a focus on highly individualized and contextualized understanding of the dynamic processes (e.g., searching for meaning) and outcomes (e.g., description of meaning) involved in grieving (Neimeyer, 2009). Meaning reconstruction is one such contemporary theory and its grounding is in constructivism.

Constructivist theory is foundational to understanding how people develop their descriptive understanding of death. People process life experiences in a way that gives rise to a descriptive and meaningful understanding of events in their life. In a dialectical way, *who* people are affects *how* they process life experiences and the events they experience shape who they are. People carry forward their meaningful understanding of events which they revise and use to interpret future events. They come to understand the world through layers of meaning that help them to believe, for example, that the world is safe, predictable, and just. These layers also assist people in understanding basic, everyday situations.

Language is the medium people use to package meaning in a way that can be stored in memory and conveyed to others. For example, “car” is a word people use, but one person may

picture a sedan while another person may picture a convertible. While people understand what someone means when a person uses the word “car,” people will have differences in the specific car that comes to mind. However, language is not just a way of expressing meaning, differentiating between words and choosing specific words to describe personal life events actually *forms* meaning. People who experience a death find a way to describe their experience by differentiating between words (e.g., violent, gruesome, disfiguring); deciding that certain words fit their death experience gives rise to meaning. Searching for meaning seems to be a process of trying on words and finding the correct words to symbolically capture the essence of their experience.

Further, social constructivists theorize that meaning is developed not only by individuals; meaning is consensually built and shared throughout culture and society (Davis, Quilan & Baker, 2016; Dennis & Kunkel, 2004; Kunkel & Dennis, 2004; Neimeyer et al., 2014). For example, cultural and societal norms develop as a meaningful way to interpret interactions with others, giving meaning to social interactions (e.g., etiquette), and to build relationships. People exist within cultural and societal bound realities, realities that shape how people come to define, react to, and place value on life. Through social dynamics people learn about themselves as they are defined within a set of roles and they negotiate their individual sense of self in reflection of the rules and roles defined by society. At times, individuals find that social meaning conflicts (e.g., homosexuality is a choice) with their meaning (e.g., sexuality naturally develops outside of personal control), having possible negative effects on them in a number of ways. In other words, individuals' sense of the world can be discrepant from their society's understanding of the world.

A key premise of constructivist theory is that meaning is not a fixed network of inflexible beliefs, rather meaning is built, revised, and challenged throughout life. Death is an excellent

example of a life event that can challenge, and even contradict, how people understand the world (Davis & Nolen-Hoeksema, 2001; Davis, Nolen-Hoeksema & Larson, 1998; Gillies & Neimeyer, 2006; Janoff-Bulman & Franz, 1997; Park, 2010). Specifically, murder can challenge griever's sense of justice and fairness. Theoretically, contradicting beliefs (e.g., murder and justice in the world) arouse distress (e.g., how could murder happen in a just world) and initiate a process of searching for meaning to minimize the contradiction (e.g., determining how this could happen and determining whether the world is just).

A current primary grief theory, meaning reconstruction, is rooted in the assumption that griever's rework how they understand the world because death arouses contradictions (e.g., children dying before their time) in their beliefs (Gillies & Neimeyer, 2006). Sense-making is central to comprehending a death and is a key construct within meaning reconstruction (Holland, Currier, Coleman & Neimeyer, 2006; Keesee, Currier & Neimeyer, 2010) and a particular focus of the current study. Sense-making involves process (i.e., searching for meaning) and content (i.e., meanings made) of meaning (Gillies et al., 2014; Park, 2010). In other words, the process of *searching for meaning* involves gathering information and interpreting the information into words that fit the meaning of their death loss, while *meanings made* are the specific words people use to symbolically convey the meaning they perceive in their death experience. Finding words befitting their death experience *forms* meaning (Lupyan, 2012).

Individual meaning (i.e., griever's meanings made) can contradict societal meaning (i.e., societal meanings made) which can lead to discrepant meaning between griever and others in their society. Through social interaction (e.g., conversation), griever encounter meaning that does not align with their individual meaning. Social meaning can describe specific deaths in ways that are discrepant to griever's descriptions. For example, socially, griever hear that

people who die by suicide are cowards (Batterham et al., 2013), people who die through capital punishment are monsters who deserved to die (Jones & Beck, 2007), and pregnancies that end in stillbirth are not worth grieving (Flenady et al., 2014).

In summary, the level of the complexity regarding how individuals use words to describe and, thereby, make meaning of the deaths they experience is not being captured by current empirical approaches. Additionally, there is no existing measure that assesses for possible discrepancies between individual and societal meaning. Therefore, my primary purpose is to develop a measure that captures the descriptive complexity of death and assesses for discrepant meaning. Researchers, who have investigated how griever describe deaths, have found that sudden, violent, ambiguous, preventable and stigmatized deaths appear to be more distressing than other deaths. Additionally, dying-related researchers (e.g., hospice, palliative medicine) have focused on how people who are near in time to their own deaths describe the concept of good death. Constructs that rise are often connected to pain, control, time, awareness and social support. Each word (e.g., violent, sudden, pain, control) is a descriptive category and in itself may be connected to a number of other death-related descriptors.

### **Importance of the Study**

The current study was focused on developing a novel measure that allows griever to describe specific deaths in a nuanced way, a way that is descriptive of both the potentially good and bad aspects of the deaths. Further, discrepant meaning exists between individual meaning and societal meaning of death and the current study is focused on developing a way to measure both individual and societal meanings simultaneously. Currently, there is no way to measure the perceptions that griever have of single deaths they have experienced. Measures of good death have been developed to capture what dying individuals hope for their own deaths (i.e.,



prospective). However, there is not a measure that allows griever the opportunity to retrospectively describe the death of another person. Humans think in complex ways about death and griever need a tool that allows them to go beyond the specific cause of a death to offer a richer, more meaning making-based and subjective description of the single death losses they experience.

My process for developing the Descriptive Death Scale (DDS) began with gathering words from the empirical literature used to describe death. Two areas of research were pertinent (i.e., grief-related and dying-related research) to build an expansive list of death descriptors. Grief-related researchers are predominantly focused on grief experiences and are most focused on factors that exacerbate grieving and their investigations are most often with people who have experienced bad deaths; whereas, dying-related researchers are most focused on how people describe death in order to facilitate good deaths. The DDS provides a new approach to assessing death because it is guided by griever, instead of researchers, and allows griever to describe their specific perceptions in nuanced ways. In addition to indicating their individual perceptions, griever use the same list of death descriptors to identify how well each word fits the way their society would describe their loved ones' deaths. The current study expands grief-related research by capturing a discrepancy score and measuring societal descriptions of death simultaneously with individual descriptions of death.

The DDS can also be used in the professional practice of psychology. The scale has clinical utility in that clinicians could use it to quickly understand how grieving clients describe their death experiences in nuanced ways. Further, clinicians could use it as an intervention in couples, family, and other systems focused interventions. The DDS would help clinicians uncover the dynamics of meaning within a system and facilitate systemic growth through

inventions targeting discrepant meaning within the system. For example, each member of a family may perceive a death by lung cancer differently. One may view the death as sudden because they “expected” the person to live beyond the doctor’s prognosis, whereas another might view the death as “timely” because they believed that the person’s death came at the reasonable end of his/her life course. Each perspective can be shared within family counseling which would enable growth for families searching for meaning and allow for enhanced empathy for each individuals’ unique perspective.

### **Statement of Purpose**

The purpose of the present study was to develop the DDS, a scale that assesses individual descriptions of a death as well as how individuals perceive societal descriptions of a death. From a constructivist perspective, the language that griever use to describe a death is a symbolic representation of the meaning that they have made from a death experience. Collected from qualitative research, I compiled a broad list of words associated with death and this list became the foundation of my multidimensional descriptive death scale. Respondents to the DDS rate the fit of each death descriptor twice, (a) once for how well the death descriptor fits their individual view of the death and, (b) again for how well they believe the death descriptor fits with society’s view of the death.

Central to the construction of the DDS, and the present study, is the statistical validity of the scale. Following the initial construction of the scale, I used exploratory factor analysis (EFA) to assess for underlying factors, and then I used confirmatory factor analysis (CFA) to test the initial factor model in a new sample. Finally, I assessed convergent validity by determining the relationships between DDS subscale scores and measures of grief distress, good death, and social desirability.

## **Relevance to Counseling Psychology**

The present study is grounded in the unique perspective counseling psychologists bring to their work. First, the focus of the study is on the experience of a death loss which is a normative life experience. Second, the study aligns with the identity of counseling psychologist through the unifying themes (i.e., strengths-based approach, person-environment fit, systemic interventions) described by Gelso and Fretz (2001) and Meara and Myer (1999). Finally, the study is connected to roles (i.e., remedial, educative, preventative) of the counseling psychology profession (Gelso & Fretz, 2001).

Counseling psychologists attend to normative concerns (Gelso & Fretz, 2001) and grief is a normative reaction to the death of a loved one. Just as death is a universal experience, grief is a normative response to death losses. Rather than viewing grief through symptomology and psychopathology, searching for meaning engages both cognitive and emotional processes which people use to make sense of death and integrate their sense into their overall understanding of the world.

Two key themes of the counseling psychology profession are a focus on client strengths (Gelso & Fretz, 2001), and each are connected to the current project through my theoretical foundation in constructivism and my emphasis on the needs of bereaved clients who present for therapy. At its core, constructivism is a strengths-based approach because each individual is viewed as having a natural propensity to move toward growth after trauma. Through constructivism, grievers move towards growth by harnessing cognitive and emotional processes that are innate to them. Clinicians who follow a constructivist approach focus on their innate strengths and many grievers experience growth within a few sessions.

Counseling psychologists see people within the context of their environment (i.e., person-environment; Gelso & Fretz, 2001), and the focus in the present study on the possible

discrepancy between individual and societal descriptions of a death is aligned with this focus. Individual meaning is intimately connected to societal meaning. As people come to understand and describe a death in their life, they must negotiate their meaning with the meaning others have of their death experience. Societal meaning of personal death experiences is a component of the environment counseling psychologists strive to understand as they work with an individual. The present study is rooted in understanding griever within their environment. The DDS allows for the specific assessment of both individual and societal descriptions of death.

Counseling psychologists bring attention to systemic biases (Meara & Myer, 1999) and the DDS has the potential to allow for a decrease in assumptions and stigma regarding specific causes of death. Grief researchers have predominantly used methods that stereotype grievers' experiences (e.g., categorizing bereft by suicide as sudden death), which has likely affected the understanding of grief overall. The present study is focused on developing a nuanced measure of death descriptions that focuses on grievers' descriptions of their personal experience. My hope is that the new measure will allow grievers more power in describing their experience rather than researchers categorizing them based on a specific cause of death. Additionally, grievers are regularly stigmatized by social descriptions of death. For example, family members who experience the death of a loved one by capital punishment may view the death as "unjust" because they have known the person to be more than what they were convicted for. However, society would describe the death as "just" and unworthy of grief because they view the person based solely on their crime. The DDS could be used to understand how social descriptions of death differ across a community and might allow for awareness-building community interventions.

Counseling psychology will benefit from the present study because the findings will directly apply to the functional roles (i.e., remedial, educative, preventative) of counseling psychologists. Counseling psychologists take a remedial role with their clients which means that they work with their clients to remedy a specific concern (e.g., grief; Gelso & Fretz, 2001). The findings of this study will help counseling psychologists to better understand the death experiences of their clients in a more nuanced and individualized way. Such deeper understanding will allow for more effective and efficient treatment of distress than those that current exists. In their educative role, counseling psychologist will have the option to use the DDS in grief workshops and outreach efforts. They can work with clients to educate them about the uniqueness of their own descriptions and predict for them how societal perspectives may be different. Closely connected to education is the process of prevention. Counseling psychologists could use the DDS with grieving family members as the measure has the potential to identify families who could be at risk for future grief-related difficulties (e.g., discrepant beliefs across family members). If family members have highly discrepant descriptions of a death, counseling psychologists could work with them prior to problems even arising.

In conclusion, the current study is connected to the unique perspectives counseling psychologists bring to their work. Grief is a normative developmental process. Further, in the current study, I am focused on developing a new method that can be used to address systemic biases in the measurement of death. Finally, the findings from the current study could be used by counseling psychologists in any of the roles they commonly take to work with people and their communities.

## Terminology and Concepts

Throughout this study, I use terms that may be unfamiliar to some readers. I have provided definitions for these terms in this section.

- The term *grief distress* is used to refer to the normative cognitive and emotional reactions people have after the death of someone important to them.
- The term *bereavement* refers to the death event.
- For this study, I have decided to use the term *discrepancy* to refer to the differences between individual descriptions of death and their perception of social descriptions of death.
- The term *meaning reconstruction* is used to refer to the intrapersonal and interpersonal processes people engage in to resolve distress that arises from stressful life events that challenge how they understand the world (Neimeyer, 2006). An essential feature is that meaning reconstruction functions within a narrative structure where meaning is symbolically conveyed through language and people understand their lives through an autobiographical narrative.
- The term *sense-making* is used to refer to a specific process in meaning reconstruction that compels grievers to search for a way to explain how their loved one died.
- The term *content of sense-making* is used to refer to the outcome of searching for meaning. As people choose the words that fit their experience, their words convey the meaning a life experience has for them and through their words grievers are able to symbolically share the meaning of life experiences.
- The term *individual descriptions* refers to the words an individual griever uses to describe a death they have experienced.

- The term *social/societal descriptions* is used to refer to a socially built description of specific deaths. These descriptions are generally associated with the label given to a cause of death and are built from the collective knowledge and myth about death that is exchanged across individuals in any given social group.

## **CHAPTER 2. LITERATURE REVIEW**

Despite empirical and clinical need, there is currently not a quantitative measure that captures griever's multidimensional descriptions of a particular death loss. The purpose of the present study is to construct and test the Descriptive Death Scale. The scale will expand how death experiences are understood; through descriptive breadth and multidimensional capacity, griever's will be able to convey their experience with complexity and in a quantitative format.

In this chapter, I summarize the literature related to my research questions and hypotheses and in so doing highlight the critical need for a multidimensional approach to measuring descriptions of specific death losses. First, I briefly describe (a) constructivism which is a theoretical framework that lends itself well to the process of how people come to describe death experiences and (b) social constructivism which shapes how individuals come to describe death experiences through their interactions with society. Second, I review grief-related theories and grief-related empirical findings relevant to how individuals perceive specific death losses. In so doing, I describe the theory of meaning reconstruction which is focused on making sense of and finding the words to describe personal experiences with death. Third, I outline the ways death descriptions are shaped by social interactions and societal meaning. Then, I briefly critique grief-related research and the current approach to measuring death descriptions. Finally, I review the current grief-related and dying-related empirical research on descriptions of death because these areas laid the foundation for the items I have included in the DDS. Finally, I provide my research questions and hypotheses.



## **Constructing Knowledge**

Although historical theories of grief (e.g., Kübler-Ross, 1969) simplified grief into concrete and seemingly universal stages, contemporary theories have shifted toward idiosyncratic and unique aspects of individual grief experiences. Constructivism has become a foundational theoretical approach used by contemporary grief theorists to conceptualize the idiosyncratic experiences of griever. I have selected constructivism as the theoretical foundation for my study because my focus is linked to the unique ways in which individuals describe their understanding of a death. According to constructivism, language symbolically represents the meaning people make of their life events; essentially, the words people use to describe their experiences are related to how they react to their life experiences. Social constructivism adds to the notion that people construct an idiosyncratic understanding of the world through their life events. Most specifically, people learn about the world through culture and society which means individual constructs are intertwined with socially constructed knowledge and descriptions of the world are intertwined with systemic descriptions of the world.

## **Constructivism**

A key focus of constructivism is that people grow to understand the world through their perception; perception captures their experiences and coalesces the meaning of their experiences into an entirely individual understanding of the world. Constructivism is defined as an epistemological theory grounded in the idiosyncratic system of knowledge people actively create (Neimeyer, 2001; Raskin, 2002). People create knowledge through their interpretation of experiences, and they then use that knowledge to understand and react to the world (Neimeyer, 1995; Neimeyer, 2009; Raskin, 2002). Neimeyer (2001) stated that important life events (e.g., death loss) often carry much of the meaning conveyed in autobiographical stories because these

experiences can become defining and pivotal moments for identity development and the shifting of world views. Meaning is formed into a coherent structure which represents an individual's understanding of existence in the world (e.g., I am safe, death is around the corner), and defines their autobiographical structure of personal identity (e.g., being a parent based on experiences with parents and cultural norms of parenthood). Therefore, the world is uniquely viewed and experienced from person to person. People exist and are guided by their interpretation of reality rather than reality itself. Additionally, the structure and organization of knowledge are dependent on the experiences of individuals within their society and in the context of their language (Chiari & Nuzzo, 1996).

Language captures meaning in a way that can be stored concisely in memory and can be communicated between people. Language is essential to organizing meaningful knowledge in that it provides a narrative structure that moves beyond a chronological remembering to the meaning-based linking of events throughout life. While memories include episodic memories (e.g., his car hit an evergreen tree), people can describe their thoughts and feelings from events (e.g., I've never liked evergreen trees since then). Over time, their thoughts and feelings form a narrative that describes a series of formative events as they have shaped their lives (Firvush, 2011; Moshman, 1982). Firvush (2011) offered, "whereas a chronology specifies a temporally organized sequence, a coherent narrative explains why this sequence unfolded as it did and why it matters for understanding of self and other in the context of a social cultural world" (p. 564). Instead of simply remembering events across time, people remember events as an autobiographical story that can be shared and can describe how they have come to be who they are in general and who they are specifically within the context of their unique life (Firvush, 2011; Neimeyer, 2009).

Further, language enables the social exchange of meaning through conversation (Firvush, 2011). Through conversation, people gain a better sense of self by sharing their perspective about the past. When people talk about the past, they hear how their perspective is similar to or different from the perspectives of others and then through comparison, they develop a sense of self as they differentiate their nuanced perspective from others' perspectives (Firvush, 2011). Therefore, language is a tool because it captures meaning in ways that can be organized, revised and conveyed (Firvush, 2011; Kelly, 1955, Neimeyer, 2009).

Although language provides structure for meaning, specific words are the vehicles people use to describe, convey, and differentiate nuances in their meaningful understanding of individual experience. Language is not just a way of *expressing* meaning, the specific choices people make about the words they use to describe specific life events actually *forms* meaning (Guidano, 1995). Words are a symbolic representation of the meaning people make of their experiences. Researchers have found that the specific words people choose to use to describe their experiences activate parts of the brain related to remembering emotional imagery (Gundel, O'Connor, Litterell, Fort, & Lane, 2003). An fMRI study assessed neurological responses of griever when they viewed grief-related words (i.e., words taken from their own grief narratives; Gundel et al., 2003). Gundel et al. (2003) paired either grief-related or neutral words with either a picture of the deceased or a picture of a stranger and then compared the neurological responses of the subsequent four groups. They found that grief-related words evoked grief distress even when these words were paired with pictures of strangers. The grief-related words alone activated an area of the brain (i.e., the precuneus) related to remembering imagery from lived experiences. The words elicited memories that specifically represented the events of their loved one's death;

the words symbolically captured their experience and triggered memories specific to their loved one's death. Words are integral to how people understand their life and their life events.

## **Social Constructivism**

While reality is subjective, meaning is dialectically connected to culture or society (Kelly, 1955; Neimeyer, 2001/2009; Raskin, 2002). Social constructivism emphasizes spheres (e.g., different cultural groups) of reality developed through interpersonal interaction. Cottone (2007) offered that “what is known derives from a consensual process that is linked to the traditions that underlie the language and culture within which consensualizing takes place...what is learned in language or in other ways of understanding comes from relationships” (p. 193). Through language, people learn the co-constructed meaning of their culture or society, which guides individuals as they navigate the social demands (e.g., etiquette; Firvush, 2013) of their culture or society and enables people to build social relationships (Cottone, 2007). In addition, social constructivism defines reality as not only constructed by individual perceptions but further defined within cultural or societal circles, therefore, creating culturally or societally bound realities (Cottone, 2001/2007; Maturana, 1985). For example, religious beliefs have been the center of war and conflict throughout history due to conflicting definitions of truth (Cottone, 2007).

Cultural systems (e.g., religions) influence the way people define, react to (e.g., punished or rewarded), place value on (e.g., good or bad), and ultimately make meaning of death (Kearle, 1989; Neimeyer, Klass & Dennis, 2014; Neimeyer, Prigerson, & Davies, 2002). Religious meaning-systems and traditions have defined the meaning of life and death for centuries (Flacks, 2010; Kearle, 1989). For example, *Pratica de asistir a los sentenciados a muerte*, written in the 17<sup>th</sup> century by a Jesuit priest of Mexico City, transformed death by public, criminal hanging into

a graceful, noble death through standards and traditions such as redemptive prayers, confessions of sin, public speeches imploring forgiveness, and displays of courage, dignity, repentance, and virtue (Flacks, 2010). Individuals sentenced to die had to preform to social demands to shift how their community would describe their death (i.e., from punishment brought on by criminal, sinful behavior to a graceful, noble or courageous death). From a cultural or societal perspective, deaths are ruled by and interpreted through social norms and values, where people may be offered redemption prior to death.

Across the United States, religion plays a significant role in defining death and dying even beyond the circumstances. In the Cherokee tradition, death is not sudden, rather it occurs over the course of a year as the four souls depart the body (Lefler & Weithaus, 2009). Religious ethical codes guide individuals in how they should care for the dying and define the meaning of deaths. For example, Judaism, Christianity and Buddhism take different views on medical treatment and disease. In Jewish Talmudic law, seeking medical care is essential because the body is property of God. Dorff (2009) wrote “Because the body belongs to god, each person is duty-bound to seek preventative and curative medical care and to follow the expert’s advice in preserving one’s health” (p. 93). In Christianity, allowing the disease to take its course could be interpreted as a natural death, particularly to avoid suffering. Moreover, Buddhist ethics of right and wrong are motivated by selfless intention (Mullen, 2009). Suicide can be unobjectionable so long as the state of mind is selfless at the moment of passing.

Religion has guided the behavior of the living to prepare them for death. When death occurs, people may believe, within the context of their cultural or society meaning systems, that bad deaths are the result of bad behavior and good deaths are the result of good behavior. In their qualitative study of good and bad death in a sample of elderly Bangladeshi people who identified

as Hindu or Muslim, Joarder, Cooper, and Zaman (2014) found that over half of their participants directly linked bad deaths to bad behavior and good deaths to good behavior. The view of death within cultural or societal systems are likely to be based on broad generalizations, whereas specific individuals who are coping with specific deaths are aware of and knowledgeable of the intimate details and uniqueness of the specific deaths. Grievors of suicide often feel compelled to hide how their loved one died (Bailey, Kral & Dunham, 1999; Doka, 2003; Jordan, 2006) because the word suicide is associated with meaning that has nothing to do with the person who died. It is, therefore, quite possible that individual descriptions of a specific death will be distinct from the cultural or societal descriptions of that same death.

Irrespective of specific deaths and specific grief experiences, societally driven definitions of deaths “police grief” (Neimeyer, Klass & Dennis, 2014) and define some deaths as unworthy of grief (Doka, 2002; Neimeyer, Klass & Dennis, 2014). Doka (2003) explained that when a death is identified as taboo (e.g., autoerotic asphyxiation, drug-related overdose, suicide) or insignificant (e.g., miscarriage, abortion) by cultural or societal norms, mourners often experience a number of obstacles in their search for support. Specifically, the way that society defines death, informs who should *be grieving* and who should *be grieved* (e.g., insignificant deaths are unworthy of grief). Families of people who die by capital punishment are particularly influenced by their communities because the person who dies is publicly, in media and court proceedings, often described as evil due to their crimes (Beck & Jones, 2007; Jones & Beck, 2007). The family may continue to love and cherish the person, whereas their community’s view of their loved one is shaped by the criminal proceedings and the media (Jones & Beck, 2007). Jones and Beck (2007) interviewed families of people who died by capital punishment and found that families were subjected to violent behavior from the community after their loved one was

executed. Participants in their study experienced their “vehicles being shot up, jobs lost, human feces left on doorsteps, and children being asked to leave their middle school,” (p. 293). Grievors can and do experience social avoidance, or harmful and invasive comments, questions, and behavior related to how their loved one died when their death is described as unnatural, bad or deviant in their culture (e.g., suicide, homicide, HIV/AIDs; Bailey, Kral & Dunham, 2000; Doka, 2002). Social definitions of death are key to understanding individual descriptions of death because grievors are still subject to social descriptions of death even when the broader social definitions of death conflict with the events of a specific death or the needs of a specific griever.

