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“We Just Didn’t Talk About It:” Strategies of Stigmatized Grief Management

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Master of Arts in Communication and Storytelling Studies

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by

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ABSTRACT

“We Just Didn’t Talk About It:” Strategies of Stigmatized Grief Management

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This study explores the experiences of people who have lost loved ones due to socially stigmatized deaths. Drawing from eight individual interviews, the author argues that the stigma associated with death due to drug overdose, suicide, substance abuse, or murder can cause traumatic or prolonged grief and can complicate the way the bereaved talk about grief as a part of their healing process. With the mortality rate in the U.S. rising, there is an epidemic of disenfranchised grief affecting millions of bereaved individuals. Using Coordinated Management of Meaning and Communication Privacy Management theories, the author uncovers strategies the traumatically bereaved employ to manage interactions and relationships with others. A qualitative analysis of participant interviews revealed that social stigma, whether experienced or anticipated, affects the way the bereaved communicate and can cause self-silencing. Findings indicate a need for safe, supportive, and non-judgmental spaces for the traumatically bereaved to share their stories.

DEDICATION

For my mother, who endured a lifetime of grief with a grace that belied her sorrow.

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To my husband, Perry Selleck: there will never be words to express how much I love and appreciate you. I had no idea what I was asking of you when I enrolled in grad school but, in true form, you have been my rock and my shelter every step of the way. I adore you.

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Chapter 1. Introduction

In 2015 my fifty-nine year old sister we called Petey, home alone with three grandchildren under the age of five, called her drug dealer for the last time. Hours later, the children were found crawling over her body on the floor. The autopsy and subsequent toxicology report would list a number of drugs in her system, including the synthetic opioid Fentanyl. This was the culmination of many years of drug abuse, mental illness, addictive behaviors, and general failure to thrive, so her death was no surprise to anyone in the family. We knew it was coming; we just never knew when. Despite this, her death had a devastating effect on my mother, who had spent years trying to save her firstborn child's life—years primarily spent in resolute denial of the severity of the problem.

To be brutally honest, I suspect I was not the only one in my family who felt a marginal amount of relief amidst the horror and grief of my sister's passing. I had lost my sister—my best friend for years—long before her death. Her choices in life were traumatizing to our family and left us with wounds that still cause pain all these years later. My reaction to her death is admittedly damning in many ways, but this does not make my admission any less valid. We all suffered through years of physical, mental, and emotional abuse, and through the disappointment and heartache that is watching someone you love destroy herself and your family in agonizing increments. My mother's health almost immediately started failing and I became her caretaker for the remaining four months of her life, during which time we spoke little of our loss.

Once again, if I'm being honest, Mom had no one to talk to—at least no one who hadn't already blamed her for enabling Petey's drug abuse. I can't count the times I said, in anger and frustration, "When Petey dies, it will be with drugs you paid for." It's not easy knowing I contributed to the stigma Mom felt that prevented her from talking about her grief. I've learned a great deal about disenfranchised grief in the five years since her death; it has been an education I wouldn’t wish on anyone. I have also learned that addiction is a response to emotional pain and physical trauma, and this realization has helped me feel a great deal more compassion for my sister than I ever felt when she was alive.

This thesis focuses on how people communicate, or fail to communicate, after the loss of a loved one who has died in a way that is considered socially stigmatized. In some ways, it is an effort to make sense of a profound personal experience by studying similar experiences of others. More importantly, however, it is an attempt to add to a body of work that has largely overlooked a significant portion of a larger problem: disenfranchised grief.

Chapter 2. Literature Review

It is the year 2021 and all eyes are on the worldwide COVID-19 pandemic. The onset was sudden and overwhelming, the infection and death rates staggering. As of March 4, 2021 the CDC reported 503,587 deaths in the United States due to the SARS-CoV-2 virus, also known as the coronavirus, since January 1, 2020. Though the pandemic has been politicized—masks vs. no masks, hoax vs. scientific proof—news outlets and social media are saturated with COVID stories; people are talking about the disease, as they should be. But there is another growing epidemic in this country that eludes headlines and social media attention, even as it threatens millions of lives.

Opioid addiction in the United States is a “serious national crisis that affects public health as well as social and economic welfare” (NIH, 2020). The Substance Abuse and Mental Health Services Administration (2015) reports an estimated 22 million individuals admitted to having used or abused illicit drugs or alcohol in the previous year with numbers on a steady incline. Fentanyl, one of the synthetic opioids most common in drug overdose deaths in the United States, is a powerful pain relieving drug similar to morphine, but 50 to 100 times stronger. Since 2010, overdose deaths in the United States involving predominantly illicit opioids like Fentanyl have increased by more than 200%, rising from 14.3 percent in 2010 to 59.8 percent in 2017 (NIDA, 2019). From this data it is clear that the number of drug-related deaths (DRD) in recent years have reached epidemic proportions.

In fact, there were more than a half-million accidental drug overdose deaths in the U.S. during the first two decades of the 21st century, leaving the number of family members and close friends left grieving their loved ones easily totally in the millions. For every person deceased by a DRD, there will be at least ten next of kin left behind who are likely to suffer the effects of bereavement (Dyregrov et al., 2018). When one considers the additional number of deaths due to suicide, homicide, alcoholism, or other socially stigmatized behavior, all of which come with their own unique and complicated forms of grief for the survivors, it is no overstatement to claim a pandemic of grief in this country. Millions of family members have lost brothers, sisters, sons, daughters, parents, and cousins; still millions more live every day with a mentally ill and/or addicted loved one. This "anticipatory grief" begins long before a related death occurs, which influences how they grieve if and when it does. For this study, I have focused on how survivors grieve and how they communicate with others when the death of a loved one is socially stigmatized.