Discrepancies can exist between societal meaning and the individual meaning grievors make from the intimate details of their loved ones’ death. Even so, grievors must make sense of their loved ones’ deaths within the societal meaning system that defined their loved ones’ deaths. Whether grievors perceive a death to be good or bad, if their meaning is discrepant from society’s general meaning (e.g., grievors describes the death as good while socially describes the death as bad), grieving can be made more complex. For example, societal meaning within the United States (US) does not consistently describe the death of a child to miscarriage as significant (Doka, 2002). However, parents often describe the death of their child by miscarriage as significant and note they do not feel that they have the right to grieve because of the discrepancy between their individual meaning and the meaning prescribed by society (Doka, 2002; Hazen, 2003). To understand how people come to describe a death and the way that their death description is related to their grief, researchers must measure not only individual descriptions but also assess for the possible discrepancy between individual and societal descriptions.

## Grief-Related Theory

Constructivist theory has formed the foundation of meaning reconstruction, a current and key theory within the grief and bereavement field; meaning reconstruction has been expansively applied throughout grief research and practice. In this section, I introduce meaning reconstruction theory and describe sense-making. Sense-making is most related to how griever come to describe death and, therefore, sense-making is the activity that is most central to the present investigation. As people work to make sense of a death loss, they work to make meaning of it and select the words that seem to fit to describe it. Sense-making as a *process* involves gathering information about their loved one's death (e.g., circumstances of the death), and interpreting that information to develop an explanation for their loved one's death. Grievers interpret all of this information to form their perspective and ultimately describe the experience in their own words. The words they select are therefore the *content* of their sense-making. However, griever are confronted by discrepant meaning from society about their specific death experience and this discrepancy could influence the shape their grief experience.

One of the primary theories within the field of thanatology is the meaning reconstruction and loss model. Rooted in constructivism, this model is grounded in griever's idiosyncratic relearning of the world after a death. Additionally, theorists have begun to incorporate systemic and social constructivist elements into meaning reconstruction theory. Meaning reconstruction theory is grounded in a narrative meaning constructed from life experiences (Gillies & Neimeyer, 2006; Neimeyer & Prigerson, 2002). Making meaning is a continuous process as griever encounter new information about their loved one's death and encounter the meanings other people have for their loved one's death (Neimeyer, Klass & Dennis, 2014; Neimeyer & Prigerson, 2002). Additionally, it theorizes that people engage in multiple activities (i.e., benefit finding, identity change, sense-making) when life experiences challenge their narrative.



Meaning reconstruction is initiated by a rupturing experience, events such as death losses. Meaning can fail to predict events which challenges how people understand the world (Davis & Nolen-Hoeksema, 2001; Davis, Nolen-Hoeksema & Larson, 1998; Gillies & Neimeyer, 2006; Janoff-Bulman & Franz, 1997; Park, 2010). For example, people may no longer feel safe riding in a car after a loved one's death in a car accident (Gillies & Neimeyer, 2006; Janoff-Bulman & Franz, 1997). Park (2010) divides meaning into three distinct categories, (a) global meaning, (b) situational meaning, (c) content of meaning. Park (2016) subdivides global meaning into global beliefs (e.g., self-identity, religion/spirituality, human nature), goals (e.g., priorities, values), and sense of meaning (e.g., comprehensibility, purpose, and mattering). Situational meaning is the meaning that people make from situations that have not yet been integrated into their global meaning systems. The content of meaning is what people describe - the words they use to symbolically convey their meaning - when they describe their beliefs. Park (2016) argued that experiences, like a death loss, can challenge global meaning/belief systems.

Meaning reconstruction scholars have stated that sense-making is the central process in meaning reconstruction in that it has a stronger association with grief distress than benefit finding and identity change (Holland et al., 2006; Lichtenthal et al., 2010). Specifically, Holland et al., (2006) found that the extent of sense-making, in a large sample of college students, was negatively related to grief distress in the first two years after the death. Additionally, Davis et al. (1998) found that griever's extent of sense-making was positively associated with growth-related grief outcomes in the first 6 months of grief within a sample of 207 family members. Despite sense-making being an ongoing process, some people may not be able to comprehend why or how a death happened (Bailey, Kral & Dunham, 1999; Davis et al., 1998) and the ramifications of continuing to search for meaning, while never fully comprehending it, is associated with

greater grief distress. Keesee, Currier, and Neimeyer (2008) found that parents' extent of sense-making was associated with their grief severity, where parents with greater grief distress found little meaning in their child's death at the time of the survey. Finding an answer to the question, "Why" is often a focus of griever, particularly for those who experience violent or shocking deaths (Bailey et al., 1999; Currier et al., 2006; Lichtenthal et al., 2013).

Sense-making is most central to the present investigation because sense-making is a process focused on comprehending the death event – answering the why question. Making sense of the why is one area of narrative complexity. In other words, internal discrepancies trigger distress, distress initiates meaning making processes to minimize the discrepancy, and the result is the content of meaning (e.g., words) in their reorganized narrative. Indeed, sense making is an individual process which produces an idiosyncratic understanding of their death experience. Moreover, two griever of the same death could perceive different answers for why their loved one died. Discrepancies occur interpersonally because meaning is consensually built and exchanged within society.

Neimeyer (2014) theorized that meaning reconstruction engages people in intrapersonal (e.g., sense-making) and interpersonal (e.g., conversation, ritual mourning) activities that reorganize the global narrative structure they use to understand the world. Making sense of a death engages griever in a process of drawing conclusions from information to develop a descriptive narrative which, when they come to a comfortable explanation of how their loved one died, their worded description conveys the content of their developed meaning. *Sense-making* is defined as the process of articulating the experience into language, whereas *content of sense-making* is the product and content of making meaning (e.g., the specific words they use to

describe a death; Gillies et al., 2014; Park, 2010). Sense-making is particularly important because it is related to finding words that are the best fit to describe a death.

Searching for meaning is a process of finding the words that describe why a loved one died. Meert et al. (2007) found that parents of children who died by cancer sought follow-up meetings with the healthcare staff (e.g., doctors, nurses) to gain needed information about their children's deaths. Parents wanted to discuss the events that led to the child's death (e.g., a chronology of events, the cause of death, treatment) and understand that there was nothing more they could have done. One parent stated, "I want to know about her medicines and the different beds they had her in and what role they played and what were they hoping to accomplish by putting her in those beds and with the machines that they used on her," (p. 551, Meert et al., 2007). As grievors gather information, they begin to organize the information into a narrative that explains what caused their loved one to die. For example, parents discussed how their role could have contributed to the death (e.g., making choices about treatment), and they worked to ascribe blame (e.g., self-blame, blame medical staff; Eggly et al., 2015). The parents offered that hearing clear and direct language from medical professionals was essential because it enabled them to comprehend and describe the meaning of their child's death in words (Eggly et al., 2015). Through the conversations with medical professionals, grievors were able to begin to explain how their loved one died. The explanation of the death loss is the content of their meaning. For example, parents blamed themselves for their child's death, which means they view it as preventable.

As grievors come to describe a death, their meaning can be challenged by the broader societal definitions of death (e.g., heard through conversation with others). Neimeyer et al. (2015) argued that grievors explore meaning within their societal milieu (e.g., conversation with

co-workers, support groups, self-help books, fictional stories) and must interpret social meanings that may validate, reframe or be discrepant with their meaning made from the death. To understand how griever find the words to describe a death loss, researchers must understand how their society describes their death loss as well. Even in their conversations with medical professionals, parents encounter social meaning and not just facts about how their loved one died. Using qualitative grounded theory to analyze 75 interviews with physicians, Good et al. (2015) found that their discussion of specific deaths not only described the medical causes for death but described the meaning (e.g., good, bad) medical professional made of the death as well. Good et al. found that even though physicians may not “use the terms ‘good’ and ‘bad’ to describe their patients’ deaths, they clearly have reflected on their experiences and thought hard about what makes for positive, gentle, peaceful dying versus prolonged, torturous, painful dying,” (p. 23). The sense that physicians make becomes a part of the sense that griever make of death.

Eulogies are a concrete example of how meaningful conversations about death are facilitated by cultural and societal traditions and how societal sense-making (e.g., words used by eulogists to describe death) about death is passively communicated to griever. In a qualitative study of messages communicated during a eulogy, Davis, Quinlan, and Baker (2016) reported that eulogists described deaths (e.g., peaceful, painless, welcomed) to shape the meaning griever take away from the service and ultimately, shape how people grieve. However, one eulogist described the sense of responsibility, confusion, and pain of suicide and reframed the circumstances to imbue new meaning for the listeners (e.g., there was nothing that could be done, so no one is responsible; Davis, Quinlan & Baker, 2016).

Social meaning can be discrepant from individual meaning and can have a corrosive effect on grief. Nadeau (1998) conducted qualitative interviews with 10 grieving families to understand how meaning was built collectively after a family member died. To avoid rejection by their family, individuals and family subsystems often limit their discussion of discrepant beliefs to maintain their sense of belongingness. However, reluctance to disclose discrepant content of sense-making limits their support and ability to make sense of the death (Doka, 2002; Nadeau, 1998). Stillbirth deaths are an example of how social meaning can be discrepant from individual meaning. Parents can feel the need to grieve their child's death may but feel stigmatized and shamed by society for not simply moving on (Flenady et al., 2014). In the case of homicide, families often feel invisible under the criminal justice system and the public attention. Armour (2002) stated, "the social context that attends death by murder is different because the institutions and needs of society take precedence over the personal needs of the family," (p. 380). Discrepancies can invalidate the whole person who died or perceivably smaller circumstances of a death (e.g., preventable, mismanaged) which can influence how people grieve and inhibit sense-making. It is essential to understand how sense is made within the context of other meaning systems with respect to a multidimensional view of death that allows for specific words to rise and fall in levels of importance across grievers.

### **Death-Related Research: Death Descriptors**

To understand death in a balanced way, I needed to pull from interdisciplinary work. Specifically, grief researchers, who focus on deaths that intensify grief distress and end-of-life researchers, who focus on the factors that contribute to a good death. The direct investigations of death descriptions have been relatively dichotomous and divided by these research areas. Specifically, grief-researchers have been primarily interested in deaths that intensify grief

distress and grief literature is dominated by negative descriptors of death. End-of-life researchers are focused on facilitating positive end of life experiences. Most often qualitative investigation focus on factors that contribute to a good death. The descriptions of death have remained relatively dichotomous. Most pointedly, the end-of-life researchers most often investigate “good deaths.” I have structured research around this valence dichotomy. However, it is my purpose to unify death descriptions so researchers and clinicians may understand that it is a truly complex experience.

In this section, I outline the current findings of research focused on death descriptors broken into three parts. The first section is an overview of the methodological concerns that form the core rationale for creating the DDS. Specifically, the dichotomous treatment of death as good and bad, the categorization of griever driven by researchers' assumptions, the inconsistent use of descriptive terms by researchers, and the lack of focus on discrepant individual and societal descriptions of death. The following two sections offer the language used to describe death taken from grief-related research and dying-related research. I pull from both of these areas of thanatological research because I am focused on developing an expansive list of words that thoroughly captures a broad variety of death descriptions. Grief-related research is more clearly connected to my target population (i.e., grievers describing specific deaths) but researchers have explored grief and how death can exacerbate grieving (i.e., bad death descriptions). Whereas dying-related researchers more directly ask participants for descriptions of death, they are most focused on understanding how to facilitate a good death for dying patients and, therefore, are not focused on deaths outside of hospital settings.

### ***Grief-Related Research: Methodological Concerns***

The DDS makes a substantive contribution to the literature because there are currently not any instruments within the field of thanatology that allow for griever to retrospectively indicate their descriptive understanding of single death experiences. The dying-related literature includes measures that focus on “good deaths” and these measures are targeted toward the individuals who are moving through the dying process, but these measures are not focused on the perceptions of those who are companioning the dying individuals (e.g., family members, friends). In addition, the descriptions of deaths are actually quite complex and nuanced and do not neatly fall on a continuum from good death to bad death. With that in mind, the constructs measured by the existing good death measures, from within the dying-related literature, likely only correspond with select aspects of how good deaths might be described by griever. Most specifically, what a dying individual may view as elements of a *personally experienced* good death may be quite distinct from what their companions may view as elements of an *observed* good death. It is possible for a dying individual to wish for a swift death whereas their loved ones may hope that the death is more extended to allow for more engagement and interaction.

Researchers who do focus on how griever experience single deaths they tend to oversimplify the meaning or description of these deaths. They often categorize griever based on oversimplified labels or specific causes of death. For example, sudden and violent deaths are defined separately in the literature, but researchers do little to separate these variables methodologically. Predominantly, sudden and violent are used as a-priori descriptive categories. Researchers assign griever to these categories if they are bereaved by suicide, homicide and accidental deaths in order to study their target variable (i.e., sudden and/or violent). This assignment is done in a way that can and likely does stereotype perceptions of specific death experiences. For example, griever bereaved by suicide vary widely in their sense of suddenness,

whether or not the death was viewed as sudden, and, in fact, many do *not* view it as sudden (e.g., previous attempts; Armour, 2006).

Grief-related researchers use descriptive terms for death in different ways which can make the general interpretation of findings difficult. Whereas sudden and violent deaths are different experiences, there has been little done to separate these terms methodologically. Over the last three decades, at least 33 articles (i.e., I found these using Google Scholar) used sudden and/or violent death in the title of their publication (Appendix A). Of these studies, 20 sampled grievers only bereaved by suicide, homicide and accident deaths, and categorized them into sudden and violent deaths based only on cause of death. While researchers have tried to isolate sudden death by, for example, including natural, sudden deaths (e.g., heart attack), there has been little effort to separate sudden and violent deaths in their sampling method. Suddenness and violence are not exclusive to, nor defined by causes of death such as suicide, homicide and accidental deaths. However, grievers of suicide, homicide and accidental death have been automatically grouped as experiencing sudden and violent deaths which is problematic when these grievers might not use those words to describe their death experience (Armour, 2006). It is likely that these types of methodological problems have contributed to the recent inconsistent findings reported by Kristensen, Weisæth & Heir (2012) in their review of research focused on sudden and violent deaths.

Even when researchers appear to be working to be more nuanced in their description of deaths, the most specificity they seem to use is a focus on good versus bad death, an approach that is just not enough to capture the complexity of grievers' death descriptions. For example, physician-assisted death could be categorized as both a good or bad death. In reality, death is



much more nuanced and the DDS will measure death in a nuanced way by offering good and bad death words.

Another key and overarching criticism of the current research on death descriptors, is that it has been focused solely on individual (or researcher) descriptions of death and has lacked a focus on possible discrepancies between individual and societal descriptions of specific death losses. Descriptions of death can be just as complex from a cultural or societal perspective as they are from an individual perspective, but social descriptions of death are generalized assumptions about death disconnected from specific experiences. Discrepancies can arise at the intersections of these two complex descriptions and can conflict in ways yet to be understood. To understand discrepant meaning and how descriptions of death are shaped within a cultural or societal meaning system, it is essential to measure beyond cause of death and allow for idiosyncratic variability to rise in both individual and cultural and societal death descriptions.

The DDS is focused on improving upon each of these concerns and criticisms because the DDS is composed of a large list of death descriptors used by griever to describe both good and bad deaths. Grievers are able to identify how well each death descriptor describes their death experience which would for example, allow a griever to freely decide if their loved ones death was sudden, instead of a researcher deciding based on the cause of death. The DDS is composed of both good and bad death descriptors taken from qualitative investigations of death descriptions, allowing for an assessment that truly takes a complex, multidimensional view of death. Finally, the DDS allows for the assessment of potential discrepancies between individual and societal perceptions of specific deaths as respondents will use the same list of death descriptors to offer their view of how their society would rate the fit of each item.

### ***Grief-Related Research: Death Descriptions***

Despite the methodological challenges that do exist, research does indicate that griever convey the meaning of death experiences and how that meaning shapes their grief. For example, in Nadeau's (1998) qualitative study of grieving families, griever used a number of words to convey their nuanced meaning from particular aspects of a death, such as the nature of a death (e.g., random, natural, inevitable, controllable, preventable), the timing of a death (e.g., timely, prolonged, premature, hastened, expected, predetermined), the circumstances of a death (e.g., sudden, confusing, mysterious, comforting, self-caused, calm, peaceful, welcomed, unwanted, planned, prepared, unbelievable), the philosophical/spiritual meaning of a death (e.g., unfair, unjust, purposeless, purposeful, senseless, karmic, fateful, destined). While there are a number of concerns in grief-related research, it was essential to understand the research associated with the dominant terms in the field because it may be that some of the subscales that emerge from the DDS are likely to be related to the past research done on these words. The most dominant death descriptors used in the grief literature and research are (a) sudden, (b) violent, (c) preventable, (d) ambiguous, (e) stigmatized.

***Sudden.*** Sudden deaths are shocking and unpredictable, and associated with greater grieving distress, sense-making and psychological distress than non-sudden death losses (Armour, 2006; Kristensen Weisæth & Heir, 2012; Neria, Nandi & Galea, 2007; Sveen & Walby, 2008). Often, sudden deaths are premature and occur outside of what is considered natural to a person's life course. People bereaved by sudden deaths may have difficulty believing that their loved one is dead, and griever can be left with a sense of unfinished life/business (e.g., no goodbye, premature death; Kearle, 1989; Kristensen, Weisaeth & Heir, 2012). As they grapple with unnatural and incomprehensible circumstances, griever of sudden deaths often

report a difficult process of sense-making and exhibit greater rates of psychological distress than non-sudden deaths (Armour, 2006; Kristensen Weisæth & Heir, 2012).

***Violent.*** Grievors of violent deaths, often experience greater grief distress and higher levels of psychological distress than non-violent deaths (Armour, 2006; Currier et al., 2006; Kristensen, Weisæth & Heir, 2012; Neria, Nandi & Galea, 2007; Sveen & Walby, 2008). Violent deaths are characterized by their violent circumstances (e.g., physically disfiguring, grotesque). Many grievors report difficult processing and making sense of violent deaths (Currier et al., 2006) because violent deaths are physically painful for the victim and involve incomprehensible circumstances. Kristensen et al. (2012), in a review of the literature on violent and sudden deaths, indicated that grievors experience a greater risk for psychological concerns, namely post-traumatic stress disorder, major depression disorder, and prolonged grief disorder than non-violently bereaved.

***Preventable.*** The extent to which grievors perceive a death as preventable versus unpreventable is positively associated with grief distress, difficulty in the process of making sense, and greater endorsement of psychological concerns (Bailey, Kral, Dunham, 1999; Guarnaccio, Hayslip, & Landry, 1999; Jordan & McIntosh, 2011; Mathews & Servaty-Seib, 2006; Melham et al., 2007; Nadeau, 1998; Rynearsen, 2001; Sveen & Walby, 2007). Believing that death could have been prevented, grievors may blame the person who died for behavior that contributed to their own death, or may blame themselves, family members, or medical staff for behavior that contributed to the death of their loved one (Bailey, Kral, Dunham, 1999; Jordan & McIntosh, 2011; Kovarski, 1989; Nadeau, 1998; Rynearsen, 2001; Sveen & Walby, 2007). Grievors who blame the deceased, the self or others exhibit greater psychological distress than grievors who do not perceive a death as preventable (Melham et al., 2007).

***Ambiguous.*** Ambiguity shapes griever's experiences of death, the process of making sense of death and ultimately grief distress and psychological well-being overall. Ambiguity can exist within the circumstances of specific deaths which goes beyond what can be captured by cause of death. In their study of grieving parents, Egglee et al. (2015) found that griever's of natural deaths (e.g., respiratory, cardiac causes) can experience ambiguity. One family stated, "when we got the results back, basically we were told they didn't find anything wrong. So we're still left without an answer..." (p., 456). Ambiguous deaths occur when the circumstances of the death are poorly defined, confusing or unknown (e.g., missing person of war/kidnapping/natural disaster, circumstances of homicide/suicide, spontaneous miscarriage; Boss, 2002; Jordan & McIntosh, 2011; Kauffman, 2002; Keese, Currier, & Neimeyer, 2008; Kristensen et al., 2010; Parkes, 2008; Powell, Batello, & Hagl, 2010). Research indicates that the longer griever's spend waiting for a death to be confirmed, the greater the likelihood of being diagnosed with Prolonged Grief Disorder (Kristensen et al., 2010). Powell, Batello, and Hagl (2010) found that griever's of missing persons scored higher on measures of grief and depression than did griever's of people confirmed dead.

***Stigmatized.*** Societal meaning systems can stigmatize certain deaths and griever's who describe deaths as stigmatized experience a more difficult process of making sense of death, greater grief distress and score higher on measures of psychological distress (e.g., depression) than griever's of non-stigmatized death. If a death is defined as embarrassing (e.g., autoerotic asphyxiation, Doka, 2003; Rando, 1993) or punitive (e.g., capital punishment; Beck & Jones, 2007; Doka, 2003; Jones & Beck, 2007; Rando, 1993), griever's by their society, griever's report that they feel shamed by society for their loved ones' death. Grieving within the context of social stigma, griever's of suicide and abortion are compelled to hide the circumstances of these deaths

(Bailey, Kral, & Dunham, 1999; McIntosh & Kelly, 1992; Reed & Greenwald, 1991; Silvermen et al., 1994). Stigma is often attributed to violent losses (e.g., suicide, homicide, accidents) and the majority of research on stigma has focused on grievors of suicide and homicide (Armour, 2006).

### ***Dying-Related Descriptions: Death Descriptions***

Research about dying grew parallel to the growth of the hospice care movement in the late 1960's (Mak & Clinton, 1999; Saunders, 2000) and since then, researchers in hospice have developed a complex, multidimensional view of death and dying. The main goal of hospice is to facilitate a good death for those who in the midst of the dying process through holistic intervention by tending to the unique needs of individuals as they arise. Mak and Clinton (1999) asserted that a good death is defined as meeting the patient's wants and needs. Facilitating a good death means managing physical pain, preparing for death and meeting dying individuals' relational needs, while balancing their autonomy and sense of control as they grow to accept their impending death.

Findings from the dying-related literature indicate that pain, control and dignity, timing, awareness, and relational support are important dimensions of good and bad deaths (Mak & Clinton, 1999; Steinhauser & Tulsky, 2015). However, researchers continue to define death as a highly idiosyncratic, multidimensional experience, and nuanced meanings of a good death or bad death can differ from patient to patient (Carpenter & Van Brussel, 2012; Cipolleta & Oprandi, 2014; Hales, 2015; Mak & Clinton, 1999; Steinhauser & Tulsky, 2015; Vig, Davenport, & Pearlmen, 2002). The dying-related literature is critical as it is where I drew words from to form the items for the DDS and this literature will likely have relevance for the factors that emerge as a part of the DDS. It is essential to note that dying-related researchers predominantly sample

from dying and critically ill patients, whereas grief-related researchers sample from grieving populations. Despite, developing a measure for griever, I found that it was essential to use both areas of research to understand how good and bad deaths are empirically described.

***Pain.*** Pain is a prevailing concern consistent across studies, so much so that Meier et al. (2016) noted that pain is the key factor in understanding the difference between good deaths and bad deaths (Adorno & Brownwell, 2014; Broom, 2012; Gott et al., 2008; Hales, 2015; Holdsworth, 2015; Hughes, et al., 2008; Ko, Kwak, & Nelson-Baker, 2015; Lawrence et al., 2011; Pestinger et al., 2015; Robinson et al., 2010; Semino, Demjen, & Koller, 2014; Trankle, 2014; Volker & Wu, 2011). Dying without pain is essential for a good death experience. Studies have indicated that many people fear pain in different ways (e.g., physical, psychological, symptom or treatment related). As a result, people identify the need to control their pain symptoms throughout the process of dying. For example, people chose to hasten their death to mitigate prolonged suffering or lingering agonizing pain (Pestinger, et al., 2015; Pierson, Curtis, & Patrick, 2002). Additionally, dying is emotionally painful, and patients often experience a broad range of emotions (e.g., anxiety, fear, anger, sadness) as they grieve their own life and they may move towards denial or acceptance.

***Control.*** People who are dying wish for comfort, peace, respect, and dignity; they hope to control their physical care and course of treatment, maintain their ability to function both physically and psychologically, and die at a good time and place (Aleksandrova-Yankulovska & ten Have, 2015; Broom, 2012; Gott et al., 2008; Hales, 2015; Hattori & Ishida, 2012; Holdsworth, 2015; Hughes et al., 2008; Robinson et al., 2010; Semino, Demjen, & Koller, 2014; Trankle, 2014; Vig, & Pearlman, 2004). In a qualitative study, Adorno and Boswell (2014) found that dying veterans who felt in control of their symptoms and believed they could function as

usual felt a greater sense of purpose, felt more self-respect, and felt more dignity at the end of their lives. Volker and Wu (2011) found, through interviews with twenty terminally ill patients, that people identified control as a central need for them in order to experience dignity in the process of dying. Often they were proud of their ability to control their treatment, “bringing in reams of paper” (p. 1624) detailing the course of their failing health. When medical professionals fail to acknowledge the needs and desires of dying patients, they lose their sense of control (Lawrence et al., 2011; Lloyd-Williams et al., 2007; Pierson, Curtis, & Patrick, 2002; Semino, Demjen, & Koller, 2014; Trankle, 2014) and feel that their treatment is mismanaged (Masson, 2002; Payne, Langley-Evans, & Hillier, 1996; Steinhauser et al., 2000; Trankle, 2014; Volker & Wu, 2011).

***Dignity.*** Dignity is a complex concern central to patient distress while dying (Chochinov, McClement, & Kredentser, 2015; Chochinov et al., 2002a; Chochinov et al., 2002b) because it is connected to self-image at the time of death. Chochinov et al. (2002a) conducted semi-structured interviews with 50 patients with advanced stage terminal cancer. They asserted that “terms such as pride, self-respect, quality of life, well-being, hope, and self-esteem all overlap conceptually with the term dignity” (p. 444). Chochinov et al. (2002a) found that dignity was shaped by the course of the illness (i.e., independence, symptom distress) and the dynamic of relationships (e.g., social support, burden to others, aftermath concerns). Patients want to make decisions about their treatment and take part in end-of-life planning but their capacity to be involved could be stripped by their illness and their social support. Researchers conducting qualitative studies with dying patients have found that dignity is related to physical functioning, independence, the quality of treatment, emotional and physical pain, and personhood (e.g., respected, dehumanized, stigmatized; Broom, 2012; Chochinov et al., 2002; Gott et al., 2008; Holdsworth, 2015; Ko,

Kwak, & Nelson-Baker, 2015; Semino, Demjen, & Koller, 2014; Trankle, 2014). Through the course of dying, people face debilitating symptoms that can strip them of their ability to function independently, an experience often tied to identity and self-worth in Western ideology. For example, patients mentioned in multiple studies that they just wanted to feel heard and respected by medical staff. One person stated, “The doctors tried to talk me out of it [ending treatment], and it’s just like, it’s MY body. I feel it’s not going to do anything for me... it was important for me to have control over that.” (p. 1623, Volker & Wu, 2011).

**Timing.** Approaching death, people hope to die at a good time by trying to balance their deteriorating health and closing their life (e.g., saying goodbye, end of life planning) without prolonging their death and lingering in pain (Adorno & Brownwell, 2014; Broom, 2012; Holdsworth, 2015; Ko et al., 2012; Pestinger, et al., 2015; Trankle, 2014). Uncertainty is embedded within the nature of end-of-life planning because terminal illnesses are often unpredictable and treatment may do little to mitigate the symptoms. Most people wish to avoid a prolonged death which is frequently associated with living in pain (e.g., agony, suffering) or with unnecessary medical intervention (e.g., intubated vegetative state; Broom, 2012; Ko et al., 2012; Ko, Kwak, & Nelson-Baker, 2015; Lloyd-Williams et al., 2007; Low, & Payne, 1996; Masson, 2002; Payne, Langley-Evans, & Hillier, 1996; Steinhauser et al., 2000). Conversely, some people wish to die suddenly without any knowledge of their imminent death. Vig, Davenport, and Pearlman, (2002) found that many participants described dying suddenly and in their sleep as a good time for their death because they would not be conscious at the *moment* of death. Whereas a sudden death may undermine their ability to speak to family, patients who prefer a sudden death, in their sleep, describe that death as peaceful, calm and comfortable.



***Awareness.*** Awareness is related to feeling prepared for death and finding peace, rather than denying death and feeling unprepared for death. Linked with the construct of time is the awareness of dying with the key elements being the chance to prepare for death, close life, and, therefore, experience a sense of peace. Historically, the awareness of dying has been viewed as an opportunity for personal growth through open communication about death in order to move toward acceptance (Kubler-Ross, 1969). Patients who welcomed awareness, viewed awareness of death as an opportunity to close and grieve their life (i.e., initiates acceptance, end of life planning; Broom, 2012; Gott, et al., 2008; Hales, 2015; Holdsworth, 2015; Ko, Kwak, & Nelson-Baker, 2015; Pestinger et al., 2015; Semino, Demjen, & Koller, 2014; Steinhauser et al., 2000; Volker & Wu, 2011). At times, patients do not want to know that they are dying. For example, Gott et al. (2008) interviewed 40 elderly people diagnosed with advanced heart failure. All participants were aware of their impending death and all, but one, experienced difficulty living peacefully without denying their death. Gatt et al. (2008) asserted that denial could be an important aspect of coping and enable people to balance the weight of their impending death and enjoy their life peacefully in the ways that they can.

***Relational Support.*** Relational support (e.g., family, friends, professional staff) is related to whether people die feeling connected, comfortable, and loved versus lonely and unloved (Adorno & Brownwell, 2014; Aleksandrova-Yankulovska & ten Have, 2015; Broom, 2012; Hales, 2015; Ko, Cho, Perez, Yeo, & Palomino, 2012; Ko, Kwak, & Nelson-Baker, 2015; Lawrence et al., 2011; Semino, Demjen, & Koller, 2014; Trankle, 2014). Many patients reported that caring support from family and friends was important for them to feel comfortable and that the presence of their loved ones would be integral at the moment of their death (Adorno & Brownwell, 2014; Gott et al., 2008; Hales, 2015; Ko, Kwak, & Nelson-Baker, 2015; Semino,

Demjen, & Koller, 2014; Steinhauser et al., 2000). Dying alone is generally considered a bad death by most patients but may be a particular fear for people who are homeless (Ko, Kwak, Nelson-Baker, 2015) and elderly people living alone (Lloyd-Williams, Kennedy, Sixsmith, & Sixsmith, 2007).

### **Summary of Research Questions and Hypotheses**

Death is both described and experienced in complex and multidimensional ways. The description of specific deaths are not measured by grief researchers in a way that parallels the experience of death or the process of grieving. Rather, researchers often create descriptive categories based on mode of death rather than asking participants to describe their own sense of a single death. In fact, this concern is likely connected to the fact that there has not been, to this point, a quantitative measure that could allow griever to endorse a variety of death descriptors.

To determine how grief distress may be connected with the meaning (i.e., death description) that grievers associate with specific death losses, it is essential to develop a new scale that multidimensionally captures grievers' idiosyncratic descriptions of specific deaths. Through the DDS, researchers will be better able to capture unique descriptions of death in a multidimensional and continuous way. In addition to measuring individuals' individual descriptions of a death, I have designed the current version of the DDS to also assess individuals' descriptions of how their society would generally describe the death. This dual focus (i.e., individual and society descriptions) allows for the quantification of the potential discrepancy between individual and perceived societal views of specific deaths.

The purpose of the present study is to further the process of development and validation of the DDS. Specifically, I will (a) use the first half of my community-based sample of grievers to determine the underlying factors/subscales of the Descriptive Death Scale and (b) use the

second half of my community-sample to confirm the initial factor structure. Additionally, I will (c) assess for convergent and divergent validity by determining the associations between DDS factors/subscales and measures of good death (i.e., subscales of The Concept of a Good Death Measure – Closure, Personal Control, Clinical) and social desirability (i.e., Marlowe-Crown Social Desirability Scale- Form C), (d) assess the associations between the underlying DDS factors/subscales and a measure of grief distress (i.e., Core Bereavement Items), and (e) determine whether the discrepancy between individuals' individual descriptions of the death and their perceptions of societal descriptions of the death contributes to grief distress beyond the individuals' individual descriptions alone (i.e., their scores on the underlying DDS factors/subscales).

The present study has five primary questions, each with at least one associated hypothesis. The first three questions are focused on scale development and validation, whereas the final two are focused on examining the relationships between the DDS factors/subscales that emerge and grief distress.

**Research Question #1:** What are the underlying factors/subscales of the DDS?

Hypothesis 1: At least two factors/subscales will emerge that generally reflect constructs of good and bad death.

**Research Question #2.** Do the underlying factors/subscales fit the data from a similar sample?

Hypothesis 2: The initial factors/subscales will be consistent, with regard to fit, across samples.

**Research Question #3.** Will the DDS factors/subscales that emerge (e.g., good and bad death) be associated with existing measures of good death and social desirability?

Hypothesis 3: The good death factors/subscale will be positively associated with the subscales of the good death scale (i.e., Concept of a Good Death Measure – Closure, Personal Control, Clinical).

Hypothesis 4: The DDS factors/subscales that emerge will not be associated with social desirability.

**Research Question #4:** Will the DDS factors/subscales that emerge (e.g., good and bad death) be associated with grief distress?

Hypothesis 5: The good death factor/subscale will be negatively related to grief distress.

Hypothesis 6: The bad death factor/subscale will be positively related to grief distress.

**Research Question #5:** Will the discrepancy between individual and societal descriptions of the death make a significant contribution to grief distress above and beyond the individual descriptions (e.g., DDS good and bad death factors/subscales)?

Hypothesis 7: The extent of discrepancy will positively and significantly contribute to grief distress above and beyond individual descriptions of death (e.g., DDS good and bad death factors/subscales).

## **CHAPTER 3. METHOD**

The current study grew out of the need to develop a scale that quantitatively assesses the way that people describe specific deaths within the context of societal meaning. The process of scale development began with building an initial version of the DDS based on theoretical literature and qualitative scholarship.

Most of the method section is focused on describing the foundation of the DDS and on delineating how I designed the DDS to capture a multidimensional description of death. Prior to the DDS development process, I provide details regarding my sample and data collection procedure. Following those sections, I describe the process I used to develop the DDS. In addition to the process of building the DDS, I more briefly describe my how I captured the discrepancy scores between individual responses to the DDS items and the item responses based on their view of the how they believe society would describe their specific death experience.

### **Participants**

The final sample included 572 adults (i.e., 18 and older) from the United States (US) who experienced the death of a loved one within the prior two-year period. See data screening section for information regarding the data screening procedures that reduced the sample down from the initial response group. To perform independent analyses and meet minimum magnitude for significance, 400 participants were required to create two independent samples for the exploratory factor analyses and the confirmatory factor analysis (Tabachnick & Fidell, 2014). Therefore, the final sample surpassed the minimum number required to perform my primary analyses. The sample was limited to English-speaking participants, as the items in the DDS have not been translated into other languages. The sample was not limited by geography (i.e.,

recruitment was throughout the US) or any demographic variables (e.g., race/ethnicity, sex, sexuality).

The final sample consisted of 491 (85.8%) cisgender female, 54 (9.4%) cisgender male participants, and 27 (4.8%) trans Male or trans Female participants. Participants ranged in age from 18 to 80 years old ( $M = 42.7$ ;  $SD = 12.9$ ;  $n = 572$ ). The sexual orientation distribution of the participants was: 83.6% ( $n = 478$ ) Heterosexual, 4.2% ( $n = 24$ ) Same-Sex, 10.1% ( $n = 58$ ) Bisexual and 2.1% ( $n = 12$ ) self-identified (e.g., Asexual, Sapiosexual). The participants self-reported as: 477 (83.4%) White/European American (not of Hispanic origin), 11 (1.9%) Black/African American, 3 (.5%) Asian, 23 (4%) Hispanic/Latino, 21 (3.6%) Biracial/Multiracial, 26 (4.5%) self-identified (e.g., American), and 3 (.5%) did not report race/ethnicity. Further, the participants identified their US regional location as 195 (34.1%) South, 160 (28%) Midwest, 110 (19.2%) Northeast, and 107(18.7%) West. Finally, participants identified their religious context as 231 (40.4%) Christian, 119 (19.8%) Spiritual but not religious, 85 (14.9%) Agnostic, 68 (11.9%) Atheist, 9 (1.6%) Buddhist, 9 (1.6%) Jewish, 9 (1.6%) Pagan, 8 (1.4%) Wiccan, 2 (.3%) Muslim, 3 (.5%) Secular, 18 (3.1%) preferred not to answer, and 29 (5%) self-described (e.g., polytheist, non-practicing catholic).

With regard to death losses, participants indicated how they were related to the person who died with 219 (38.3%) indicating parent, 93 (16.3%) partner/spouse, 65 (11.3%) child, 65 (11.3%) grandparent, 45 (7.9%) sibling, 30 (5.2%) friend, 19 (3.3%) aunt/uncle, 6 (1%) cousin, and 30 (5.2%) self-described (e.g., love of my life, best friend). Age of the deceased ranged from 0 (e.g., stillborn) to 105 years ( $M = 59.9$ ,  $SD = 22.1$ ). Causes of death included 121 (21.3%) cancer, 85 (14.8%) other illness, 51 (8.9%) heart attack, 44 (7.7%) organ failure, 42 (7.3%) lung cancer, 34 (5.9%) suicide, 29 (5.1%) drug overdose, 23 (4%) accident, 19 (3.3%) Chronic

Obstructive Pulmonary Disease, 18 (3.1%) unknown, 17 (3%) Alzheimer's/dementia, 17 (3%) old age/natural, 15 (2.6%) car accident, 12 (2.1%) homicide/murder, and 25 (4.2%) self-identified (e.g., complications from surgery, stillbirth). Time since the death ranged from less than 1 month to 24 months ( $M = 12.29$  months,  $SD = 7.3$ ).

## **Measures**

In this section, I describe the measures I used for the present study. In each case, I describe the purpose of the measure, provide scaling information, offer example items, note any applicable subscale information, and indicate reliability and validity. The measures I used were a demographic questionnaire, an assessment of closeness to the deceased, an assessment of social desirability, an assessment of good death beliefs, and an assessment of grief distress. The primary focus of the present study was the development of the DDS so details regarding this scale are included in its own development section rather than in the measure section.

### ***Demographic Questionnaire***

Participants responded to a series of questions focused on demographic data (Appendix B). Specifically, the demographic questions asked for information regarding their sex, age, sexuality, race/ethnicity, religion/spiritual, socioeconomic status, relationship status and regional location. Participants also responded to questions specifically focused on the death they experienced (i.e., relationship to the deceased, cause of death, and time since death).

### **Emotional Closeness**

The Scale of Emotional Closeness (SEC; Servaty-Seib & Pistole, 2006) is a 7-item measure that was developed to assess bereaved participants' emotional closeness (i.e., emotional

awareness, openness, and understanding) to the deceased (Appendix C). Participants respond to the items using a 7-point scale ranging from 1 (*very strongly disagree*) to 7 (*very strongly agree*). Example items include, “I felt I could share my most intimate feelings with this person.” and “I kept my distance emotionally from this person.” I will use the total score in the present study with higher scores indicating greater closeness.

With regard to psychometrics, Servaty-Seib and Pistole (2006) found the SEC total scale scores to be reliable ( $\alpha = .87$ ). The internal consistency of SEC scores based on the current sample was .92. In terms of the validity, total SEC scores are positively correlated with grief (Texas Revised Inventory of Grief; Servaty-Seib & Pistole, 2006), prolonged grief (Prolonged Grief Disorder-13, Ring, 2009), and post-death suicidality (The Yale Evaluation of Suicidality, Ring, 2009).

### **Social Desirability**

The Marlow-Crowne Social Desirability Scale- Form C (MCSD-C; Crowne & Marlowe, 1960; Reynolds, 1982) is a 13-item measure that was developed to assess how likely participants were to have answered in ways that are more socially appropriate (i.e., faking-good; Appendix D). Participants indicate whether the items are true or false. Example items include, “I sometimes feel resentful when I don’t get my way,” and “I always try to practice what I preach.” I will use the total score in the present study with higher scores indicating more social desirability.

Regarding psychometrics, Reynolds, (1982) found scores on the total scale to be reliable ( $\alpha = .91$ ) as did Servaty-Seib, 2014 ( $\alpha = .75$ ). The internal consistency of MCSDS-C scores based on the current sample was .66. In terms of the validity, total MCSDS-C scores were



positively correlated with other scales of social desirability (Edwards Social Desirability Scale, Reynolds, 1982).

## **Good Death**

The Concept of a Good Death Measure (CGDM; Schwartz, Mazor, Rogers, Ma, & Reed, 2003) is a 17-item measure that was developed to assess the core dimensions of a good death (e.g., peaceful, acceptance of dying, intact mental awareness, closure, pain; Appendix E). The measure was originally designed for research within the field of hospice. As the measure was created to prospectively assess the importance of a good death for people in the dying process, I minimally edited the scaling anchors and question stems to focus retrospectively on a specific death experience. For example, in response to the item “that it [death] be painless or largely pain free,” I modified the negative scaling anchor from *not necessary* to *not at all*. In this way, the items could be evaluated by someone grieving a death rather than someone facing their own death. Participants respond to the items using a 4-point scale ranging from 1 (*not at all*) to 4 (*a great deal*). Example items include, “the dying period was short” and “loved ones were present.” Schwartz et al., (2003) found the CGDM items grouped into three distinct subscales (i.e., closure, control, clinical). However, I used the subscale scores (i.e., Closure, Personal control) with higher scores indicating greater endorsement of the CGDM core dimensions of a good death.

With regard to psychometrics, Schwartz et al., (2003) found scores on the subscales to be reliable (closure,  $\alpha = .75$ ; control,  $\alpha = .83$ ; clinical,  $\alpha = .62$ ). The internal consistency of CGDM subscale scores based on the current sample was .78, .87 and .41, respectfully. In terms of validity, Closure was positively associated with death anxiety (approach-acceptance,  $r = .18$ ; Death Anxiety Profile- Revised, DAPR; Wong, Reker & Gesser, 1999) and religious coping

(beliefs practices,  $r = .12$ , support,  $r = .06$ ; Systems of Belief Inventory, SBI; Holland et al., 1998). Personal control positively associated with death anxiety (fear of death,  $r = .24$ , death avoidance,  $r = .25$ ; DAPR, Wong, Reker & Gesser, 1999) and negatively associated with religious coping (beliefs practices,  $r = -.14$ , support,  $r = -.18$ ; SBI, Holland et al., 1998). The CGDM clinical subscale was positively associated with death anxiety (escape-acceptance,  $r = .19$ ; DAPR, Wong, Reker & Gesser, 1999).

### **Grief Distress**

The Core Bereavement Items (CBI; Burnett, Middleton, Raphael, & Martinek, 1997) is a 17-item measure that was developed to assess the core grief/bereavement experience of grieving adults (e.g., distressing/intrusive images and thoughts, reaction to separation, emotional experiences; Appendix F). Participants respond to the items using a 4-point scale ranging from 1 (*a lot of the time*) to 4 (*never*) which were reversed scored in the analysis. Example items include, “Do thoughts of the important person make you feel distressed?” and “Do you experience images of the events surrounding your family member’s death?” Burnett et al. (1997) found the CBI items grouped into three subscales (i.e., images and thoughts, acute separation, grief). However, I will use the total score in the present study with higher scores indicating greater grief distress.

With regard to psychometrics, Burnett et al. (1997) found scores on the total scale to be reliable ( $\alpha = .91$ ) as did Holland, Nam & Neimeyer, 2012 ( $\alpha = .95$ ). The internal consistency of CBI scores based on the current sample was .93. In terms of the validity, total CBI scores are negatively correlated with sense-making and benefit finding (Keesee, Currier, & Neimeyer, 2008) and positively correlated with The Inventory of Complicated Grieving- Revised (ICG-R, Holland, Nam, & Neimeyer, 2013).

## **Procedures**

The present study was approved with exemption from the Purdue University IRB. Following the receipt of exemption, I began recruiting participants through online recruitment and alternatively planned to advertise with hardcopy flyers. I chose these recruitment methods because I believe they will optimally result in a large US community sample.

In the first method, I used online snowball sampling by posting a recruitment flyer to organizational listservs and social media websites. To reach a broader community, I asked for the help of organizations with a significant internet presence and requested to send an email or post the recruitment message (Appendix H) to the listserv or online forum. The recruitment message briefly described the nature of the present study and contained a link to my survey. I planned to ask national organizations focused on the topics of grief, bereavement, and mourning (e.g., Open to Hope, AfterTalk, Compassionate Friends).

Through social media (e.g., Facebook), and online blogs (e.g., Reddit; Appendix I), I reached potential participants through interacting with forum leaders, personally posting advertisements in online groups, and paid advertising campaigns. I was purposeful in the process of recruiting participants from underrepresented religious groups (e.g., Hindu, Sikh, Muslim, Jewish), racial/ethnic representation and regional culture. Additionally, I posted and advertised in high traffic groups (e.g., reddit announcements, dataisbeautiful) and topic driven grief support groups (e.g., general grief support, specific family member death). After taking these steps, I had 2015 participants. For this reason, I did not continue to recruit participants. Both the flyer and recruitment message contain the recruitment criteria (i.e., 18 or older, English speaking, experienced a death of a within the last two years).

In my alternative recruitment, I would have advertised for the study by posting flyers at local organizations (Appendix G). I planned to visit community groups and organizations (e.g.,

churches, hospitals, libraries, restaurants, community organizations) and ask if I could post a recruitment flyer. With permission, I would have posted the flyer with a general date for the flyer to be discarded. The flyer briefly described the nature of the study. Further, I planned to have perforated pull tabs with the web address of the survey.

People who wished to participate followed the link and read the online consent. The online consent described the purpose of the study, the risks and benefits of their participation, the voluntary nature of their participation, the time required to complete the survey and the contact information of the IRB and the researchers. Participants chose between, “I agree to participate. I understand I can choose to withdraw at any time,” or “I do not agree to participate and wish to exit the survey now.”

Participants who decided to continue were directed to the online Qualtrics Survey and were given the option to leave the survey on every page. Those who completed the survey were directed to a thank you message. If participants chose to opt out at any point in the survey, they were directed to the thank you message no matter when they opted to leave the survey. Participants were required to answer any specific question, but if they left a question blank they were prompted regarding their lack of response and asked if they would like to complete the missing items or continue forward while leaving the item blank.

The participants’ responses were protected in multiple ways. No identifying information was gathered beyond the demographic data. The collected data will only be reported anonymously and in aggregate. Additionally, data was stored on a secure password-protected online server which is only accessible to the researchers and will be made available to the Purdue IRB, if requested.

## **Construction of the DDS**

Below I describe my process for constructing the DDS which began with a review of the best practices for scale development. Following my scale development process, I discuss the construction and calculation of the discrepancy score.

To construct a reliable and sound scale, Worthington and Whittaker (2006) and Kuhn (2006) provide best practice recommendations for scale development. I provide an overview of the procedures for (a) item development and scale structure, (b) preliminary analyses, (c) EFA and (d) CFA. Integrated within the description of best practices are the steps I have followed thus far and my assumptions for steps and analyses as I move forward with the present study.

### ***Item Development and Scale Structure***

To begin, Worthington and Whitaker (2006) referred to Devellis (2003) who offered specific steps for the process of item development: (a) determine the construct, (b) generate items, (c) develop the format, (d) acquire expert critique, (e) consider validation items, (f) administer to a test sample, (g) evaluate the items, and (h) optimize length.

An essential component of scale development is defining the construct and maintaining the construct validity through the item development process. Through sound theory and research, a clearly defined construct will guide not only the item development process but also the format and structuring process. Gaining expert opinion is recommended after developing an initial item pool because experts can offer constructive critiques of the construct definition, formatting, design, and item level concerns (i.e., construct validity).

My initial scale development process began with operationalizing the construct and theoretically grounding it in constructivism (i.e., determine the construct). The focus of my scale is to capture how people meaningfully describe the specific death of a family member. From a

constructivist perspective, griever's use words to symbolically describe their idiosyncratic perspectives of specific deaths. Searching and finding words to convey death experiences is an integral component of sense-making; the sense-making process is intrinsically grounded in constructivism and is an essential process of grieving a death.

To develop items for the DDS, I focused on qualitative death descriptions of death from griever's (i.e., from the grief-related research) and death descriptions from individuals who were dying (i.e., dying-related research). In this initial stage, it was my goal to develop a broad definition of death and surveyed interdisciplinary qualitative work. I focused on death descriptions that conveyed meaning about the process of dying and circumstances of death. The two areas of research I sampled from were grief-related and dying-related. I began with grief-related research but quickly noticed that researchers in grief are interested in the determinants increase grief distress (e.g., violent, traumatic, stigmatized). While the dying-related literature does not sample strictly from griever's, palliative medicine and hospice care researchers are most interested in facilitating wellness and positive growth in the process of dying so their qualitative research has focused on positive descriptions of death. Therefore, the death descriptors I selected as the foundational items for the DDS were gathered from a total of 36 studies and the death descriptors were only retained if I found them in at least 3 of the 36 studies. To illustrate my results at this step, I created two tables that include the list of death descriptors with the corresponding studies I found them in. Additionally, Appendix J, Table 1 contains the death descriptors I gathered from grief-related research, whereas Appendix J, Table 2 contains the death descriptors I gathered from dying-related research.

To develop the DDS structure, I used the repertory grid technique (Kelly, 1955) and The Threat Index (TI, Rigdon, Epting, Neimeyer, & Krieger, 1979) as example scales with similar

constructs and scale structure. The format of the DDS is modeled on Kelly's (1955) repertory grid because researchers and clinicians use the repertory grid technique to explore individual meaning. Through in-person interviews, a professional guides a participant through the development of a list of paired death descriptors that describe their perception of a particular experience (Neimeyer, 2009). However, the TI (Rigdon, Epting, Neimeyer, & Krieger, 1979) was more directly applicable to my scale development. Through qualitative interviews, Rigdon et al. (1979) developed a list of bipolar death descriptors that described the general public's overall sense of the construct of death. The scale was developed for the purpose of measuring death anxiety. The self-administered measure is a 40-item list of common bipolar constructs related to death (e.g., good vs. bad, predictable vs. random). In this way, constructivist methods tend to use opposite adjective anchors and to direct participants to respond based on the alignment of their perceptions using a continuum that runs between the two adjectives. However, in order to capture the most multidimensional description as possible, I decided to direct griever to offer the fit of each individual death descriptor. So, for example, I could have asked them to identify their death experience on a continuum between predictable or random. Instead, griever will indicate the extent of the fit for each death descriptor (e.g., predictable, random) separately. Importantly, a bipolar scale does not lend itself to EFA and CFA and the possible emergence of factors/subscales. Additional guidance was provided by the Positive Affect and Negative Affect Schedule-X (i.e., formatting of the scale; PANAS-X; Watson & Clark, 1999) and the Perceived Impact of Life Events Scale (i.e., pilot data on various formats) as they are both single-word item scales.

The initial version of the DDS contained 65 items and each item was only a single word death-descriptor (e.g., insignificant, judged) which allowed for depth and breadth to capture

multidimensional descriptions of death as well as minimize the burden of the survey. The DDS items are scored on a 5-point scale 1 (*not at all fits*) to 5 (*absolutely fits*). Please reference Table 1 which includes the DDS items, administration formatting, structure, and directions.

Table 1 Descriptive Death Scale

Directions: From your perspective, please indicate how well each word below **fits** with how **you would describe** the particular death that you indicated earlier (i.e., the closest period who has died in the past two years) and how **others in society would describe** the death you indicated earlier. As there are many ways that people can and do describe a particular death, there are no right or wrong answers.

Please indicate how well each word **fits** with **your** description of the death and how well each word fits other descriptions in **society** of the death on a scale of 1 to 5.

1 = fits not at all    2 = fits a little    3 = somewhat fits    4 = mostly fits    5 = fits extremely well

	not at all	a little	somewhat	mostly	extremely well	not at all	a little	somewhat	mostly	extremely well
How well does each word fit	<b>YOUR</b> description					<b>Society's</b> Description				
Accidental	1	2	3	4	5	1	2	3	4	5
Agonizing	1	2	3	4	5	1	2	3	4	5
Ambiguous	1	2	3	4	5	1	2	3	4	5
Anticipated	1	2	3	4	5	1	2	3	4	5
Burdensome	1	2	3	4	5	1	2	3	4	5
Calm	1	2	3	4	5	1	2	3	4	5
Caring	1	2	3	4	5	1	2	3	4	5
Chaotic	1	2	3	4	5	1	2	3	4	5
Cold	1	2	3	4	5	1	2	3	4	5
Comfortable	1	2	3	4	5	1	2	3	4	5
Confusing	1	2	3	4	5	1	2	3	4	5
Dehumanizing	1	2	3	4	5	1	2	3	4	5
Deserved	1	2	3	4	5	1	2	3	4	5
Desirable	1	2	3	4	5	1	2	3	4	5
Dignified	1	2	3	4	5	1	2	3	4	5
Discussed	1	2	3	4	5	1	2	3	4	5
Expected	1	2	3	4	5	1	2	3	4	5
Fated	1	2	3	4	5	1	2	3	4	5
Fearful	1	2	3	4	5	1	2	3	4	5
Happy	1	2	3	4	5	1	2	3	4	5
Hastened	1	2	3	4	5	1	2	3	4	5
Hopeless	1	2	3	4	5	1	2	3	4	5
Ideal	1	2	3	4	5	1	2	3	4	5



Table 1 continued

How well does each word fit	YOUR description					Society's Description				
Insignificant	1	2	3	4	5	1	2	3	4	5
Intentional	1	2	3	4	5	1	2	3	4	5
Judged	1	2	3	4	5	1	2	3	4	5
Just	1	2	3	4	5	1	2	3	4	5
Lingering	1	2	3	4	5	1	2	3	4	5
Lonely	1	2	3	4	5	1	2	3	4	5
Meaningful	1	2	3	4	5	1	2	3	4	5
Misunderstood	1	2	3	4	5	1	2	3	4	5
Mysterious	1	2	3	4	5	1	2	3	4	5
Natural	1	2	3	4	5	1	2	3	4	5
Negligent	1	2	3	4	5	1	2	3	4	5
Painful	1	2	3	4	5	1	2	3	4	5
Peaceful	1	2	3	4	5	1	2	3	4	5
Planned	1	2	3	4	5	1	2	3	4	5
Premature	1	2	3	4	5	1	2	3	4	5
Preventable	1	2	3	4	5	1	2	3	4	5
Prolonged	1	2	3	4	5	1	2	3	4	5
Quick	1	2	3	4	5	1	2	3	4	5
Random	1	2	3	4	5	1	2	3	4	5
Relieving	1	2	3	4	5	1	2	3	4	5
Respectful	1	2	3	4	5	1	2	3	4	5
Self-determined	1	2	3	4	5	1	2	3	4	5
Self-induced	1	2	3	4	5	1	2	3	4	5
Sensationalized	1	2	3	4	5	1	2	3	4	5
Shocking	1	2	3	4	5	1	2	3	4	5
Spiritual	1	2	3	4	5	1	2	3	4	5
Stigmatized	1	2	3	4	5	1	2	3	4	5
Sudden	1	2	3	4	5	1	2	3	4	5
Suffering	1	2	3	4	5	1	2	3	4	5
Taboo	1	2	3	4	5	1	2	3	4	5
Timely	1	2	3	4	5	1	2	3	4	5
Traumatic	1	2	3	4	5	1	2	3	4	5
Unacceptable	1	2	3	4	5	1	2	3	4	5
Uncontrollable	1	2	3	4	5	1	2	3	4	5
Unfair	1	2	3	4	5	1	2	3	4	5
Unwanted	1	2	3	4	5	1	2	3	4	5
Violating	1	2	3	4	5	1	2	3	4	5
Violent	1	2	3	4	5	1	2	3	4	5
Wasteful	1	2	3	4	5	1	2	3	4	5
Welcomed	1	2	3	4	5	1	2	3	4	5
Moral	1	2	3	4	5	1	2	3	4	5
Immoral	1	2	3	4	5	1	2	3	4	5

To clarify the content validity of a scale, Worthington and Whitaker (2006) recommended that researchers seek expert opinion to critique the measure. It is most important to receive feedback on the content of the scale; however, feedback on, for example, the clarity and conciseness of a measures' instructions and items, and the overall structure of a measure can also be quite helpful. From the expert feedback (G. Thornton, personal communication, October 28, 2016), I made suggested changes by removing seven item and added two items (i.e., happy and shocking). Thornton stated that a five-point scale should be sufficient. Overall, he commented that the content and structure of the scale overall and the directions were straightforward and clear.

Although running a pilot study is a recommended practice, such a process for the present study would be limited to gathering feedback on the structure and clarity of the DDS. The content of the DDS is straightforward in that participants were asked how much the single-word death descriptors fit their description. When appropriate, researchers with broadly exploratory measures and solid constructs have continued without a pilot study. The Positive Affect and Negative Affect Schedule-X (PANAS-X; Watson & Clark, 1999) is one example which is composed of 60 single word items rated on 5-point scale informed the formatting of the DDS. Specifically, the PANAS-X takes 5 to 10 minutes to complete indicating that the current 63 items of the DDS may not be overwhelming for respondents. Further, the Perceived Impacts of Life Events Scale (PILES; Servaty-Seib, 2014) is another single-worded item scale which informed the formatting of the DDS. Specifically, Servaty-Seib (2014) found in her pilot study that participants responded to her measure despite the length (i.e., 80 items). As a safeguard, I will include an open-ended question for participants to offer feedback on the scale content at the end

of the measure. By foregoing a pilot study, I will also be able to reserve my main recruitment procedures for my primary purposes.

### **DSS Factors, Discrepancy, and Grief Distress**

In order to test Hypothesis 7, I needed to compute a discrepancy score for each participant. I accomplished this task through a series of steps. First, I calculated item level differences between each participants' individual ratings of each item and their perceptions of society's ratings of each item. For example, if a participant marked one for their individual description and five for social description then their score was 4; moreover, the calculation would be the same if the scores were switched. In other words, I used the absolute value. Therefore, I had 65 columns of difference scores. Finally, I summed the absolute values of the differences for all 65 items and created a final column of total discrepancy score for each participant. In other words, I calculated the difference between individual and societal descriptions. I focused on a simple discrepancy score to explore the function of the discrepancy score with the novel scale.

After computing the discrepancy scores, I performed a hierarchical multiple regression. A hierarchical multiple regression allows researchers to test the unique contribution of nested variables in a linear model by controlling for covariates in the first step of the regression. The dependent variable for the regression was grief distress. In step 1, I entered the control variables (i.e., age of the deceased and closeness). In step 2, I entered the independent variables of individual DDS factor/subscales scores (e.g., good and bad death). In step 3, I entered the independent variable of discrepancy (i.e., difference between individual and the societal ratings). Step 2 allowed me to determine if the good death factor/subscale of the DDS and the bad death subscale factor of the DDS are negatively and positively related to grief distress (H5, H6). Step 3

allowed me to determine if death discrepancies significantly contributed to grief distress above and beyond individual death descriptions (H7).

## **CHAPTER 4: RESULTS**

In this chapter, I describe the results of my analyses toward developing a descriptive measure of death. To begin, I explain my initial data screening. Following, I detail my primary analyses. Specifically, I describe my procedure for exploratory factor analyses and confirmatory factor analysis and highlight my integration of best practices in my decision-making process. After I provide the findings of the EFA and CFA to confirm the DDS factors, I go on to describe concurrent and discriminant validity through providing correlations between the DDS factor scores and planned measures of comparison. Next, I examine the predictive validity of the DDS factor scores through performing a multiple regression with grief as the dependent variable. Finally, I report the findings related to my adding discrepancy scores to the multiple regression; my focus here was to determine if discrepancy scores explained variance in grief above and beyond that offered by the DDS factor scores.

### **Data Screening**

In this section, I explain how I cleaned my data set (e.g., criteria for inclusion). I go on to detail how I processed and critiqued missing data and outliers given the recommendations for best practices. Finally, I report the internal consistency and normality for the measures I used to assess validity (i.e., Good Death – Subscales, Social Desirability Scale).

### **Missing Data, Outliers, and Internal Consistency**

My data screening procedure began with identifying participants who gave their consent, fit the inclusion criteria, and responded to 95% or more of the total survey. Of the 2015 individuals who initially followed the link to the Qualtrics survey, 1.4% ( $n = 30$ ) did not consent

and 17.9% ( $n = 361$ ) discontinued after giving consent, reducing the total number to 1624.

Regarding my inclusion criteria, .8% ( $n = 17$ ) were under 18, 5.7% ( $n = 115$ ) lived outside of the United States, 30.5% ( $n = 315$ ) reported more than 24 months had passed since their loved one died, and 1% ( $n = 21$ ) indicated deaths beyond my recruitment criteria (e.g., multiple deaths, non-human family), reducing the total number to 1156.

Regarding missing data, I reviewed the data and determined that 582 participants had left more than 5% of the survey blank. Whereas the majority of those removed for missing data were missing a whole measure or more, there were two participants who skipped answers throughout, and their missing responses totaled more than 5% missing across all questions. Based on the recommendation made by Tabachnick and Fidell (2014), I removed these participants from the data file reducing the sample to 575. Finally, I removed 2 participants for invalid responses (i.e., single responses for whole measures, “me” as deceased loved one) bringing the sample down to 573. By using the Missing Values Analysis in SPSS, I determined 49 individual missing responses across 33 different items. Little’s MCAR did not reach significance ( $p = .98$ ), which indicated that these 49 missing data points were likely missing at random. After ensuring randomness, I used linear trend at point to impute the missing data.

Following the missing value analysis, I computed total scores for each of the demographic and validation variables and analyzed the total scores for univariate and multivariate outliers. Issues related to outliers in terms of the DDS items are addressed below in the primary analyses section. I analyzed univariate outliers by first visually examining the boxplots for each variable. Closeness to the deceased was the only variable to have outliers. Following the recommendations of Aguinis et al., (2013), I analyzed the z-scores of the closeness measure and found six participants exceeded the recommended cut-off score of  $\pm 3.29$ .

Although some scholars would argue that univariate outliers should always be removed, more recent opinion is that retaining outliers may present a more realistic picture of the data (Aguinis et al., 2013; Watkins, 2018; Zijlstra, et al., 2011). I determined to retain these six participants in the data set because low closeness to the deceased can be normative in some cases. Finally, I used Mahalanobis distance and identified one participant as a multivariate outlier and determined to remove the participant from the data set. Resulting in a final sample size of 572, representing 28% of the 2015 individuals who initially clicked on the link to the survey.

Following data screening, I determined the internal consistency of my continuous demographics, validity variables, and my dependent variable (see Table 2). Scores for most of my scales displayed strong internal consistency. Specifically, my results indicated alphas as follows: Good Death – Closure ( $\alpha = .78$ ), Good Death - Control ( $\alpha = .87$ ), Social Desirability ( $\alpha = .66$ ), closeness to the deceased ( $\alpha = .92$ ) and grief distress - CBI ( $\alpha = .93$ ). See Table 1 for additional descriptive data on these variables.

Table 2. Descriptive Data of Validity Measures, Closeness, and Grief

Variable	Mean	SD	Minimum	Maximum	Cronbach's alpha
1. Good Death – Closure	21.97	6.59	9.00	36.00	.78
2. Good Death – Control	7.56	3.35	3.00	12.00	.87
3. Social Desirability	16.67	2.41	11.00	22.00	.63
4. Closeness	39.95	9.60	7.00	49.00	.92
5. Grief Distress	48.23	11.47	19.00	68.00	.93

As I computed the consistency scores, I determined that I needed to eliminate the Good Death – Clinical Subscale ( $\alpha = .41$ ) from further consideration in my study. It was one of my planned validity measures. Tabachnick and Fidell, (2013) indicated reasonable internal consistency with Cronbach alphas of above .70 and the result for scores on the Good Death – Clinical was far below this guideline. I worked to explore issues such as data entry errors, reverse scored items, and weak items. At best, my results indicated an internal consistency for Good Death – Clinical of .54. With limited literature to attempt further theoretical and statistical exploration, I determined the prudent choice was to drop the subscale. I believe that the questions may not have functioned well to capture “good” qualities of death outside of a hospital. The Good Death - Clinical subscale contains questions about suddenness (e.g., the dying period was short, the death was sudden and unexpected). The scale was constructed to capture descriptions of death in hospital settings; descriptions that may not translate across all settings where deaths occur. Suddenness is often associated with shocking deaths and could have mixed meaning depending on the context of their loved one’s death (e.g., sudden deaths in hospitals versus in homes).

Although it was below .70, the reliability for scores on the Social Desirability scale in the present study was comparable to other short forms in terms of length (i.e., Form X1 = 10 items, Form X2 = 10 items, Strahan & Gerbasi, 1972; MC Form A = 11, Reynolds, 1982) and internal consistency (i.e., X1  $\alpha = .64$ , X2  $\alpha = .62$ ; Strahan & Gerbasi, 1972; MC Form A  $\alpha = .69$ , Reynolds, 1982; 11-item  $\alpha = .69$ , Ballard, 1992).

### **Testing Assumptions**

After I cleaned the data and prepared total scores, it was necessary to check that the data met the assumptions of normality and homoscedasticity. Issues of linearity and multicollinearity



are addressed in the primary analyses section, after the DDS factors were determined and prior to my performing of the multiple regression using DDS factor scores as the independent variables and grief distress as the dependent variable.

Beginning with normality, I checked if the data (i.e., for grief, good death subscales, and social desirability) were skewed and kurtotic based on the recommendations of Cohen et al. (2003). They recommended dividing skewness and kurtosis by the respective standard errors scores, wherein a variable is skewed or kurtotic if it is beyond  $\pm 2.58$ . One variable scored outside of Cohen et al.'s (2003) cut off score. The CBI was negatively kurtotic and flat (i.e., kurtosis =  $-.770$ , SE =  $.204$ ) with a kurtotic statistic of  $-3.77$ . Curran et al. (1996) argued that researchers should be critical and cautious of data kurtotic at  $\geq 7$ . Because the CBI did not reach this level, I determined to not perform any transformations.

Next, I examined homoscedasticity for grief distress as well as the good death subscales and social desirability. I visually assessed scatterplots of the standardized residual values plotted against standardized predicted values. I did not see any clear patterns in the scatter plot and determined that it did not violate homoscedasticity.

### **Preliminary Analyses**

In preparation for the multiple regression analysis that I ultimately performed between the DDS factors and grief distress (RQ4, RQ5), I needed to analyze the relationships between my primary DV of grief distress and the dichotomous and continuous demographic and background variables to assess for possible significant effects.

To evaluate the magnitude of the correlations between my dependent variable (i.e., grief distress), and my continuous demographic (e.g., age,) and death-related variables (e.g., age of deceased, closeness to the deceased), I performed bivariate correlations and reviewed the results

for significant, strong effect sizes (i.e.,  $r \geq .30$ ; Cohen, 1988). Because closeness to the deceased and age of the deceased were strongly correlated with grief distress, I determined that I would include closeness ( $r = .40, p < .001$ ) and deceased's age ( $r = -.45, p < .001$ ) in step 1 of the multiple regression I performed to address RQ4 and RQ5. However, the results of the correlation for participants' age ( $r = -.13, p < .001$ ) and subjective social class ( $r = .12, p < .001$ ) did not indicate strong effect sizes.

Following the bivariate analysis, I performed a series of ANOVAs to determine possible group differences in grief distress based on the categorical demographic variables (i.e., race, ethnicity, sex, sexual orientation, religious identity, regional location, employment status, relationship status) and the death-related categorical variables (i.e., cause of death, relationship to the deceased). Based on the results of the one-way ANOVAs (see Appendix K), I found cause of death had significant group differences in grief distress (i.e., CBI scores),  $F(11,561) = 3.037, p < .001$ . However, additional testing indicated that the effect was small. Specifically, the partial eta squared value was .056 which is below the recommended cut off medium effect size (i.e., partial eta squared,  $\eta_p^2 \geq .13$ ; Pierce, Block, & Aguinis, 2004).

## **Primary Analyses**

In this section, I describe how I developed the DDS. Specifically, I used the best practices for EFA (RQ1, What are the underlying factors/subscales of the DDS?) and I used best practices for CFA (RQ2, Do the underlying factors/subscales fit the data from a similar sample?). I also provide my statistical and/or theoretical rational for changing my proposed processes given the results or updated best practices (e.g., Watkins, 2018). Then, I describe the results of the discriminant and convergent validity tests (RQ3, Will the DDS factors/subscales that emerge be associated with existing measures of good death and social desirability). Finally, I review my

regression findings in connection with assessing the predictive validity of the DDS factors (RQ4, Will the DDS factors/subscales that emerge be associated with grief distress?) and the discrepancy total score (RQ5, Will the discrepancy between individual and societal descriptions of the death make a significant contribution to grief distress above and beyond the individual descriptions).

### **Data Screening of DDS items**

I visually and statistically examined the DDS data for missing data points. Of the missing data on the DDS, a total of 32 items were missing 41 random data points. Of the missing items, two items (i.e., calm missing 5; shocking missing 4) were missing more than two data points. When there is less than 5% of data missing at random, best practices indicates multiple methods as appropriate (Schumacher, 2015; Watkins, 2018) for statistically replacing missing data. I used linear trend at point to estimate the missing data points.

### ***Dividing the Sample***

To randomly divide the sample, I used the Select Cases function under the Data tab in SPSS. With Select Cases, I selected the random sample selection option and specified the number of cases to be drawn from the entire sample (i.e.,  $n = 286$ ).

### **Exploratory Factor Analyses**

In this section, I describe the process I used to perform EFA using half ( $n = 286$ ) of my overall sample in order to address my first research question (i.e., What are the underlying factors/subscales of the DDS?). With regard to the best practices for EFA, Worthington and Whitaker (2006) focused on specific procedures including (a) sample characteristics, (b) the

criteria assessing factorability, (c) the extraction methods, (d) the rotation methods and the rationale used to choose the method, (e) the criteria for factor retention, (f) the criteria for item deletion, and (g) the rationale and the criteria in editing scale length. In addition, Watkins (2018) expanded on these areas with updated references and resources which I refer to throughout. However, the basic content of his recommendations was aligned with those offered by Worthington and Whittaker (2006).

### ***Sample Characteristics***

The sample ( $n = 286$ ) exceeded my minimum sample of 200 participants to conduct the EFA (Watkins, 2018; Worthington & Whitaker, 2006). Also, the sample was well represented by the description of the overall participant pool which means the sample was mostly White/European American, cisgender female and heterosexual (83.2%, 78%, and 83.6%, respectively). Ages ranged from 18 to 80 ( $M = 42.19$ ,  $SD = 12.51$ ). Participants reported that they were mostly grieving the death of a parent (37.8%), child (11.2%) or romantic partner (10.5%) who died by cancer (27%) or another illness (26%). When they were filling out the survey, participants reported a mean of 12.09 ( $SD = 7.34$ ) months had passed since their loved one died.

### ***Factorability***

In terms of factorability, I used the Bartlett's Test of sphericity and Kaiser-Meyer-Olkin (i.e.,  $> .6$  indicate adequacy) to assess whether the sample was sufficient in size to assess for factors beyond chance (Kahn, 2006; Watkins, 2018; Worthington & Whitaker, 2006). Both the Bartlett's Test of sphericity ( $p < .001$ ) and the Kaiser-Meyer-Olkin (.85) indicated sampling adequacy for factorability in these data and I proceeded with the analysis.

### ***Factor Extraction***

Factor extraction was the first step in uncovering the factor structure of the DDS. I used common-factors analysis, more specifically principal-axis factoring, as it is the most preferred procedure indicated in EFA best practice articles. Common-factors analysis is recommended for researchers attempting to build a measurement instrument and identify meaningful, latent constructs (Fabrigar & Wegener, 2012; Watkins, 2018). Principal-Axis Factoring (PAF) and Maximum Likelihood (ML) are primarily recommended (Kahn, 2006; Watkins 2018; Worthington & Whittaker, 2006). I chose to start with PAF because Watkins (2018) indicated, in his review of best practices, that PAF outperforms ML. Although, Watkins (2018) stated that it is good practice to ensure results are replicated with another estimation method which is why I decided to use ML in a secondary analysis.

### ***Factor Rotation***

As with extraction, I followed best practices in selecting my *initial* rotation method based on statistical assumptions and analyzed my data with Promax. Promax is recommended because it begins as an orthogonal rotation and becomes oblique. Whereas Promax provides theoretical and statistical flexibility, I determined that the data were too intercorrelated to extract meaningful factors. I continued to use PAF for extraction but shifted to Varimax for rotation which minimized the interitem correlations and rendered appropriately discreet factors based on the data.

### ***Factor Retention Process***

For the present study, I used visual assessment of the scree plot and parallel analysis to determine the appropriate number of factors to retain. Parallel analysis is an example of a factor

retention method where researchers compare the eigenvalues of the original data to randomly generated eigenvalues. The randomly generated eigenvalues are plotted against the original eigenvalues and factors are retained if the original data exhibit larger eigenvalues than the generated eigenvalues, with the assumption that the factor structure is not random (Kahn, 2006). Kahn (2006) asserted that this is the strongest methods for assessing factor retention and recommended syntax for SPSS written by Thompson and Daniel (1996).

Although I was guided by statistical best practices and theoretical sense, the factor retention step was protracted and iterative. I began with visual analysis of the scree plot which indicated 5 factors and I used parallel analysis to generate eigenvalues at random. Parallel analysis did little to add to my decision making because my results did not drop below the randomly generated eigenvalues for the first factors. Specifically, the original eigenvalues were higher than the randomly generated values for 11 factors. The eigenvalues from data reflected the sharp drop at the fifth factor (i.e., 3 to 2).

Therefore, my analysis began without forcing any factors and I then analyzed the results for factor solutions ranging from 3 to 10. I attempted to understand a range of solutions to capture the information given by the scree plot and parallel analysis. I found factor solutions made little sense below 4 factors and above 6 factors because factors began to lose internal theoretical meaning beyond that range. I determined that a 5-factor solution represented the strongest model. Specifically, the forced 5 factors structure emerged as theoretically meaningful and statistically robust.

### ***Item Deletion Process and Scale Length***

To reduce the length of the DDS and to increase the interpretability of the factors, I adjusted the factor loadings and cross-loadings to maximize the simple factor structure.

Worthington and Whittaker (2006) explained that these criteria are based on preference and they recommend adjusting criteria (i.e., factor loadings at highest minimum, cross-loadings lowest absolute magnitude) to maximize the simple structure of the scale with fewer low magnitude cross-loading items. Worthington and Whittaker recommend a minimum difference of .15 between factor loadings and cross-loadings. The criteria I used to determine item retention and deletion included factor loadings (i.e.,  $\leq .50$ ), cross-loadings (i.e.,  $\geq .35$ ), absolute loadings (i.e.,  $\geq .32$ ), and item communalities (e.g.,  $\leq .30$ ). As I analyzed the factor solutions, my initial cut-off criteria were factor loadings of  $\leq .50$  and cross-loadings of  $\geq .30$ . Initially, I attempted to exceed the Worthington and Whittaker difference criteria of .15. However, I relaxed my criteria to retain two additional items which minimally enhanced the internal consistency of two factors.

### ***EFA Findings***

Based on EFA process described above, the EFA results indicated 5 theoretically and statistically robust factors and addressed my first research question (i.e., What are the underlying factors/subscales in the DDS?). In total, I deleted 33 items because they did not meet statistical criteria. The remaining 32 items loaded on five factors that I labeled as Factor 1, Factor 2, Factor 3, Factor 4, and Factor 5. I specifically determined not to name these initial factors until determining if they were stable following confirmatory factors analysis (see confirmatory analysis below). Factor 1 included the following 8 items ( $\alpha = .87$ ): shocking, sudden, random, unfair, premature, unacceptable, traumatic, and mysterious. Factor 2 included the following 10 items ( $\alpha = .85$ ): respectful, peaceful, moral, meaningful, spiritual, calm, happy, desirable, ideal, and natural. Factor 3 included the following 4 items ( $\alpha = .83$ ): intentional, self-induced, taboo, stigmatized, and planned. Factor 4 included the following 5 items ( $\alpha = .70$ ): lingering, prolonged, suffering, painful, and fearful. Factor 5 included the following 4 items ( $\alpha = .72$ ):

caring, chaotic dignified, and comfortable. Please see Table 3 for the rotated factor loadings and Cronbach's alpha scores.

The purpose of the EFA was to answer RQ1 (i.e., What are underlying factors/subscales of the DDS?) Based on the analyses, I found five factors to appropriately fit these data. My hypothesis for RQ1 was at least two factors/subscales would emerge that generally reflected constructs of "good" and "bad" death (H1). The results indicated support for my hypothesis. Most specifically, Factors 2 and 5 generally reflect good death and Factors 1, 3, and 4 generally reflect bad death.



Table 3. Exploratory Factor Analysis: Rotated 5 Factor Loadings

<i>Rotated Factor Matrix</i>					
	Factor				
	1	2	3	4	5
Shocking	<b>.80</b>	-.23	.10	.20	-.01
Sudden	<b>.78</b>	-.26	.09	.02	-.09
Random	<b>.65</b>	-.15	-.01	.10	-.02
Unfair	<b>.58</b>	.01	.16	-.27	.02
Premature	<b>.56</b>	-.14	.13	.29	-.03
Unacceptable	<b>.54</b>	-.11	.09	.30	-.01
Traumatic	<b>.53</b>	-.19	.21	.35	-.05
Mysterious	<b>.51</b>	.12	.16	.15	.06
Respectful	-.20	<b>.69</b>	-.11	-.11	.03
Peaceful	-.16	<b>.67</b>	-.12	-.37	-.01
Moral	-.03	<b>.62</b>	.03	-.02	.01
Spiritual	.00	<b>.57</b>	-.10	-.07	.08
Meaningful	-.04	<b>.57</b>	.10	.03	-.15
Calm	-.29	<b>.56</b>	-.07	-.31	.06
Happy	-.05	<b>.53</b>	.03	-.07	.07
Natural	-.18	<b>.52</b>	-.29	-.15	-.01
Desirable	-.19	<b>.51</b>	-.01	-.10	.07
Ideal	-.17	<b>.50</b>	-.02	-.26	.00
Self-induced	.08	.03	<b>.75</b>	.03	.07
Taboo	.13	-.02	<b>.73</b>	.17	.02
Intentional	.07	-.10	<b>.72</b>	.15	-.07
Stigmatized	.18	.02	<b>.70</b>	.24	.02
Planned	-.14	.20	<b>.54</b>	-.05	.01
Suffering	.09	-.14	.13	<b>.62</b>	.09
Painful	.18	-.27	.06	<b>.61</b>	.09
Fearful	.24	-.07	.16	<b>.61</b>	-.04
Lingering	-.21	.22	.00	<b>.56</b>	.06
Prolonged	-.30	.18	.00	<b>.50</b>	.01
Caring	-.08	.13	-.06	.21	<b>.69</b>
Chaotic	.11	.25	.06	.12	<b>-.64</b>
Dignified	-.08	.18	.11	-.01	<b>.63</b>
Comfortable	.03	.23	.07	-.02	<b>.53</b>

## **Confirmatory Factor Analysis**

In this section, I describe my process of confirming the EFA factors using the second half of my data set in order to address RQ2 (i.e., Do the underlying factors/subscales fit the data from a similar sample?). I hypothesized that my initial emergent DDS factors would be consistent, with regard to fit, across another sample (H2). I followed best practices, according to Worthington and Whitaker (2006), who emphasized the following components of CFA: (a) sample-size criteria, (b) using SEM over alternative methods, (c) fit indices and the criteria for their use, and (d) concerns of model-modification.

### ***Sample and Sample-Size***

Indeed, Worthington and Whitaker (2006) recommended a sample size of at least 100 participants. My sample ( $n = 286$ ) was the second half of the greater participant pool which was gathered in a single recruitment phase (see Servaty-Seib, 2014 for a similar approach). The subsample I used for the CFA, as was the case for the EFA subsample, reflected the overall sample population. The subsample was mostly White/European American, cisgender female and heterosexual (83%, 85%, and 84%, respectively). Their ages ranged from 18 to 73 ( $M = 43.13$ ,  $SD = 13.40$ ). Participants reported that they were mostly grieving the death of a parent (38.4%), child (11.1%) or romantic partner (11.8%) who died by cancer (30%) or another illness (27%). Participants reported a mean of 12.54 ( $SD = 7.14$ ) months had passed since their loved one died.

### ***SEM versus Exploratory Structural Equation Modeling***

Whereas it was my original plan to use AMOS to perform the CFA/SEM (Worthington & Whittaker, 2006), the complexity of my factor structure was more appropriate for ESEM using

Mplus (Marsh et al., 2014; Muthén & Muthén, 2011). AMOS is well suited for independent clusters model of confirmatory factors analysis (ICM-CFA) when there is a unidimensional structure. However, the factors on my scale would not intuitively provide a total score because of the apparent dimensional complexity across the factors. For example, Factor 5 was significantly correlated with *only* Factor 2 ( $r = .11$ ,  $p = .05$ ). Marsh et al., (2014) reported that it is common for researchers to not meet goodness of fit using traditional ICM-CFA for dimensionally complex scales because “all cross-loadings typically constrained to be zero in CFA are freely estimated in EFA, so ICM-CFA structures are much more restrictive than EFA structures” (p. 87).

Marsh et al., (2014) described ESEM as a robust statistical process that overcomes many of the problems in CFA (e.g., exaggerated factors correlations in CFA, poor tests of fit due to biased estimates in SEM). They identified a growing body of literature on ESEM (e.g., Aparouhov & Muthen, 2009; Brown, 2006; Byrne, 2010; Cudeck & MacCallum, 2007; Marsh et al., 2009; Sass & Schmitt, 2010) and highlighted researchers who used ESEM to address structural concerns in complex measures due to limitations of CFA (e.g., Big Five personality measures; Furnham et al., 2013; Marsh et al., 2010). I chose to transition to ESEM with Mplus (Muthén & Muthén, 2011) because it is well supported. Further, I was still able to apply the best practices statistical tests I originally proposed.

### ***Fit-Indices and Model Modification***

To evaluate fit, I followed the recommendations of Worthington and Whitaker (2006) and Kline (2005) who argued for the following fit indices: (a) the chi-square (including  $df$  and significance), (b) the Root Mean-Square Error of Approximation ( $RMSEA < .10$ ;  $RMSEA$  confidence interval = 90%), (c) the Comparative Fit Index ( $CFI \leq .90$ ; Kahn, 2006), and d) the Standardized Root Mean-square Ration ( $SRMR < .10$ ). Initially, my model did not pass these

standards. I expected to make modifications based on the flexible approach I used in retaining items in the EFA process.

Taken together, I used the modifications indices, item loadings and cross-loadings, item residuals and theoretical rationale to make my decisions in the model modification process. First, I removed two items (i.e., chaotic, fearful) because they loaded moderately on their factor (.35 & .29, respectively) and nearly equally with all other factors. I removed three more items (i.e., happy, desirable, and fearful) because their item residuals scores indicated significant differences between the proposed model and data (.91, .96, .70, respectively); in addition, they exhibited mediocre factor loadings (.47, .42, .40, respectively). At this point, I noticed that the remaining items for Factor 4 (i.e., caring, dignified and comfortable) loaded more significantly with Factor 2 (.67, .79, .74) than as a separate factor (.56, .73, .64, respectively). Even though these items could have continued to be a separate factor, it seemed more cogent and parsimonious to collapse Factors 2 and 4, to better represent fit with the data.

With these changes, the fit indices indicated that the new four-factor model met the cut-off scores for incremental and absolute fit: (a) the chi-square ( $\chi^2 = 313.39, df = 237, p = .0006$ ), (b) the Root Mean-Square Error of Approximation (RMSEA = .03; RMSEA ci = .23-.43), (c) the Comparative Fit Index (CFI = .98; Kahn, 2006; TLI = .97, Marsh et al., 2014), and d) the Standardized Root Mean-Square Residual (SRMR = .03). Chi-square statistic has been criticized in its use with SEM given sample size restrictions which is why several fit criteria are recommended when evaluating goodness of fit (Worthington & Whittaker, 2006). Researchers who use ESEM do not often include the chi-square statistic in their goodness of fit criteria (Marsh et al., 2014; Prudon, 2015).

It was my initial plan to test the new data against competing models (i.e., 5 factor vs. 4 factor model). However, through the model modification process, I found that a four-factor model was a stronger fit for these data than my initial five-factor model. Table 4 contains the internal consistency and factor correlations of the four-factor solution.

The remaining 27 items formed four factors that I labeled, following consultation with the grief and loss research team, as Incomprehensible, Warm, Ostracized, and Withering death. Incomprehensible deaths include the following 8 items ( $\alpha = .88$ ): shocking, sudden, random, unfair, premature, unacceptable, traumatic, and mysterious. Warm deaths include the following 11 items ( $\alpha = .90$ ): respectful, peaceful, moral, meaningful, spiritual, calm, ideal, natural, caring, dignified, and comfortable. Ostracized deaths include the following 4 items ( $\alpha = .82$ ): intentional, self-induced, taboo, and stigmatized. Withering deaths include the following 4 items ( $\alpha = .70$ ): lingering, prolonged, suffering, and painful. Figure 1 contains the individual items and factor loadings.

Table 4. Factor Correlations and Reliability

	Cronbach's alpha	F1	F2	F3	F4
Incomprehensible	.88	1	-.47**	.30**	.12**
Warm	.90		1	-.24**	-.18**
Ostracized	.82			1	.20**
Withering	.70				1

*Note.*  $n = 286$  \*  $p < .05$ , \*\*  $p < .01$

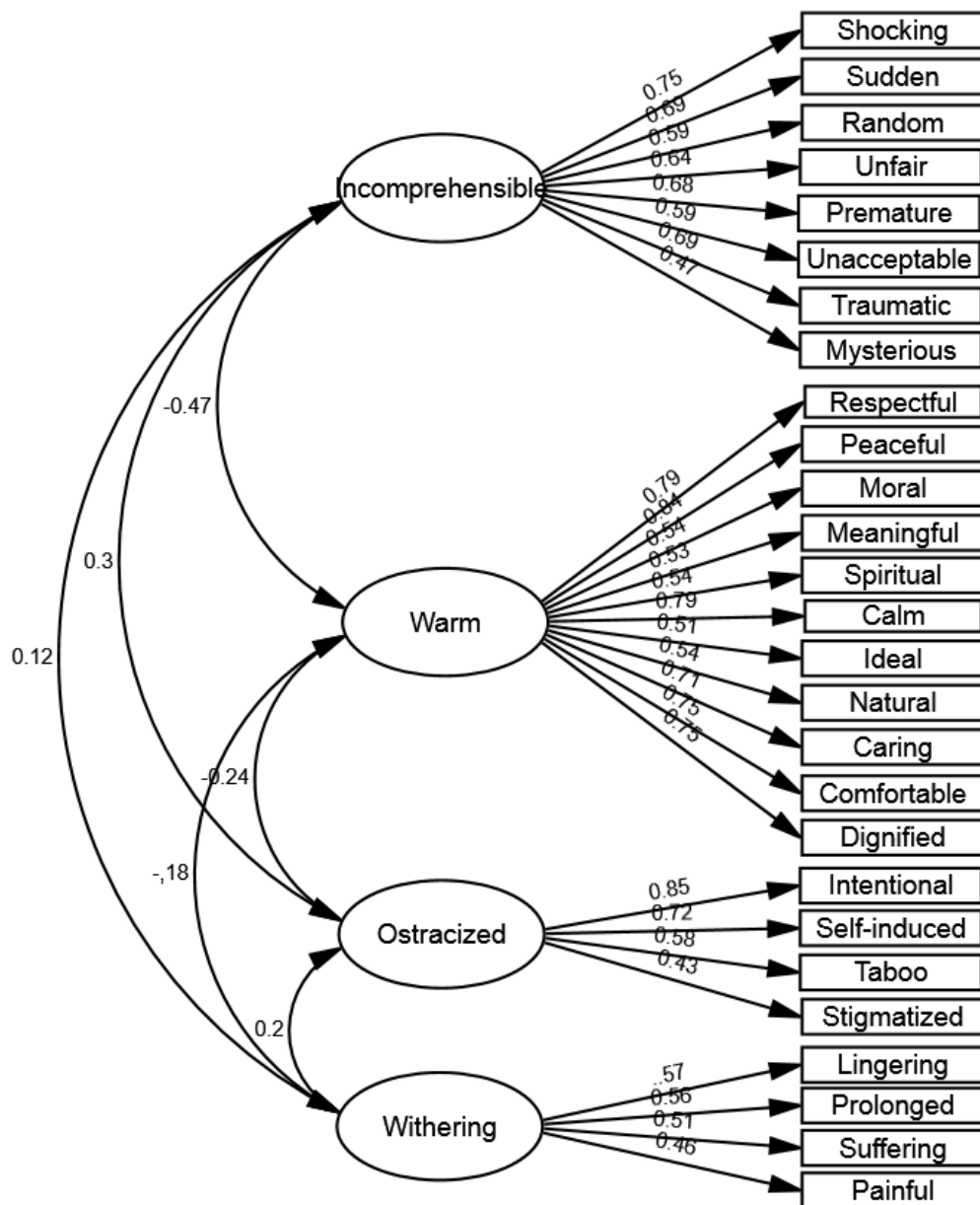


Figure 1. Confirmatory Factor Analysis model for the Descriptive Death Scale (DDS)

The purpose of ESEM was to answer RQ2 (Do the underlying factors/subscales fit the data from a similar sample?). Based on these analyses, I found four-factors appropriately fit these data. My hypothesis was that the initial factors/subscales would be consistent, regarding fit, across samples (H2). The results indicated partial support for my hypothesis. Despite removing items and collapsing two factors into one, the content of the initial factors was largely unchanged with a positively valanced factor and separate negatively valanced factors.

### **Validity of the DDS Factor Scores**

After performing the CFA, I tested discriminant and convergent validity of the DDS factors scores (RQ3) using two subscales of the modified Good Death Scale and the Marlow Crowne Social Desirability Scale. To validate the DDS, I followed the recommendations of Worthington and Whitaker (2006) by including two measures to assess convergent and discriminant validity (i.e., social desirability, modified good death scale). Worthington and Whitaker (2006) assert that researchers use measures to determine how well a new scale is capturing the target construct and its added value beyond existing similar measures.

I hypothesized (H3) that the DDS good death factor(s) would be positively associated with the good death subscales (i.e., Concept of a Good Death Measure- Closure, Personal Control). Also, I anticipated (H4) that the DDS factors scores that emerged would *not* be associated with social desirability. For the following analyses, I used the total sample ( $n = 572$ ).

Based on the results of the correlation matrix (see Table 5), the Warm death subscale of the DDS was significantly and positively correlated with both Good Death - Closure and Good Death - Control. Therefore, H3 was supported.

In addition, although not hypothesized, the Incomprehensible and Withering subscales of the DDS were significantly and negatively correlated with Good Death - Closure. Whereas

Incomprehensible was positively correlated with Good Death - Control and Withering and Ostracized were negative associated with Good Death - Control.

Regarding H4, none of the DDS Factor scores were significantly correlated with social desirability. Therefore, H4 was supported.

Table 5. Descriptive Statistics and Correlations between DDS Factors, Validity Scales, Dependent Variable

	M	SD	GD Closure	GD Personal Control	Social Desirability	Grief Reaction
Warm	26.95	11.29	.72**	.16**	.06	-.15**
Incomprehensible	26.19	9.37	-.51**	.10*	-.02	.55**
Withering	7.03	4.29	-.26**	-.14**	-.04	.21**
Ostracized	11.09	4.19	-.07	-.52**	-.07	.12**

Note.  $n = 572$ . \*  $p < .05$ , \*\*  $p < .01$

### DSS Factors, Discrepancy Score, and the Prediction of Grief Distress

In this section, I outline the analysis I used to answer RQ4 (Will the DDS factors/subscales that emerge (e.g., good and bad death) be associated with grief distress?) and RQ5 (Will the discrepancy between individual and societal descriptions of the death make a significant contribution to grief distress above and beyond the individual descriptions?) I hypothesized that the good death factor/subscale would be negatively related to grief distress (H5) and that the bad death factor/subscale would be positively related to grief distress (H6). I also expected that the extent of discrepancy between individual and societal descriptions would positively and significantly contribute to grief distress above and beyond individual descriptions of death (e.g., DDS good and bad death factors/subscales; H7).

I performed a hierarchical regression analysis to address RQ4, RQ5 and to test H5, H6, and H7. Most specifically, regression allowed me to determine the extent to which the DDS



factors and the discrepancy score would predict grief distress. I used the total sample for this analysis ( $N = 572$ ).

At step 1, grief distress was regressed onto emotional closeness to the deceased and age of the deceased. At step 2, I added the primary variables into the regression model, including Incomprehensible death, Warm death, Ostracized death, and Withering death. At step 3, I included the discrepancy score.

Overall, the regression model for grief distress was significant, such that after step 3 with all IVs in the equation,  $R^2 = .41$ ,  $F(67, 565) = 56.62$ ,  $p < .001$  (see Table 6). At step 1, the analysis yielded a significant regression model accounting for 17% of variance in grief distress,  $R^2 = .31$ ,  $F(2, 569) = 128.17$ ,  $p < .001$ . Emotional closeness to the deceased ( $\beta = .35$ ,  $p < .001$ ) emerged as a significant positive predictor of grief distress and age of the deceased ( $\beta = -.38$ ,  $p < .001$ ) emerged as a significant negative predictor.

At step 2, the regression model,  $R^2 = .41$ ,  $F(6, 565) = 65.93$ ,  $p < .001$ , and  $R^2$  change,  $\Delta R^2 = .10$ ,  $F(4, 565) = 24.31$ ,  $p < .001$ , were significant. Emotional closeness to the deceased ( $\beta = .29$ ,  $p < .001$ ) and age of the deceased ( $\beta = -.16$ ,  $p < .001$ ) remained significant predictors of grief distress. In addition, Incomprehensible death ( $\beta = .541$ ,  $p < .001$ ), Withering death ( $\beta = .07$ ,  $p = .04$ ) and Warm death ( $\beta = .13$ ,  $p < .001$ ) emerged as significant positive predictors of grief distress. However, Ostracized death ( $\beta = .05$ ,  $p = .19$ ) did not emerge as a significant predictor of grief distress. The DDS subscales (i.e., Incomprehensible, Withering, Warm) accounted for an additional 10% variance in grief distress beyond closeness with the deceased and age of the deceased.

To summarize thus far, the results did not support H5 but offered partial support for H6. Hypothesis 5 was not supported because I hypothesized a negative relationship between the good

death factor (i.e., Warm death) and grief distress and the results indicated a significant and positive relationship. Hypothesis 6 was partially supported because both Incomprehensible and Withering death made significant and positive contributions to the variance in grief distress. However, Ostracized death did not emerge as a significant predictor of grief distress.

At step 3, the regression model,  $R^2 = .41$ ,  $F(6, 565) = 62.97$ ,  $p < .001$  remained significant. However, the  $R^2$  change was not significant,  $\Delta R^2 = .001$ ,  $F(1, 564) = .84$ ,  $p = .36$ . The results indicated the discrepancy score did not explain additional variance in grief distress. Therefore, H7 was not supported.

Table 6. Predictors of Grief Distress

	Grief Distress					
	$R^2$	$\Delta R^2$	$B$	$SE$	$\beta$	$sr^2$
Step 1	.31***	.31***				
Closeness to the Deceased			.42	.04	.35***	.12
Age of the Deceased			-.20	.02	-.38***	-.14
Step 2	.41***	.10***				
Closeness to the Deceased			.34	.04	.29***	.11
Age of the Deceased			-.08	.02	-.16***	-.02
Incomprehensible Death			.50	.05	.41***	.13
Warm Death			.13	.04	.13**	.02
Ostracized Death			.12	.09	.05	.00
Withering Death			.19	.09	.07*	.00
Step 3	.41***	.00				
Closeness to the Deceased			.34	.04	.28***	.07
Age of the Deceased			-.08	.02	-.15***	-.01
Incomprehensible Death			.51	.06	.42***	.09
Warm Death			.13	.04	.13**	.02
Ostracized Death			.15	.10	.06	.00
Withering Death			.21	.09	.08*	.00
Discrepancy Score			-.02	.02	-.03	.00

\* $p < .05$ . \*\* $p < .01$ . \*\*\* $p < .001$ .

Table 7. Summary of Hypotheses Testing

Hypothesis#	Hypothesis	Outcome
H1	At least two factors/subscales will emerge that generally reflect constructs of “good” and “bad” death	Supported
H2	The initial factors/subscales will be consistent, with regard to fit, across samples.	Partially Supported
H3	The good death factors/subscale will be positively associated with the subscales of the good death scale (i.e., Concept of a Good Death Measure – Closure, Personal Control, Clinical).	Supported
H4	The DDS factors/subscales that emerge will not be associated with social desirability.	Supported
H5	The good death factor/subscale will be negatively related to grief distress.	Not supported
H6	The bad death factor/subscale will be positively related to grief distress.	Partially Supported
H7	The extent of discrepancy will positively and significantly contribute to grief distress above and beyond individual descriptions of death (e.g., DDS good and bad death factors/subscales).	Not supported

## **CHAPTER 5: DISCUSSION**

Constructivist theory served as the theoretical base for the development of the DDS. Specifically, the language that griever use to describe a death is a symbolic representation of the meaning that they have made from the death experience. From this constructivist rationale, I reasoned that griever could convey their meaning in a brief, quantitative and multidimensional way if they could rate a list of adjectives for how much each word fit their perception of the death. However, meaning is developed and shared within a society and culture and participants in the current study were asked to rate the fit of each death descriptor included in the DDS twice; (a) once for how well the death descriptor fit their individual view of the death and, (b) again, for how well they believed the death descriptor fit with society's view of the death.

The purpose of the present study was to develop the DDS, a scale that captures descriptions of death in a brief, quantitative, and multidimensional way. Specifically, I used the first half of my community-based sample of griever to determine the underlying subscales of the DDS and used the second half of my community-based sample to confirm the initial factor structure. Next, I assessed for convergent and divergent validity by determining the associations between DDS factors/subscales and measures of good death (i.e., subscales of The Concept of a Good Death Measure - Closure, Control, Clinical) and social desirability (i.e., Marlowe-Crown Social Desirability Scale- Form C). I then assessed the contributions of the DDS factors/subscales in predicting grief distress (i.e., Core Bereavement Items). Finally, I determined whether the discrepancy between participants' individual descriptions of the death and their perceptions of societal descriptions of the death contributed to grief distress beyond the participants' individual descriptions alone (i.e., their scores on the underlying DDS factors/subscales).

In this chapter, I offer possible explanations for the study findings. Beginning with my hypotheses, I provide tentative explanations for findings specific to my research questions and hypotheses. Following, I offer my impressions of the results I had *not* anticipated in my hypotheses. Then, I summarize novel contributions of this study and describe the research implications and clinical implications of the DDS and the current findings. Finally, I review the limitations of the present study and suggest areas for future research.

### **Primary Study Findings: Hypotheses Testing**

The present study had five primary questions, each with at least one associated hypothesis. The first three questions were focused on scale development and validation, whereas the final two were focused on examining the relationships between the DDS factors/subscales and grief distress.

#### ***Good Death and Bad Death***

For RQ1, I hypothesized that at least two DDS factors/subscales would emerge and would generally reflect constructs of “good” and “bad” death (H1). My first hypothesis was supported by my findings. As predicted from my literature review, my results indicated that at least one positively valenced factor and one negatively valenced factor emerged. Researchers have indicated that peace, dignity, respect, comfort, calm, predictability/appropriate timing are all words that connect with good deaths (Broom, 2012; Hales, 2015; Hattori & Ishida, 2012; Holdsworth, 2015; Robinson et al., 2010; Semino et. al., 2014; Trankle, 2014). Regarding my initial EFA findings, two factors that emerged appear to be related to good death. More specifically, one of these factors (Factor 2) included the descriptors respectful, peaceful, moral, meaningful, spiritual, calm, happy, desirable, ideal, and natural; the other (Factor 5) included the

descriptors caring, chaotic, dignified, and comfortable with chaotic loading negatively. These factors appear distinct. Specifically, Factor 5 appears to describe the environment the death occurred, and Factor 2 appears to be more general.

With regard to the negatively valenced factors, researchers have indicated deaths described as shocking, sudden, painful, prolonged, premature, intentional and stigmatized deaths are associated with higher scores on measures of grief reactions (Bailey, Kral, Dunham, 1999; Guarnaccio, Hayslip, & Landry, 1999; Jordan & McIntosh, 2011; Mathews & Servaty-Seib, 2006; Melham, 2007; Nadeau, 1998; Rynearsen, 2001; Sveen & Walby, 2007). With regard to my initial EFA findings, three factors emerged that appear related to bad death. More specifically, Factor 1 included the descriptors shocking, sudden, random, unfair, premature, unacceptable, traumatic, and mysterious; Factor 3 included the descriptors lingering, prolonged, suffering, painful, and fearful; and Factor 4 included the descriptors intentional, self-induced, taboo, stigmatized, and planned. Additionally, these factors appeared to be quite distinct.

Descriptively, Factor 1 is a sharp rupture in everyday life, whereas Factor 3 is more protracted. Factor 4 is quite unique and appears related to intention and judgement,

Evidence from previous research supported my hypothesis regarding the emergence of at least one positive and one negative valenced factor, but I could not a priori build a rationale for any other possible factors. Moreover, there has not been a study focused on assessing descriptors of death in a broad, general, and collective way which limited the scope of my predictions. More specifically, most researchers have used a more narrow focus and have investigated manifestations of good death as a concept (i.e., a uniform definition to build practices for end-of-life; Hattori & Ishida, 2012; Ko, Kwak & Nelson-Baker, 2015), specific modes of death (e.g., homicide, car accident; Kaltman & Bonanno, 2003; McClatchy et al., 2009), or specific sub-sets

of descriptors (e.g., sudden, shocking, violent, natural; Currier et al., 2015; Lohan & Murphy, 2006). My initial EFA findings supported a five-factor structure that changed with the ESEM (see next section).

In my literature review, I argued that it was likely more factors than good and bad death would emerge because deaths are complex and multidimensional. Stigma has been broadly applied to grievors (e.g., Doka, 1989) but I was not confident in forming a hypothesis beyond the idea of at least one good and at least one bad factor because prior research had been limited. Most specifically, research on stigma has been specifically studied in connection with suicide as a mode of death, in contrast to the idea of stigma being a possible construct that could be applied to many modes of death. Therefore, because my focus was on collecting data from participants experiencing a broad range of modes of death, I was unclear on whether a factor focused on stigma would emerge. However, the Factor 4 that emerged from the EFA does have a sense of stigma to it.

### ***Consistent Factors Across Samples***

For RQ2, I hypothesized that the initial subscales would be consistent, regarding fit, across samples (H2). The hypothesis was partially supported by the findings from this study. Overall, the content and structure of the DDS remained quite consistent from EFA to CFA. The primary difference was that the data fit the model better when the two good death factors that emerged in the EFA were combined to form just one good death factor/subscale. The results of the ESEM indicated four DDS subscales (i.e., Incomprehensible, Ostracized, Withering, Warm) with 27 items.

Incomprehensible Death included the following 8 items ( $\alpha = .88$ ): shocking, sudden, random, unfair, premature, unacceptable, traumatic, and mysterious. These items taken together

appear to represent a death loss experience that is unprecedented in the lives of griever, and unfathomable when considered in light of their understanding of the world prior to the death occurring. Traumatic and violent as well as shocking and sudden, are paired frequently by grief researchers and are often used as labels to identify griever of violent deaths (Currier et al., 2006; Sanders, 1988; Stroebe & Schut, 2001). Specifically, traumatic grief is often identified as a significant subcategory of grief associated with sudden and violent deaths which typically involve modes of death such as suicide, homicide and accidents (Currier et al., 2006; Norris, 1992). It is not uncommon for the circumstances traumatic deaths to be mysterious, particularly in situations where the person is missing and assumed dead (Armour, 2002; Searle, 1989). There were no changes in the items of this factor from the EFA to the CFA using ESEM.

Ostracized Death included the following 4 items ( $\alpha = .82$ ): intentional, self-induced, taboo, and stigmatized. The items intentional and self-induced are indicative of volition which has been connected to stigma by researchers (Currier et al., 2010; Jordan & McIntosh, 2011; Sveen & Walby, 2007). The results of the present study indicate stigma and taboo as closely connected with the descriptors of intentional and self-induced. Intuitively, death by suicide is a mode of death that fits all of the descriptors included in the Ostracized death subscale (Bailey, Kral, Dunham, 1999). Researchers who investigate grief after suicide have advocated for the qualitative differences between the grief of these individuals and griever following other modes of death (Jordan & McIntosh, 2011). Research indicates that individuals grieving deaths by suicide exhibit higher scores on measures of stigma when compared to other grieving deaths due to other modes of death (Bailey et al., 1999; Jordan & McIntosh, 2011). However, it is important to note that the Ostracized subscale emerged in the present study even though the participants ranged widely with regard to the mode of death experienced by the deceased.



Regarding changes made during CFA, I removed one descriptor (i.e., planned) from the initial structure, which did little to modify the overall subscale.

Withering Death included the following 4 items ( $\alpha = .70$ ): lingering, prolonged, suffering, and painful. Pain and suffering were among the most referenced words in the dying-related literature (see table 2a in Appendix J.). Pain and suffering are key terms of focus within palliative medicine. For example, pain and suffering are key when families are deciding to remove medical interventions that artificially prolong life (Meier et al., 2016). Withering death pointedly describes a protracted death (i.e., prolonged, lingering) and pain takes time to mature into suffering. Regarding changes made during ESEM, I removed one word (i.e., fearful) from the initial structure in the CFA using ESEM which did little to reshape the overall subscale.

Warm death included the following 11 items ( $\alpha = .90$ ): respectful, peaceful, moral, meaningful, spiritual, calm, ideal, natural, caring, dignified, and comfortable. Theoretically, these form a clear connection with what is described as a good death in palliative care. End-of-life researchers characterize good deaths as minimizing pain, maximizing comfort, maintaining dignity through autonomy, and care that respects the decisions of the dying (Aleksandrova-Yankulovska & ten Have, 2015; Broom, 2012; Gott et al., 2008; Masson, 2002; Payne et al., 1996).

The Warm death subscale involved the most significant changes in moving from the initial EFA to the CFA. Most specifically, the initial factor structure included two good death factors/scales. One seemed to describe controllable environmental circumstances and the other more generally described positive deaths. Despite the possible nuance presented by this difference, the CFA indicated that collapsing these two subscales resulted in a better fit with the data. Warm death takes the place of what were initially two subscales from the EFA. During the

ESEM, I first removed happy, desirable and chaotic. It is possible that there was more variability in how these words were applied by participants to conceptualize deaths. For example, happy and desirable could have been confusing items for participants (e.g., happy/desirable for participants or for the deceased?). Moreover, chaotic is an item I expected to load with Incomprehensible death but it had initially loaded more significantly, and in the opposite direction, with a positively valenced subscale. Although there was complexity and nuance regarding the two subscales in the EFA, collapsing them ultimately resulted in the structure being stronger and did not significantly impact the overall usefulness of the DDS.

The correlations among the four DDS factors were small to moderate. The largest correlation that emerged was negative and it was between Incomprehensible and Warm death. The items connected with the Incomprehensible and Warm death subscales represent core sets of descriptors frequented researched (Currier et al., 2006; Sanders, 1988; Stroebe & Schut, 2001) and commonly used by griever to convey meaning about death experiences (Aleksandrova-Yankulovska & ten Have, 2015; Broom, 2012; Gott et al., 2008; Masson, 2002). Indeed, the strong negative correlation between these factors indicates the extent to which these factors are distinct. It could be the items that loaded on the Incomprehensible subscale most clearly represent what the majority of people would believe defined a bad death. For example, Incomprehensible represents a life ripped unexpectedly out of its expected course with unfinished business, whereas Warm death represents an expected, comfortable ending with no unfinished business. Additionally, Withering death appears more correlated with Incomprehensible death rather than Warm death. It makes sense that Withering death would be less associated with Warm death because pain and suffering contrast care and comfort. Finally, Ostracized is more correlated with Incomprehensible rather than Warm death. Stigma, as a key

element of the Ostracized death subscale, is more broadly connected with sudden and traumatic deaths (e.g., Armour, 2006).

The findings indicate that general descriptions of good deaths may be clearer and function more uniformly in society than do the descriptions of what might be termed bad deaths. Interestingly, three negatively valenced factors emerged whereas only one positively valenced factor emerged. The dominant and perhaps unidimensional sociocultural description of good death is illustrated by the items included in the Warm death subscale (Hattori & Ishida, 2012; Ko, Kwak & Nelson-Baker, 2015).

The content of the negatively valenced scales are complex, nuanced, and distinct. For example, Incomprehensible death and Withering death each occupy different ends of spectrum with regard timing of death (e.g., sudden vs. prolonged, premature vs. lingering). In addition, Withering death appeared to have the least association with any of the other subscales, suggesting a particular uniqueness and distinction from the other subscales. Withering death is connected to what is often avoided in good death (e.g., suffering, lingering) and it is often disconnected from acute and confusing circumstances of Incomprehensible death.

### ***Validity: DDS, Good Death, and Social Desirability***

In connection with RQ3, I hypothesized that the good death factor would be positively associated with the subscales of the good death scale (i.e., Concept of a Good Death Measure – Closure, Personal Control, Clinical; H4). Additionally, I hypothesized that the DDS factors/subscales that emerged would not be associated with social desirability (H5). My results supported these hypotheses.

Regarding convergent validity, the Warm death factor/subscale was significantly and positively associated with both Good Death - Closure and Good Death - Control. Based on past

research, it makes sense that the results indicated strong positive relationships between Warm death and the Closure and Control subscales. There are parallels across these constructs and scales. Specifically related to Good Death - Closure, researchers have reported that respect, comfort and dignity relate to following the wishes of the deceased and meeting their needs (e.g., calm, spiritual; Masson, 2002, Pestinger et al., 2015; Semino et al., 2014). Moreover, dignity connected to individuality and a continuous sense of personhood. At the end of life, people hope to continue to make decisions and maintain their autonomy which is lost with declining mental alertness and with declining control over bodily functions (Semino et al., 2014; Trankle, 2014). The Good Death Scale was developed to assess individuals' desires regarding their own deaths (e.g., that my death be painless or largely pain-free). I modified the scale for the present study such that individuals could retrospectively assess the death of another person (e.g., that others' death was painless or largely pain-free). The data offered support for convergent validity and indicated that it is possible, at least with regard to specific aspects, for others to rate the past death of others' in a parallel way to how they would describe their desires regarding their own future death.

Regarding discriminant validity, none of the DDS subscales were significantly associated with the social desirability scale. The results indicated that scores on the DDS subscales were not associated with the tendency to answer in socially desirable ways. Socially desirable answering would indicate that these participants were more likely to be disingenuous in their answers. It appears, although death is a sensitive and often times taboo topic, participants did not experience the need to answer the DDS in ways that they might anticipate were socially or societally acceptable.

As I described in Chapter 4, the Good Death - Clinical subscale did not function as expected. The clinical subscale includes items that assess aspects of death timing (e.g., “the dying period be short” and “that it be sudden and unexpected.”). However, sudden and unexpected are DDS descriptors that loaded on Incomprehensible death (i.e., negative valence) but not Warm Death. Researchers in palliative medicine have found that individuals prefer not to be conscious at the moment of death and may wish death to occur suddenly in their sleep (Schwartz et al., 2003). In contrast, griever use sudden to describe death at an existentially inappropriate time or a death without appropriate closure (Jordan & McIntosh, 2011). The contrast in the application of these concepts to personal dying versus the dying of another may help in explaining why this particular subscale of the Good Death measure did not exhibit internal consistency with the present sample; it did not translate well from the application to self-dying to other-dying.

### ***DDS Subscales and Grief Distress***

For RQ4, I hypothesized that the good death factor/subscale would be negatively related to grief distress (H6). I also hypothesized that the bad death factor/subscale would be positively related to grief distress (H6). The first part of the hypothesis was not supported and the second part was partially supported. Although all four DDS factors independently correlated with grief, only three factors significantly contributed to grief when their shared variance was controlled for in the regression. Ultimately, Ostracized death did not make a significant contribution to the prediction of grief distress.

In contrast to my hypothesis, Warm death contributed significantly and *positively* to grief distress above and beyond closeness and age of the deceased. Although the relationship between Warm death and grief was negative and aligned with my hypothesis in my preliminary analyses

(e.g., correlation), when Warm death was included in the regression model with age and closeness to the deceased as well as all of the other DDS subscales the relationship between Warm death and grief distress shifted to positive. I had hypothesized a negative relationship between Warm death (i.e., the good death factor that emerged) and grief distress because good deaths are generally defined by good care, connection with family, communication, closure, minimized pain and retained physical and cognitive functioning and are often associated with lower post-death grief (Hattori & Ishida, 2012; Ko, Kwak & Nelson-Baker, 2015).

But again when age and closeness were held constant across the cases and when it is regressed with the other DDS subscales, the items Warm death collectively shifted to serve as a positive contributor to grief distress. Perhaps the dying experience of a Warm deaths allow for continued positive interactions with those who are dying right up until the time of death, such that the death brings an abrupt end to a special time. The higher grief may be an indication of this loss of peaceful and meaningful interactions and expressions. There may also be possible interactions between Warm death and age of the deceased and closeness to the deceased or between Warm death and the other DDS subscales.

Incomprehensible death made a positive contribution to the variance in grief distress above and beyond closeness and age of the deceased. This finding supported H6. The results are aligned with past findings from researchers who have investigated the traumatic effects of sudden and violent deaths (Harrington & Sprowl, 2016; Holland & Neimeyer, 2010; Lohan & Murphy, 2006). Most specifically, researchers have found that griever who are challenged by random, premature, and mysterious circumstances are likely to experience high grief distress (Aleksandrova-Yankulovska & ten Have, 2015; Armour, 2002).

Withering death made a positive contribution to the variance in grief distress. Again, this finding supported H6. Meier et al. (2016) argued that mitigating pain is a key difference in good and bad deaths. Additionally, dying at the right time is a balance between prolonging life to the point of suffering and maximizing the time lived in functional health.

Taken together, the results regarding Incomprehensible and Withering death support the findings of past researchers through quality of life in hospice care (Holdsworth, 2015; Lawrence et al., 2011) as well as grieving the traumatic effects of violent deaths (e.g., suicide, homicide, accidents; Holland & Neimeyer, 2010; Harrington & Sprowl, 2016). Specifically, grieverers are distressed when the deceased's life is prolonged beyond enjoyment, when they are lingering. Moreover, grieverers are challenged when others die painfully and experience extended suffering.

Ostracized death did not significantly contribute to grief distress. This finding contradicts the findings of researchers who have investigated stigmatized, violent, and preventable deaths (Armour, 2002). Specifically, stigma is a significant contributor to grief for those grieving deaths due to suicide; these grieverers also describe the aspect of volition as a main focus of social stigma (Bailey et al., 2000; Feigelman et al., 2011). It may be that age of the deceased and closeness to the deceased as well as the other DDS subscales (i.e., Incomprehensible, Warm, Withering) accounted for the relationship that might separately exist between Ostracized death and grief distress. For example, the shocking, sudden and traumatic death of a *young* person who died in pain may account for grief distress regardless of the addition made by Ostracized death. The CBI contains items focused on sadness, longing for the person, reminders of the deceased and avoidance behavior; these dimensions of grief may not be connected with Ostracized death. Bailey et al. (2000) asserted that suicide survivors, and, therefore, perhaps individuals grieving other stigmatized deaths, have complex and dynamic experiences of grief. Their grief

experiences may not be assessed appropriately or accurately by the CBI. For example, those who are grieving a self-induced death, may need to spend time and energy disconnecting the mode of death from their grief distress.

### ***Discrepancy Between Individual and Societal Death Descriptions and Grief Distress***

In connection with RQ7, I hypothesized that discrepancy scores would positively and significantly contribute to grief distress above and beyond the DDS subscales. The results did not support the hypothesis. More specifically, the results indicated that the discrepancy scores did not significantly predict grief distress beyond the variance explained by the DDS subscales.

Although my hypothesis was based on the general idea of stigma and a sense that the more grievers' individual perceptions of a death differed from their sense of societal perceptions of a death would add to their grief, it is possible that some respondents actually perceived society to have a more positive affect.

It could be that discrepancies between grievers' individual perceptions and societal perceptions of a death does little to shape grief distress in that the grievers' individual perceptions are simply more powerful. Discrepancies between personal death descriptions and societal death descriptions may be also be disorganized and vague. Messages from society could concurrently contradict and align with individual perceptions which could have little to no effect on grief distress. Varying levels of alignment (e.g., personal and sociocultural descriptions agree) across a broad range of items could buffer the effects of any specific discrepancies and minimize the relationship between discrepancies and grief distress. It is also possible that there was not enough variability in the discrepancies scores overall for there to be a significant correlation between discrepancy scores and grief distress.



## **Additional Findings: Beyond Hypotheses**

In this section, I detail the findings in my study that were not hypothesized. I begin with a focus on closeness to the deceased and age of deceased, as they both emerged as significant predictors of grief distress. Next, I review the results of the Good Death subscales and the negatively valenced DDS subscales. Finally, I explore the results regarding mode of death and the DDS subscales.

### ***Closeness and Grief Distress***

The results indicated that emotional closeness was significantly and positively related to grief distress. It makes good sense that griever who reported higher levels of closeness would also report higher grief distress. Grief is often considered a reflection of attachment, such that greater connection and intimacy would be associated with higher distress following separation from the attached person/object (cf. Servaty-Seib & Pistole 2006).

Moreover, the results did not support the use of the formal kinship relationship with deceased as a proxy for closeness. The results indicated that the continuous, descriptive variable of closeness (e.g., reciprocated sharing, emotional intimacy) was a significant predictor of grief distress whereas grief distress did not vary based on the a priori categorical label of relationship to the deceased (e.g., father, mother, son, daughter, aunt). Researchers have historically used the formal kinship relationship to categorize and study griever. It is essential that researchers continue to develop and employ tools that appropriately reflect the complexity of death experiences because assumptions regarding closeness based solely on kinship could be misleading and result in an over-expectation or under-expectation of grief distress.

In other words, some people experience the death of a grandparent as others might experience the death of a parent and in parallel the death of a friend as a sibling. Griever may

even make these direct statements to potential supporters such that others do not make assumptions regarding the extent of grief and/or the need for support. The modified labels more appropriately reflect their connection to the person who died as well as more meaningfully honor the magnitude of their grief. Oversimplistic labels reinforce sociocultural definitions of grief because they fail to grasp the full picture. It is like trying to paint with one eye open, a simple picture may translate well to a flat surface. However, complex paintings require two eyes to capture depth which conveys magnitude and presence.

### ***Age of the Deceased and Grief Distress***

Age of the deceased emerged as a negative predictor of grief distress. This finding indicated that people experience more grief distress when a person dies young. This finding is aligned with the results of many prior studies (Armour, 2006; Kristensen Weisæth & Heir, 2012; Neria, Nandi & Galea, 2007; Sveen & Walby, 2008). When people die young, their deaths are considered premature and griever's are challenged by the sense of unfinished life (Kearle, 1989; Kristensen, Weisaeth & Heir, 2012). Because they deviate from what is considered natural course of life, these premature deaths are challenging to make sense of, are often considered sudden and shocking regardless of the particular mode of death (Kearle, 1989; Kristensen Weisæth & Heir, 2012).

### ***Good Death and Negatively Valenced DDS Subscales***

Although my hypothesis that Warm death would be positively associated with both the Good Death - Closure and Good Death - Control was supported, I did not make any hypotheses regarding how the Good Death subscales might emerge as related to the bad death subscales of the DDS. The findings for the negatively valenced scales of the DDS were interesting.

Withering death was the only negatively valenced DDS scale that was significantly and negatively correlated with both Good Death - Closure and Good Death - Control. I would actually have expected for *all* of the negatively valenced subscales to exhibit this same pattern. In the literature, good deaths happen at the right time and occur with as little pain as possible. Withering death is a protracted and painful death which is opposite in many ways of a good death. Based on the literature, I would have predicted similar results for Incomprehensible death and Ostracized death. However, that was not the case for either.

Most specifically, Incomprehensible was positively correlated with Good Death - Control and negatively correlated with Good Death - Closure. Looking at the items of Good Death – Control, they are focused on mental alertness, control over bodily functions and the ability to communicate. It makes sense that sudden and shocking deaths (i.e., Incomprehensible) would be associated with normal physical and cognitive functioning because those who die by Incomprehensible means are likely not ill or experience challenges with daily living or with bodily functions. Good Death - Closure related strongly to Warm death and it makes good sense that Incomprehensible is negatively correlated with Good Death - Closure.

Moreover, Ostracized death was significantly and negatively correlated with the Good Death - Control subscale and it was not significantly correlated with the Good Death - Closure subscale. Looking at the item level, it makes sense that Ostracized death would be negatively associated with Good Death - Control (e.g., normal physical and psychological control). Self-induced and intentional deaths are more widely connected with concerns in decision making and psychological well-being. However, intentional behaviors that bring about death are not exclusively suicide (e.g., removing life-sustaining treatment, self-immolation). Finally, and most intriguing, the results did *not* indicate a significant correlation between Ostracized and Good

Death - Closure (e.g., complete important tasks, say goodbye, live to a specific event). Perhaps there was not enough variability in Ostracized death for there to be a significant relationship. In contrast, it may indicate almost a bipolar mixture of responses to the Ostracized subscale. Some respondents may have experienced Ostracized deaths that could have closure elements (e.g., medically hastened, self-inflicted brain death/physical death prolonged with family), whereas others experienced Ostracized deaths that might not (e.g., suicide).

### **Mode of Death and DDS subscales**

Although past research has focused a great deal on specific modes of death (see Appendix A), the DDS subscale scores across different modes of death suggest that more nuanced examination and research design is required. Most specifically, the DDS subscale scores across specific modes of death reveal much fewer differences than might have been anticipated based on past research. For example, grievors of homicide and Alzheimer's disease indicated quite similar mean scores on Withering death with less than one point difference in mean scores, and their mean scores were quite different on Warm death with a greater than 20 point difference in mean scores. The overall scores indicated some level of endorsement for every mode of death across all subscales. In other words, almost all modes of death had a DDS subscale score that might be considered counterintuitive. Deaths can be Incomprehensible, Withering, Ostracized, or even Warm, regardless of the specific natural or violent mode/cause.

### **Research Implications**

The DDS allows researchers to capture a multidimensional profile of how individuals describe single death experiences. Rather than focusing on mode of death, the DDS allows researchers to understand how descriptive experiences contribute to grief reactions. By assessing

positively and negatively valenced descriptions, the DDS offers novel complexity and a balanced profile of death descriptions. The DDS offers a wealth of opportunity to researchers in thanatology. In many ways, the results of the present study raise more questions than answers. The DDS allows for a new range of empirical questions to be considered and addressed, an indicator of its usefulness. Although questions may range widely, I have offered possible future research implications with regard to personhood, settings, and death-related factors.

### ***Personhood Factors***

There are many aspects of personhood that contribute to how individuals may make meaning of and, therefore, describe single deaths they experience. Specifically, cultural grounding, religious and spiritual beliefs, and developmental level may contribute to descriptions of death. Cultural context is significant to how individuals conceptualize death. With regard to Black Americans' historical experience with death in the United States, racism has been a critical influence in the way they would describe and make sense of specific deaths. Future researchers could explore questions such as: Do Black Americans score differently with regard to the Withering or Warm nature of deaths than their White American peers and Is perceived racism in with regard to end-of-life care associated with Black Americans Withering or Warm death scores? With regard to religion and spirituality, Abrahamic faiths view intentional deaths as incongruent (e.g., sinful) to their religious beliefs (e.g., God's expectations for sanctity of life). However, religious leaders have shifted traditions regarding suicide and often allow funeral practices to be conducted regardless of the cause of death. Future researchers could use the DDS to explore questions such as: Do those who identify with different religious traditions endorse differential levels of Ostracized death? Do differences in belief in an after-life shape descriptions of death and grief distress? and Does belief in a rewarding after-life moderate the relationship

between Warm death and grief distress? With regard to life course and development, older adults may be able compare and contrast experiences throughout their life and, therefore, people may describe deaths differently at different ages (e.g., young adults versus older adults). Future researchers could use the DDS to explore questions such as: Do older adults score lower on Incomprehensible death than their younger counterparts? Would the differences in scores DDS between age groups continue to exist regardless of mode or cause of death?

### ***Setting Factors***

The settings in which deaths may occur is a direction for future research; it may be that specific settings are related to how deaths are experienced and described. Future researchers could investigate questions such as: Do scores on Incomprehensible death differ for griever if their loved one experienced a heart attack death that occur at home or in the hospital setting? With regard to access to mental health and healthcare, individuals from rural and urban settings may describe deaths differently because of the disparities that exist in access to healthcare (e.g., nearest hospital within 5 miles versus 50 miles). Future researchers could explore questions such as: Given their differences in access to healthcare, do rural and urban populations of griever differ in their perceptions of Incomprehensible and Warm deaths. Also, Covid-19 has significantly limited contact within hospitals and many people have struggled with isolation as a result even in situations where family members could have been present for their loved one's death. Future researchers could explore questions such as: How have Warm deaths scores changed pre and post Covid-19 for deaths in hospitals?

### ***Death-Related Factors***

Relationships between specific death-related factors (e.g., mode/cause of death, time since death, formal relationship to the deceased) and death descriptions can now be examined in ways that could not be explored before the DDS. Researchers have the capacity to investigate similarities and differences in the grief experience and meaning making within specific causes of death and across causes of death. Researchers could explore questions such as: Does Withering death contribute to grief distress similarly in magnitude for griever following deaths due to Alzheimer's versus deaths due to homicide and Does the perception of risk taking behavior on the part of the deceased interact with Incomprehensible death and shape grief distress in a sample of people bereaved by accidental deaths? Additionally, there may be significant differences in descriptions of death as time passes. Future researchers could explore questions such as: Do griever 0 to 24 months score similarly on Warm death as those who are 25 to 48 months post-death loss? Finally, there may be significant differences in formal relationship with the deceased (e.g., mother, father, son daughter, cousin, aunt) across the DDS subscales. However, there may be unexpected similarities. Researchers could explore questions such as: Does Incomprehensible death scores differ between the children of the deceased, the siblings of the deceased and the parents of deceased when describing the same death?

Despite breaking them into separate categories, personhood, setting, and death-related factors are all intertwined because reality is complex. The DDS could also be used to examine more complex and nuanced research questions that involve multiple factors simultaneously. Specifically, researchers could begin to understand how descriptions of death shift across religious and non-religious griever across rural and urban settings. Similarly, do Warm death scores differentially contribute to grief distress in religious grieving parents in rural versus urban settings, but similarly for non-religious grieving parents across rural and urban settings? Finally,

how might DDS scores interact across factors such as cause of death, formal relationship with the deceased, and race?

### **Clinical Implications**

Although primarily conceptualized and developed for research, the DDS has potential to be used in as an evidence-based tool in clinical settings. The DDS could be helpful in both individual and family therapy. In Appendix X, I offer a clinical version of the DDS with specific guidance for clinicians, including practical questions for follow-up and reflection.

The DDS could be used as a significant therapeutic tool to raise understanding about death experiences and to foster awareness in clinical practice. The DDS could be used with clients to more quickly gain insight regarding griever's perceptions of single death loss experiences. Clinicians, similar to society in general, may be susceptible to making assumptions about particular modes of death and the DDS would allow for a more immediate sense of possible nuances of clients' perceptions of death losses. If clients scored higher on Warm death than Incomprehensible death, it does *not* mean that they are less likely to be grieving, but could indicate that they are struggling with the suddenness of the death or be confused by the circumstances, perhaps more than the clinician might have imagined. If one client scored highest on Withering and Incomprehensible and another scored highest on Withering and Ostracized, a clinician may approach and treat them in quite distinct ways.

Clinicians could also work with clients in examining their responses to individual items on the DDS. It may be worthwhile for clinicians to ask clients about their thoughts and emotions around key descriptors. For example, clinicians could ask which descriptor words on the measure particularly stood out or surprised clients. Moreover, clients may not notice nuances in their own descriptions and exploring the words on the DDS could help in raising insight. The DDS could



be used to explore positive and negative aspects of their death experience; as well as explore areas of intrapersonal and interpersonal conflict (e.g., shocking, prolonged). Highlighting the nuances of both positive and negative death descriptors might help clients identify a sense of balance in the experience that they had not noticed before.

Another specific recommendation would be for clinicians to include blank spaces for individuals to fill in their own words at the end of the DDS. The DDS is a tool for deeper exploration into descriptively complex and individual unique death descriptions and clinicians can walk with clients into their forest of details, accompanying them as they uncover their own path.

Clinicians working with families and couples, could use the DDS to explore the dynamics of death descriptions within and across griever. The DDS could be particularly useful to highlight differences in how individuals describe a death, an area of family grief processing that can be of particular concern. Conflicting meaning within families can be a source of discord (Nadeau, 1998). The DDS could be used to identify these differences and enable clinicians to focus in on potential areas of contention and areas requiring discussion and exploration with grieving families.

Clinicians working with groups could use the DDS as a tool for shared group awareness. Members could individual complete and reflection their DDS responses and then group leaders could encourage members to share what they learned, what surprised them, and which items seemed to describe the core of their death loss experience. Group members could compare and contrast the meaning they associate with their specific death experiences which is a normative process for griever. A critical point for counselors is to validate the uniqueness of each death loss and the uniqueness of meaning made from personal experiences.

Finally, the DDS could be used for educational workshops and groups. It could be used to introduce death and grief as multidimensional and uniquely complex experiences across individuals. For example, the Incomprehensible nature of some deaths can be an intimidating topic to approach for lay people. Using the DDS could foster the ability of potential support providers by assisting them in learning about and exploring the nuances of death losses. Presenters could introduce the idea that none of the words are exclusive to a specific mode of death and go on to role play empathic conversations within the context of interacting with griever who have experienced a whole range of modes of death.

### **Threats to Validity and Limitations**

In the present study there are a few noteworthy limitations. These limitations can be categorized based on sampling, measurement, and design.

#### ***Sampling***

Given the recruitment criteria and participant sample, generalizability is cautiously extended beyond the data and should be grounded within their demographic context. Sampling is a limitation in the current study because of the recruitment criteria. Specifically, I limited the data collection to individuals who had experienced a death in the last two years as well as to the death of a human loved one. Using these inclusion criteria necessarily limits the generalizability of the findings in that they may not apply to individuals who are grieving the deaths of family members that occurred beyond two years or grieving the death of a care giving pet (e.g., seeing-eye dog).

The sample was also relatively homogenous and participants self-selected to take part. The majority of the participants in the present study were White, cis-gender, female and

heterosexual. These data have limited generalizability and should be interpreted within the context relatively homogenous perspective. Additionally, the sample population may be biased given the nature of self-selection.

Recruitment was limited to the United States and sociocultural meaning shifts quickly across cultures. If the DDS were to be used in another sociocultural context, it would be appropriate to triangulate the present results with qualitative research in the new cultural context within which it is to be used. A priori changes to the DDS could be made by adding or changing words based on those qualitative studies. For the current study, I focused on the United States to control for cross-cultural variations in death descriptions as much as possible. However, there are many subcultures within the USA which warrant unique investigation to fully understand how the DDS could be improved to include the voices from these subcultures. Language is a dynamic medium for meaning and the DDS could change in unknown ways across languages. I am hesitant to predict how well the DDS would function in other languages, and recommend qualitative investigations to create a descriptive scale uniquely suited to any new languages and cultures. I would be interested in investigating the function of the DDS and a possible new DDS measure (i.e., non-English) translated and back translated across language and used concurrently in cultures.

Due to the nature of online recruitment, it is not possible to control the time, nor the place of participation. Additionally, not all people have access to a computer due to socioeconomic concerns (American Psychological Association Advisory Group on Conducting Research on the Internet, 2002). However, there were many benefits (e.g., greater anonymity, regional variability, larger participant pool) to online recruitment and it allowed participants the freedom to choose when and where they participated.

## *Measurement*

There are also concerns regarding measurement. Most specifically, questions may arise related to the alignment between the theoretical foundation of my study and the measures I selected for testing validity. Constructivism has a strong focus on the subjective and on individuals' unique development of internal constructs through which they view and organize their understanding of the world. Some constructivists might argue that it is inappropriate to use an a priori item selection process (e.g., Kelly, 1955) because it does not truly capture the unique nature of each individual's subjective construction of the world. However, there is precedent in terms of measures developed from a constructivist approach (Rigdon, Epting, Neimeyer & Krieger, 1979) that have used a priori item selection. Rigdon et al. (1979) used 40 a priori selected sets of dichotomous word pairs (e.g., predictable vs. random). Because I used single rather than paired words, I believe my approach aligned more closely with constructivist theory. I did not impose polar opposites, but rather allowed participants to rate the fit of the single terms. They were actually free to endorse opposing sides of any possible pairing (e.g., sudden versus prolonged).

Additionally, the DDS allows for the assessment of the dynamic, multidimensional picture of deaths and validity will need to be considered through future research. I was able to gather initial validity data for the DDS at the subscale level by examining the correlations between the DDS subscales that emerged with the good death subscales (Good death – Closure & Control; Schwartz, Mazor, Rogers, Ma, & Reed, 2003) and social desirability (MCSD-C; Crowne & Marlowe, 1960; Reynolds, 1982). Future research could explore the concurrent validity in the negatively valenced subscales of the DDS.

## *Design*

Finally, there are limitations due to the design of the current study (i.e., test-retest reliability, retrospective self-report data, uncontrolled reference group for social descriptions). A concern that is critical in scale development is test-retest reliability, an approach that I did not include in my research design. I would theoretically expect that participants' death descriptions would continue to evolve over time and that their ratings on DDS items would shift in a parallel way. Therefore, I would argue that test-retest is not a fitting assessment of reliability for the DDS.

The retrospective design of the study likely resulted in less than reliable participant perceptions as their perceptions, again, will likely shift and change with time. In an attempt to reduce retrospective bias, I limited recruitment to participants who had experienced a death within the 24 months preceding their participation.

I did not control for participants' societal reference group when I asked them to fill out the DDS the second time. More specifically, when I asked them to indicate "how others in society would describe the death," I did not impose a particular social circle or cultural influence. By not controlling the societal reference group for the participants, it is not possible to know who the participants were thinking about as they responded to the DDS items. However, leaving the instructions open allowed participants to freely associate with the most prominent reference group rather than my imposing a specific reference group.

Initial exploration of the discrepancy score yielded limited information and my method to calculate the discrepancy score was a starting place. It seemed most appropriate to use all 65 adjectives to calculate the discrepancy score. However, it may have been simpler to use only the 27 words from the DDS. However, following feedback from my proposal meeting it was recommended that my calculation of the discrepancy scores should include all 65 items. Given

the scope of my present study, I did not have the ability to run additional exploratory factor analyses on just the societal perception data. Therefore, I was unable to determine if the factor structure for the societal perceptions would have been parallel to the factor structure of the individual perceptions of the death. Future research can continue to explore theoretically appropriate methods to calculate discrepancy scores.

### ***Future Research***

Related to the limitations of the present study, researchers can continue to develop and strengthen the DDS as they make use of it in their work. Researchers should continue to explore the DDS subscales by testing their stability across a range of samples. Researchers interested in magnifying voices of historically marginalized groups may begin with a pilot study. Specifically, researchers could focus on a population of griever and begin with a focus group or semi-structured interviews to understand the qualitative experiences not captured by the current DDS.

Researchers could continue to explore the different ways of capturing and calculating the discrepancy score. Of particular interest might be experimenting with the instructions by asking participants to fill out the DDS with respect to specific groups (e.g., friends, religious/spiritual, media portrayals). Participants may be able to imagine the description more concretely from a specific group than they were able to in an open-ended way. Another direction could be to investigate a discrepancy in historically stigmatized groups of griever (e.g., suicide survivors) to pilot using a discrepancy score with griever where discrepancy may be most apparent. Additionally, researchers could continue to investigate appropriate methods for calculating the discrepancy score. I plan to continue to assess the difference in the 27-item total score and the 65-item total score.

Finally, grief researchers can consider expanding their work to include animal deaths.

When I cleaned the data, I felt tremendous injustice for grieverers of pets who were shouting (i.e., written in caps) for validation and respect. One participant wrote that they were never going to be the same after their seeing-eye dog died. Cordaro (2012) wrote that grieverers are often disenfranchised after the death a pet because the emotional connection people have to their pet is not perceived as significant. Researchers often rely on socially defined roles (e.g., immediate family) for recruitment in an attempt to control for emotional closeness. It is essential that researchers continue to develop and employ tools that appropriately reflect the complexity of death experiences as generalizations and assumption marginalize grieverers.

## **Conclusion**

In this study, I constructed the DDS and assessed the concurrent validity of the subscales. Through my analyses, I uncovered four subscales of the DDS that were statistically and theoretically meaningful. In addition, the good death factor that emerged (i.e., Warm death) was associated with existing similar scales in the expected direction and none of the DDS subscales were significantly associated with social desirability. In addition, the DDS subscales of Incomprehensible, Warm, Withering, were all positively associated with grief distress; however, the discrepancy between self-descriptions of death and personally perceived societal perceptions of death did not predictor grief distress.

The DDS opens doors for researchers to more fully investigate the nuanced ways in which grieverers might describe specific death loss experiences. Rather than having to rely on mode of death as a proxy for death perceptions, researcher can now more directly assess how grieverers view particular death losses. In addition the DDS allows for the simultaneous assessment of both positive and negative valenced views of specific deaths.

In terms of clinical implications, the DDS is an excellent tool for clinicians who wish to

explore the nuances of death experiences and foster insight with their clients. Similarly, it can be used to uncover areas of conflicting meaning in families and may be useful in preparing potential support providers in minimizing grief-related assumptions.



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## APPENDIX A. SUDDEN/VIOLENT GRIEFRELATED RESEARCH

Table A. 1 Articles from Grief Related - Sudden

Author	Adjective	Operationalized	Treatment
Anderson et al., (2005)	Sudden	Homicide or Accident	Categorized by mode of death
Brent, Melham, Donohoe, & Walker, (2009).	Sudden	Suicide, Accident, Sudden Natural	A-priori Targeted recruitment Coroner's records and participant responders to newspaper advertisement
Harrington & Sprowl (2016)	Sudden	Suicide, Homicide, Accidental and Sudden, Natural (Heart Attack)	Categorized by mode of death
Lundin, (1984).	Sudden	Natural and Traumatic (e.g., suicide); Excluded violent deaths (e.g., suspected suicide, homicide).	Unspecified
Melham, Walker, Moritz, & Brent, (2008).	Sudden	Suicide, Accident, Sudden Natural	A-priori Targeted recruitment Coroner's records and participant responders to newspaper advertisement
Merlevede, et al., (2004).	Sudden	Natural and Traumatic (e.g., suicide); Excluded violent deaths (e.g., suspected suicide, homicide).	Unspecified
Mowll, Lobb & Wearing (2016)	Sudden	Suicide, Homicide & Accidental	Categorized by mode of death
Reed, (1993).	Sudden	Suicide and Accident	A-priori Targeted recruitment Medical Examiner Reports
Reed & Greenwald, (1991)	Sudden	Suicide and Accident	A-priori Targeted recruitment Medical Examiner Reports
Rodger et al., (2006)	Sudden	Natural sudden death free of personal or criminal intent or behavior that lead to death	Categorized by mode of death

Table A. 2 Articles from Grief Related - Violent

Author	Adjective	Operationalized	Treatment
Baddeley, et al., (2015)	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Boelen & van den Bout (2007)	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Burke,& Neimeyer, (2014).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Currier, Holland, & Neimeyer, (2006).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Currier, Irish, Neimeyer & Foster (2015)	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Kitson, (2000).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Mancini, Prati, & Black, (2011).	Violent	Accident, Suicide vs. Natural	Unspecified
Murphy & Johnson (2003).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Murphy, et al., (1998).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Murphy, et al., (1999a).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Murphy, et al., (1999b).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Murphy, et al., (2002).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Murphy, et al., (2003).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Murphy, et al., (2003).	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Saindon, et al., (2014)	Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Rheingold, et al., (2015)	Violent	Suicide, Homicide & Accidental	Categorized by cause of death

## A. 3 Articles from Grief Related – Sudden and Violent

Author	Descriptor	Operationalized	Treatment
Kaltman, & Bonanno, (2003).	Sudden/Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Lohan & Murphy (2002a)	Sudden/Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Lohan & Murphy (2002b)	Sudden/Violent	Suicide, Homicide & Accidental	Categorized by cause of death
Lohan & Murphy (2006)	Sudden/Violent	Suicide, Homicide & Accidental	Categorized by cause of death
McClatchy, Vonk & Palardy (2009)	Sudden/Violent	Suicide, Homicide, Accidental and Sudden/Natural (Heart Attack)	Categorized by cause of death

## APPENDIX B. DEMOGRAPHIC AND BACKGROUND QUESTIONNAIRE

1. Age: \_\_\_\_\_

2. Sex: \_\_\_\_\_ Female \_\_\_\_\_ Male \_\_\_\_\_ Trans\* \_\_\_\_\_ Self-described (please specify: \_\_\_\_\_) \_\_\_\_\_ Choose to not disclose

3. Race/Ethnicity (Select one or more):

- \_\_\_\_\_ African American
- \_\_\_\_\_ Asian American
- \_\_\_\_\_ White (not of Hispanic origin)
- \_\_\_\_\_ American Indian or Alaskan Native
- \_\_\_\_\_ Native Hawaiian or Other Pacific Islander
- \_\_\_\_\_ Hispanic American
- \_\_\_\_\_ Middle Eastern
- \_\_\_\_\_ Biracial/Multiracial (Please specify: \_\_\_\_\_)
- \_\_\_\_\_ International Student (National origin: \_\_\_\_\_)

4. Which religion do you identify with?

- a. Agnostic
- b. Atheist
- c. Buddhist
- d. Christian
- e. Jain
- f. Hindu
- g. Muslim
- h. Sikh
- i. Zoroastrian
- j. Self-described (please specify: \_\_\_\_\_)

5. Sexual Orientation:

- \_\_\_\_\_ Straight
- \_\_\_\_\_ Gay, Lesbian
- \_\_\_\_\_ Bisexual
- \_\_\_\_\_ Self-described (please specify: \_\_\_\_\_)

6. Current Relationship Status:

- \_\_\_\_\_ Single (please specify)
- \_\_\_\_\_ Not in a relationship
  - \_\_\_\_\_ In a relationship but not cohabitating
  - \_\_\_\_\_ Cohabitating
  - \_\_\_\_\_ Married
  - \_\_\_\_\_ Divorced
  - \_\_\_\_\_ Married and separated
  - \_\_\_\_\_ Widowed

7. Current Employment Status:

- ☐ Unemployed
- ☐ Part-time employed
- ☐ Full-time employed
- ☐ Retired
- ☐ Disabled
- ☐ Student
- ☐ Not in labor force

9. Death of a loved one:

a. What was your relationship with the person who died?

\* DROP DOWN LIST\*

- ☐ Mother
- ☐ Father
- ☐ Child
- ☐ Romantic partner
- ☐ Sister
- ☐ Brother
- ☐ Other, (Specify: \_\_\_\_\_)

b. What was the age of the person who died?

\*Drop list of numbers\*

b. What was the cause of death?

\* DROP DOWN LIST\*

- ☐ Cancer (Specify: \_\_\_\_\_)
- ☐ Stroke
- ☐ Heart Attack
- ☐ HIV/AIDS
- ☐ Other Illness (Specify: \_\_\_\_\_)
- ☐ Car Accident
- ☐ Other Accident (Specify: \_\_\_\_\_)
- ☐ Suicide
- ☐ Murder/Homicide
- ☐ Drug Overdose
- ☐ Other (Specify: \_\_\_\_\_)

c. What was the date of this person's death? \_\_\_\_\_

The MacArthur Scale of Subjective Social Status (Adler, Epel, Castellazzo, & Ickovics, 2000)



Think of the above ladder as representing where people stand in the United States.

At the top of the ladder are the people who are the best off - those who have the most money, the most education, and the most respected jobs. At the bottom are people who are the worst off - who have the least money, least education and the least respected jobs or no job. The higher up you are on this ladder, the closer you are to people at the very top; the lower you are, the closer you are to people at the very bottom. Where would you place yourself on this ladder?

Please, select the letter for the corresponding rung in which you think you stand at this time in your life, relative to other people in the United States.

## APPENDIX C. SCALE OF EMOTIONAL CLOSENESS

The level of closeness we feel to others differs from person to person and over time. Please think about your relationship with the important person who died while answering the following questions. Using the following scale, circle the number that corresponds to how much you agree with each statement.

7	6	5	4	3	2	1
Very Strongly		Neither		Strongly		
Agree					Disagree	

1. I felt I could share my most intimate feelings with this person.
2. I kept my distance emotionally from this person.
3. It was very easy to talk with this person
4. I felt close to this person.
5. It was difficult to talk with this person.
6. This person understood me.
7. This person shared his/her most personal thoughts with me.

## APPENDIX D. CORE BEREAVEMENT ITEMS

These questions are about your experience in relation to the recent loss of your loved one, whose name in these questions will be signified by the symbol X

1 (*a lot of the time*) to 4 (*never*)

1. Do you experience images of the events surrounding X's death?
2. Do thoughts of X come into your mind whether you wish it or not?
3. Do thoughts of X make you feel distressed?
4. Do you think about X?
5. Do images of X make you feel distressed?
6. Do you find yourself preoccupied with images or memories of X?
7. Do you find yourself thinking of reunion with X?
8. Do you find yourself missing X?
9. Are you reminded by familiar objects (photos, possessions, rooms etc) of X?
10. Do you find yourself pining for/yearning for X?
11. Do you find yourself looking for X in familiar places?
12. Do you feel distress/pain if for any reason you are confronted with the reality that X is not coming back?
13. Do reminders of X such as photos, situations, music, places etc cause you to feel longing for X?
14. Do reminders of X such as photos, situations, music, places etc cause you to feel loneliness?
15. Do reminders of X such as photos, situations, music, places etc cause you to cry about X?
16. Do reminders of X such as photos, situations, music, places etc cause you to feel sadness?
17. Do reminders of X such as photos, situations, music, places etc cause you to feel loss of enjoyment?



## APPENDIX E. THE CONCEPT OF A GOOD DEATH MEASURE

Which response best describes how you feel about each statement?

*Note: Item answer options, 1 = Not necessary; 2 = Desirable; 3 = Important; 4 = Essential*

1. It was painless or largely pain-free.
2. The dying period was short.
3. It was sudden and unexpected.
4. Family and doctors followed the person's wishes.
5. It occurred naturally, without technical equipment.
6. It was peaceful.
7. Loved ones were present.
8. The person's spiritual needs were met.
9. The person was able to accept death.
10. The person had a chance to complete important tasks.
11. The person had an opportunity to say "good-bye"
12. The person was able to remain at home.
13. The person lived until a key event.
14. Death occurred during sleep.
15. There was mental alertness until the end.
16. There was control of bodily functions until death.
17. The ability to communicate was present until death.

## **APPENDIX F. MARLOWE-CROWNE SOCIAL DESIRABILITY SCALE**

Listed below are a number of statements concerning personal attitudes and traits.

Please read each item and decide whether the statement is true or false as it applies to you. For each item, please circle TRUE or FALSE.

1. It is sometimes hard for me to go on with my work if I am not encouraged.
2. I sometimes feel resentful when I don't get my way.
3. On a few occasions I have given up doing something because I thought too little of my ability.
4. There have been times when I felt like rebelling against people in authority, even though I knew they were right.
5. No matter who I'm talking to, I'm always a good listener.
6. There have been occasions when I took advantage of someone.
7. I'm always willing to admit it when I make a mistake.
8. I sometimes try to get even rather than forgive and forget.
9. I am always courteous, even to people who are disagreeable.
10. I have never been irked when people expressed ideas very different from my own.
11. There have been times when I was quite jealous of the good fortune of others.
12. I am sometimes irritated by people who ask favors of me.
13. I have never deliberately said something that hurt someone's feelings.

## **APPENDIX G. INDIVIDUAL RECRUITMENT EMAIL/FLYER**

FROM: Daniel Shemwell (dshemwel@purdue.edu)  
REPLY TO: Daniel Shemwell (dshemwel@purdue.edu)  
SUBJECT: Participants Needed for Grief Experience Study

Hello,

My name is Daniel Shemwell, and I am a doctoral student in Counseling Psychology at Purdue University. I am currently working on my dissertation research under the direction of my advisor, Dr. Heather L. Servaty-Seib, with the purpose of developing a scale that more appropriately measures how people describe the specific deaths they experience. This study has been determined to be exempt according to the Purdue University IRB Board (IRB Research Project Number: \_\_\_\_\_).

This study will be conducted through an on-line survey and should take about 15-20 minutes to complete. Participation is voluntary, so you can stop the survey at any time or skip questions at your discretion. If you choose to participate, you will provide all information anonymously. Your answers will be kept completely private, and no one will be able to trace your survey responses back to you.

In order to participate in this survey, you **MUST** be at least 18 years, speak English, and you **MUST** have experienced the death of an immediate family member within the last two years. If you would like to participate in this study, please click on the link below.

(Link inserted here)

If you have any questions, please feel free to contact me at dshemwel@purdue.edu or my advisor Dr. Heather Servaty-Seib at servaty@purdue.edu.

Thank you for your help,

Daniel Shemwell, M.S.  
Counseling Psychology Doctoral Candidate  
Department of Educational Studies  
Purdue University

## APPENDIX G. INDIVIDUAL RECRUITMENT EMAIL/FLYER FOLLOW-UP

FROM: Daniel Shemwell (dshemwel@purdue.edu)  
REPLY TO: Daniel Shemwell (dshemwel@purdue.edu)  
SUBJECT: Participants Needed for Grief Experience Study

Hello,

My name is Daniel Shemwell. I am emailing to follow up regarding an email I sent you last week about a study I am conducting. If you have completed the survey – thank you very much, and you need not read further. If you have not yet completed the survey, please consider taking part in my study.

I am a doctoral student in Counseling Psychology at Purdue University. I am currently working on my dissertation research under the direction of my advisor, Dr. Heather L. Servaty-Seib, with the purpose of developing a scale that more appropriately measures how people describe the specific deaths they experience. This study has been determined to be exempt according to the Purdue University IRB Board (IRB Research Project Number: \_\_\_\_\_).

This study will be conducted through an on-line survey and should take about 15-20 minutes to complete. Participation is voluntary, so you can stop the survey at any time or skip questions at your discretion. If you choose to participate, you will provide all information anonymously. Your answers will be kept completely private, and no one will be able to trace your survey responses back to you.

In order to participate in this survey, you **MUST** be at least 18 years, speak English, and you **MUST** have experienced the death of an immediate family member within the last two years. If you would like to participate in this study, please click on the link below.

(Link inserted here)

If you have any questions, please feel free to contact me at dshemwel@purdue.edu or my advisor Dr. Heather Servaty-Seib at servaty@purdue.edu.

Thank you for your help,

Daniel Shemwell, M.S.  
Counseling Psychology Doctoral Candidate  
Department of Educational Studies  
Purdue University

## **APPENDIX H. ORGANIZATIONAL RECRUITMENT**

FROM: Daniel Shemwell (dshemwel@purdue.edu)  
REPLY TO: Daniel Shemwell (dshemwel@purdue.edu)  
SUBJECT: Dissertation Research Assistance

(Name of Contact Individual),

My name is Daniel Shemwell and I am a doctoral student in Counseling Psychology at Purdue University. I am currently working on my dissertation research under the direction of my advisor, Dr. Heather L. Servaty-Seib, with the purpose of developing a scale that more appropriately measures how people describe the specific deaths they experience. This study has been determined to be exempt according to the Purdue University IRB Board (IRB Research Project Number: \_\_\_\_\_). In order to participate in this survey, volunteers **MUST** be at least 18 years, speak English, and have experienced the death of an immediate family member within the last two years.

I am emailing in the hope that your organization might be able to help me distribute this project to grievers. Would your organization be able to post a recruitment email/flyer either on its listserv or as a blog post to aid me in recruiting community members? Specifically, your organization has (preferred location to post the document). However, I am wondering if there would be a more appropriate location? I welcome any suggestions or referrals in this matter.

If you have any questions, please feel free to contact me at dshemwel@purdue.edu or my advisor Dr. Heather Servaty-Seib at servaty@purdue.edu.

Thank you for your help,

Daniel Shemwell, M.S.  
Counseling Psychology Doctoral Candidate  
Department of Educational Studies  
Purdue University

## APPENDIX H. ORGANIZATIONAL FOLLOW-UP

FROM: Daniel Shemwell (dshemwel@purdue.edu)  
REPLY TO: Daniel Shemwell (dshemwel@purdue.edu)  
SUBJECT: Dissertation Research Assistance

(Name of Contact Individual),

My name is Daniel Shemwell. I am emailing to follow up regarding an email I sent you last week about a study I am conducting. If you have passed the survey on to your organization – thank you very much, and you need not read further. If you have not yet distributed the survey, please consider taking part in my study.

My name is Daniel Shemwell and I am a doctoral student in Counseling Psychology at Purdue University. I am currently working on my dissertation research under the direction of my advisor, Dr. Heather L. Servaty-Seib, with the purpose of developing a scale that more appropriately measures how people describe the specific deaths they experience. This study has been determined to be exempt according to the Purdue University IRB Board (IRB Research Project Number: \_\_\_\_\_).

I am emailing in the hope that your organization might be able to help me distribute this project to grievers. Would your organization be able to post a recruitment email/flyer either on its listserv or as a blog post to aid me in recruiting community members? Specifically, your organization has (preferred location to post the document). However, I am wondering if there would be a more appropriate location? I welcome any suggestions or referrals in this matter.

If you have any questions, please feel free to contact me at dshemwel@purdue.edu or my advisor Dr. Heather Servaty-Seib at servaty@purdue.edu.

Thank you for your help,

Daniel Shemwell, M.S.  
Counseling Psychology Doctoral Candidate  
Department of Educational Studies  
Purdue University  
[Information in Appendix H embedded in email]

## APPENDIX I. BLOG POST

### **Public Blog Status/Posts** (e.g., Reddit, Craigslist, Facebook)

Hello! I am conducting dissertation research on how death experiences are associated with grief. In order to participate, 18 years of age or older, speak English, and experienced the death of an immediate family member within the last two years. Thank you! [link to survey]  
(Daniel Shemwell: dshemwel@purdue.edu)

## APPENDIX J. WORDS FROM GRIEF AND DYING-RELATED

Table 1a. Items for Grief Related Research

Death descriptors	Total	Specific Study
Anticipated	7	1,2,3,4,5,6,7,8
Just/Un	6	1,3,4,5,6,8
Fair/Un	6	1,3,4,5,6,8
Misunderstood	6	1,2,3,5,6,8
Robbing	6	1,3,4,5,6,8
Complex/Simple	6	1,2,3,5,6,8
Dehumanizing	5	1,2,3,5,6
Natural/Un	5	1,2,3,5,8
Stigmatized	5	1,2,3,5,6
Confusing	5	1,3,5,6,8
Wasteful	5	1,3,4,5,8
Significant/In	5	2,3,5,6,8
Chaotic	5	1,2,3,8,9
Disregarded	4	1,2,5,6
Judged	4	1,2,3,5
Unspoken	4	2,3,5,6
Preventable	4	1,3,5,8
Sensationalized	3	1,5,8
Deserved	3	1,5,8
Random	3	1,6,8
Fate	3	3,6,8
Violating	3	1,2,3
Intentional	3	1,3,8
Self-induced	3	3,5,8
Taboo	3	2,3,5
Mysterious	3	1,3,6
Moral/Im	3	2,4,6



Table 1b. Articles from grief-related research

Author	Sample	Method	N	Location	Topic
1.) Armour (2002)	Grieving Family	Qualitative Interview	23	USA	Homicide
2.) Astbury-Ward, Parry, & Carnwell (2012)	Grieving Family	Qualitative Interview	16	UK	Abortion
3.) Chapple, Ziebland, & Hawton (2015)	Grieving Family	Qualitative Interview	80	UK	Suicide and other traumatic deaths
4.) Feigelman, Jordan, & Gorman (2011)	Grieving Family	Open-ended survey	571	USA	Drug- related
5.) Gamino, Hogan & Sewell (2010)	Grieving Family	Open-ended essay	85	USA	Natural, Accidental, Suicide, Homicide
7.) Jones & Beck (2006-2007)	Grieving Family	Qualitative Interview	26	USA	Death row
8.) McCreight (2004)	Grieving Family	Qualitative Interview	14	UK	Miscarriage
9.) Nadeau (1997)	Grieving Family	Qualitative Interview	10 families	USA	Sudden, Traumatic
10.) Rodger et al., (2006-2007)	Grieving Partner	Qualitative Interview	15	Australia	Unanticipated, Sudden

Table 2a. Items from Dying Related Research

Death Descriptors	Total	Specific Study
Painless/painful	26	1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26
Controlled/Uncontrollable	19	2 3 4 5 6 7 8 11 12 13 14 15 16 17 18 20 21 23 24
Suffering	16	1 2 3 4 19 12 14 15 16 17 18 19 20 21 23 24
Peaceful	16	1 2 3 4 7 9 10 11 13 15 16 17 18 20 22 24
Good	15	2 5 7 9 10 11 12 13 14 15 18 20 21 22 24
Fearful	15	3 4 5 6 11 14 15 16 17 18 20 21 22 23 25
Un/Prepared	15	5 6 7 8 12 13 15 16 17 18 20 22 23 24 25
Comfortable	14	2 3 6 8 11 13 14 15 16 18 20 21 22 26
Caring	13	1 2 3 11 12 13 15 16 20 21 22 24 25
Un/Acceptable	13	2 3 5 6 8 11 13 16 17 18 20 21 25
Bad	12	10 11 13 15 16 17 18 20 21 22 24 26
Dignified	11	2 3 4 6 8 11 15 16 18 20 22
Religious	11	3 6 10 11 14 15 18 20 21 24 25
Cold	11	4 5 6 10 11 12 13 15 16 20 22
Timely	11	1 3 4 8 10 11 14 15 16 17 22
Spiritual	10	3 6 10 11 14 15 18 21 24 25
Dehumanizing	9	1 3 4 11 12 17 22 24 26
Lonely	9	1 5 6 11 13 15 18 25 26
Prolong	9	3 10 11 14 15 16 17 18 23
Unemotional	9	3 6 10 11 12 13 18 20 22
Sudden	9	2 6 10 14 15 16 17 18 19
Negligent	8	12 13 14 15 18 20 21 22 26
Quick	7	9 10 14 15 23 24 25
Respectful	7	3 6 8 10 11 18 22
Burdensome	6	1 6 7 11 12 14

Table 2a continued

Death descriptors	Total	Specific Study
Ideal	6	6 11 14 15 22 24
Preferred	6	6 8 10 12 18 21
Planned	6	7 12 14 18 22 25
Hope/less	6	1 5 11 14 15 24
Self-determined	6	3 12 14 16 17 25
Un/Wanted	6	3 8 13 14 15 22
Relieving	6	6 7 8 12 14 15 17
Premature	5	1 3 10 13 20
Desirable	5	1 3 11 14 17
Mismanaged/well-managed	5	15 16 21 22 25
Chaotic	5	16 17 20 21 22
Complex	5	3 11 15 16 24
Welcomed	5	6 14 15 16 22
Meaningful/less	5	5 14 20 21 22
Calm	4	3 16 18 25
Un/Natural	4	3 8 10 11
Fate	4	4 5 15 24
Regrettable	4	7 12 21 25
Agony	4	10 16 17 18
Traumatic	4	8 18 20 22
Lingering	3	11 15 16
Hastened	3	12 17 18
Preventable	3	19 20 22
Un/Expected	3	2 8 11
Confusing	3	5 20 22

*Note: Please reference table 1b for studies labeled here.*

Table 2b. Articles from Dying Related Research

Author	Sample	Method	N	Location	Topic
1. Adorno & Brownwell, 2014	Patients/Late-stage cancer	Qualitative Interview	12	USA	Quality of life at end-of-life
2. Aleksandrova-Yankulovska & ten Have, 2015	Staff, Bereaved	Self-Administered Survey	406	Bulgarian	Good death
3. Broom, 2012	Patients/ In hospice	Qualitative Interview	20	Australia	Patients views on hastened death
4. Chochinov, Hack, Kristjanson, & McClement, 2002	Patients/ Terminally ill	Qualitative Interview	50	Canada	Dignity and Death
5. Goldstien et al., 2006	Patients/ Terminally ill	Qualitative Interview	13	Netherlands	Good death
6. Gott et al., 2008	Patients/Advanced Heart Failure	Qualitative Interview	40	UK	Good death
7. Hattori & Ishida, 2012	Elderly Japanese Americans	Qualitative Interview	18	USA	Good death
8. Holdsworth, 2015	Bereaved	Qualitative Interview	44	UK	Good death
9. Hughes et al., 2008	Patients	Open-ended Content Analysis	100	USA	Good death
10. Ko et al., 2012;	Older Mexican Americans	Qualitative Interview	18	USA	Good and Bad death
11. Ko, Kwak, & Nelson-Baker, 2015	Older Homeless	Qualitative Interview	21	USA	Good and Bad death
12. Lawrence et al., 2011	Family/Carers	Qualitative Interview	40 (27/23)	UK	Good end-of-life for people with dementia
13. Low, & Payne, 1996	Carers	Self-Administered Survey	50	UK	Good and Bad death

Table 2b. continued

Author	Sample	Method	N	Location	Topic
14. Lloyd-Williams et al., 2007	Elderly (80-89)	Qualitative Interview	40	UK	Death, dying and end-of-life
15. Masson, 2002	Patients, Bereaved/ Hospice	Qualitative Interview	20	UK	Good death
16. Payne, Langley-Evans, & Hillier, 1996	Inpatient/ Hospice	Qualitative Interview	18	UK	Good death
17. Pestinger et al., 2015	Inpatient/ Hospice	Qualitative Interview	12	Germany	Hasten death
18. Pierson, Curtis, & Patrick, 2002	Patients/Advanced AIDS	Qualitative Interview	35	USA	Good death
19. Robinson, Covey, Spencer, & Loomes, 2010	General Public	Focus Group	253	UK	Death Labelling
20. Semino, Demjen, & Koller, 2014	Hospice Managers	Qualitative Interview	13	UK	Good and Bad death
21. Steinhauser et al., 2000	Patients, Carers, Bereaved	Focus Group	75	USA	Good death
22. Trankle, 2014	Hospice Physicians	Qualitative Interview	13	Australia	Good death
23. van der Geest, 2003	General Public	Anthropological	75	Ghana	Good and Bad death
24. Vig, & Pearlman, 2004	Patients/ Heart disease, Cancer	Qualitative Interview	16	USA	Good and Bad death
25. Volker & Wu, 2011	Patients/ Advanced cancer patients	Qualitative Interview	20	USA	meaning of control at end of life
26. Zukoski & Thorburn, 2009	Patients	Qualitative Interview	16	USA	Living with HIV

## APPENDIX K. PRELIMINARY ANALYSES DETAILS

In this section I provide the details of my preliminary analyses. I performed correlations to assess for significant associations between grief distress and my continuous demographic variables (e.g., age, subjective social class) and continuous death-related variables (e.g., months since the death, emotional closeness with the deceased). Then, I conducted a series of ANOVAs to assess for possible group difference in grief distress based on each categorical demographic (e.g., sex) and death-related (e.g., cause of death) variable including sex, sexuality, race, U.S. State, employment, relationship status, religious/spiritual affiliation, relationship to the deceased, and cause of death.

### **Continuous Demographic and Death-Related Variables**

For the continuous demographic and death-related variables, I determine a plan to only control for variables significantly correlated with my dependent variable of grief distress (i.e.,  $p \leq .01$ ) and had a medium or greater effect size (i.e.,  $r \geq .30$ ; Cohen, 1988).

For grief distress, age ( $r = -.12, p < .001$ ), subjective social class ( $r = .14, p < .001$ ), age of the deceased ( $r = -.45, p < .001$ ) and perceived closeness with the deceased ( $r = .42, p < .001$ ) were significantly correlated with grief distress. Hence, in the main analysis for grief distress, I controlled only for emotional closeness with the deceased and age of the deceased because these variables emerged as having a medium effect size associated with grief distress.

### **Categorical Demographic and Death-Related Variables**

For the categorical demographic and death-related variables, I performed a series of ANOVAs to test for possible group differences in grief distress. I intended to only control for variables that exhibited significant group differences (i.e.,  $p \leq .01$ ) and had a medium or greater effect size (i.e., partial eta squared,  $\eta_p^2 \geq .13$ ; Pierce, Block, & Aguinis, 2004).

With regard to sex, the ANOVA analysis indicated a significant difference in my dependent variables (i.e., grief distress) using Wilk's lambda,  $F(5, 571) = 1.25, p = .01, \eta_p^2 = .02$ . Nonetheless, because the effect size was small, I did not consider the further analysis.

With regard to sexuality, the ANOVA analysis did *not* indicate a significant difference in my dependent variables (i.e., grief distress) using Wilk's lambda,  $F(3, 571) = 3.59, p = .29, \eta_p^2 = .02$ . Hence, I did not consider the univariate findings.

With regard to race, the ANOVA analysis did *not* indicate a significant difference in my dependent variables (i.e., grief distress) using Wilk's lambda,  $F(8, 571) = .59, p = .79, \eta_p^2 = .01$ . Hence, I did not consider the univariate findings.

With regard to current relationship status, the overall multivariate findings did indicate a significant difference in my dependent variables (i.e., grief distress) using Wilk's lambda,  $F(7, 571) = 4.89, p < .000, \eta_p^2 = .04$ . Nonetheless, because the effect size was small, I did not consider further analysis.

With regard to employment, the overall multivariate findings did *not* indicate a significant difference in my dependent variables (i.e., grief distress) using Wilk's lambda,  $F(7, 571) = 1.99, p = .05, \eta_p^2 = .02$ . Hence, I did not consider the univariate findings.

With regard to religious/spiritual affiliation, the ANOVA analysis did indicate a significant difference in my dependent variables (i.e., grief distress) using Wilk's lambda,  $F(12, 571) = 1.78, p = .05, \eta_p^2 = .04$ . Nonetheless, because the effect size was small, I did not consider further analysis.

With regard to the relationship with the deceased (e.g., grandparent, child, mother/father, friend), the ANOVA analysis indicated a significant difference in my dependent variables (i.e.,

grief distress) using Wilk's lambda,  $F(13, 571) = 6.04, p < .000, \eta_p^2 = .12$ . Nonetheless, because the effect size was small, I did not consider further analysis.

With regard to the cause of death, the ANOVA analysis did indicate a significant difference in my dependent variables (i.e., grief distress) using Wilk's lambda,  $F(15, 571) = 3.57, p < .000, \eta_p^2 = .09$ . Nonetheless, because the effect size was small, I did not consider further analysis.

### **Summary**

Grief distress was significantly associated only with emotional closeness with the deceased and age of the deceased at a medium or greater effect size. As such, I controlled only for emotional closeness with the deceased and age of the deceased by adding these variables into Step 1 of the hierarchical multiple regression for grief distress.



## **APPENDIX L: DDS FOR RESEARCH USE**

The DDS can serve as a robust research tool. Although deaths are often defined or considered narrowly based on the specific cause, the DDS allows participants to select from a range of adjectives that may or may not fit with how they make meaning of or would describe a single death loss experience. The rationale behind the measure was to allow for the complexity of meaning and flexibility is necessary to allow for participants to continue to develop the complexity of the DDS as it is used in new samples.

- Researchers who use the DDS must understand the cultural context and how that shapes descriptions of death, particularly within their prospective sample.
- Researchers need to allow participants the flexibility to write in their own descriptors in the five open spaces provided; potential differences need the opportunity to rise.
- Researchers should investigate the functioning of the DDS within targeted populations to understand how context may reshape the DDS.

*Descriptive Death Scale-Research Version*

Directions: From your perspective, please indicate how well each word below **fits** with how **you would describe** the particular death that you indicated earlier.

Although this scale includes words commonly used to describe deaths, it does not include all words that can be used to describe deaths. In fact, death experiences are complex and unique experiences. This scale does not include an exhaustive list of words. Please be sure to add and rate additional words at the end of the measure that you believe fit with your death experience but do not appear on the scale.

Please indicate how well each word **fits** with **your** description of the death on a scale of 1 to 5.

	not at all	a little	somewh at	mostly	extreme
How well does each word fit					
Calm	1	2	3	4	5
Caring	1	2	3	4	5
Comfortable	1	2	3	4	5
Dignified	1	2	3	4	5
Ideal	1	2	3	4	5
Intentional	1	2	3	4	5
Lingering	1	2	3	4	5
Meaningful	1	2	3	4	5
Mysterious	1	2	3	4	5
Natural	1	2	3	4	5
Painful	1	2	3	4	5
Peaceful	1	2	3	4	5
Premature	1	2	3	4	5
Prolonged	1	2	3	4	5
Random	1	2	3	4	5
Respectful	1	2	3	4	5
Self-induced	1	2	3	4	5
Shocking	1	2	3	4	5
Spiritual	1	2	3	4	5
Stigmatized	1	2	3	4	5
Sudden	1	2	3	4	5
Suffering	1	2	3	4	5
Taboo	1	2	3	4	5
Traumatic	1	2	3	4	5
Unacceptable	1	2	3	4	5
Unfair	1	2	3	4	5
Moral	1	2	3	4	5

## APPENDIX M: DDS FOR CLINICAL USE

### Guidance for Clinicians

The DDS can serve as a robust clinical tool. Although deaths are often defined or considered narrowly based on the specific cause, the DDS allows clients to select from a range of adjectives that may or may not fit with how they make meaning of or would describe a single death loss experience. The rationale behind the measure was to allow for the complexity of meaning and, therefore, the measure should not be used as a strict quantitative assessment, but rather as a catalyst for conversation and reflection.

- The DDS does not lend itself to one overall total score and clients' total score on each subscale score should not necessarily be compared to another.
- Clients' description of a single death may shift over time such that periodic use of the DDS may be useful to assess these shifts and changes in perception.
- Descriptive flexibility is necessary for clients to convey their individual context. Please, **keep all blank spaces** for clients to write in items/adjectives that fit their meaning but or not included in the measure.
- Clients may identify core descriptors or words that are central to the description of their loved one's death.
- Additional follow-up questions are provided below.

*Descriptive Death Scale-Clinical Version*

Directions: Below is a list of words commonly used to describe deaths. Please indicate how much each word fits the way you would describe your specific experience of \_\_\_\_\_'s death.

Although the words below are commonly used to describe deaths, it does not include all words that can be used to describe deaths. In fact, death experiences are complex and unique experiences. This scale is not meant to be an exhaustive list of possible descriptors. Be sure to add additional words at the end of the measure that you believe fit with your death experience but do not appear on the scale.

Finally, some words may be more important in your description of \_\_\_\_\_'s death. Whether you think all words are equally important, or one word is more important than the rest. Please use the far right column to indicate words that you believe are core to your experience of \_\_\_\_\_'s death.

Please indicate how well each word **fits** with **your** description of the death on a scale of 1 to 5.

	not at all	a little	somewhat	mostly	extremely well	Core Descriptor
How well does each word fit						
Calm	1	2	3	4	5	
Caring	1	2	3	4	5	
Comfortable	1	2	3	4	5	
Dignified	1	2	3	4	5	
Ideal	1	2	3	4	5	
Intentional	1	2	3	4	5	
Lingering	1	2	3	4	5	
Meaningful	1	2	3	4	5	
Mysterious	1	2	3	4	5	
Natural	1	2	3	4	5	
Painful	1	2	3	4	5	
Peaceful	1	2	3	4	5	
Premature	1	2	3	4	5	
Prolonged	1	2	3	4	5	
Random	1	2	3	4	5	
Respectful	1	2	3	4	5	
Self-induced	1	2	3	4	5	
Shocking	1	2	3	4	5	
Spiritual	1	2	3	4	5	
Stigmatized	1	2	3	4	5	
Sudden	1	2	3	4	5	
Suffering	1	2	3	4	5	
Taboo	1	2	3	4	5	
Traumatic	1	2	3	4	5	
Unacceptable	1	2	3	4	5	
Unfair	1	2	3	4	5	
Moral	1	2	3	4	5	

Possible follow-up questions for discussion with clients:

- Which words resonated most?
- Which were perhaps at the core of your experience of this death?
- Which words did you add?
- Which words did you endorse that surprised you?
- Which, if any, of your personal identities seem most related to your responses (e.g., religious/faith, culture, race/ethnicity, sexual orientation, military background, socioeconomic status, rural/urban)?