Evolving Grief Literature

Perhaps one of the most interesting things about grief studies is how the literature and research themselves have evolved. Over the years, bereavement researchers and thanatologists—those who study death, dying, and grief—have established with some consensus that grief is a highly individualized and deeply painful human experience. While there are many universal aspects of grief, most researchers agree that no two people grieve exactly the same way. Feigelman et al. (2012) write: "If you've seen one grieving person, you've seen one grieving person."

Despite the fact that grief is considered a normal part of human existence, Bonanno (2001) notes that the extent to which the grieving experience varies makes it difficult to define normal or abnormal grief, which is demonstrated by the lack of a "clear, empirically defensible definition of grief" in grief literature. *Bereavement,* the experience of losing a significant person to death, is a stressor event with certain "normal and predictable consequences," including that some reactions or responses to grief have a generally time-limited disruption in the normal functioning of the bereaved (Bonanno, 2001, p. 706). For the purposes of this study the term *grief* is defined as a response to bereavement and *mourning* is recognized as the "social level process of adjustment to the death" (Hibberd, 2013, p. 671).

Parkes argues that, though the loss of a loved one is one of the most stressful events humans experience, most recover with minimal help. But that is not always the case. Some suffer lasting impairment of physical and mental health due to a wide range of factors related to loss (Neimeyer, R.A., 2019, p. 2-3). This study focuses on a specific segment of those factors—loss due to a death that is socially stigmatized.

Traditional Theories of Grief

In early years of grief studies, Elizabeth Kübler-Ross made headlines with her 1969 groundbreaking book *On Death and Dying.* In this work, Kübler-Ross describes five stages of grief which dying patients experience: denial, anger, bargaining, depression, acceptance. From this, Kübler-Ross has been often been credited with discovering the phases of grief as well as the phases of dying. Colin Parkes, however, argues that Kübler-Ross actually adapted the earlier work of Robertson and Bowlby (1952) who studied Separation Anxiety among children and mothers, as well as Parkes' own study of widows, both of which revealed certain common phases of grief (Parkes, 2002). "From the start, Bowlby and I recognized that there was a great deal of individual variation in the response to bereavement and that not everybody went through these phases in the same way or at the same speed" (Bowlby & Parkes, 1970, as cited by Parkes, 2002, p. 372).

This *stage theory* of grief has been endorsed and prescribed by healthcare professionals since its inception but has, in recent years, garnered growing opposition. Bonanno and Boerner (2007) object to the concept of grief stages based on findings that cast doubt on the idea of any sort of “typical” response to loss. If no archetypal grief exists, it is unlikely one theory would adequately inform grief therapy for all who mourn. Stroebe et al. (2017) note concerns that the theory lacks “sound empirical evidence” and is not designed to help identify prolonged grief, which can require more in-depth professional care. Moreover, Stroebe et al. (2017) argue that stage theory attempts to fit complex and fluctuating emotions into an orderly and predictable series of events culminating in recovery or closure (p. 467). Research indicates most people do not grieve in stages and, if they do, the stages are not necessarily linear. In addition, because the theory is overly simplistic and limited, and does not take into account the diversity in grief reactions or the wide variety of circumstances that can cause traumatic or complicated grief, some mourners could actually be harmed by the use of stages as a model for grief work. Parkes (2002) notes that several studies have failed to replicate the Kübler-Ross findings and cautions against counselors inappropriately imposing the model on their clients.

Years after his work with Kübler-Ross on the five stages of grief, David Kessler (2019) published new work noting a sixth stage of grief in which he describes the process of making meaning of the death as a way to avoid getting stuck in one of the other stages (p. 2). Contending with the sixth stage was one of the ways Kessler worked through his own grief over the loss of his son David to a drug overdose. “Finding meaning allows us to transform grief into something rich and fulfilling,” he said, “something bigger than pain, a way to empower ourselves to move forward” (Kessler, 2019, p. 52).

The scope of bereavement research and theory has expanded over the last 20 years to include a number of new areas of focus, including a burgeoning literature on the role of meaning reconstruction in mourning (Hibberd, 2013, p. 688). For some researchers, meaning-making has become a central feature of grieving; it is considered a process that helps the bereaved move forward. “Meaning-making is usually done either by making sense of the death, that is, finding reasons for why it happened, or by according some larger purpose or benefit to the death (Armour, 2014, p. 63).

The Experience of Grief

Grief can be experienced psychologically through feelings, thoughts, and attitudes, as well as socially through interaction and communication with others. Grief can also be experienced through the body’s physiological response to emotional stress (Rando, 1991, p. 11). These manifestations of grief evolve over time and are variable and unique to each mourner and each loss. However, there do exist commonalities that are recognizable to physicians and mental health clinicians. (Shear, 2015, p. 153) Fowlkes (1990) argues that grief is a subjective and private emotional experience with a “predictable symptomatology” (p. 636).

The symptoms and types of grief experienced, as well as the mourning process, can be influenced by many conditions. Parkes (2002) notes that more recent research highlights the importance of *social context* in grief, as well as how the nature of relationships influence people’s reactions to and experience of grief and loss (p. 367). The individual perception of loss can be influenced by the relationship between the bereaved and the decedent, whether ancestral, romantic, or platonic. Likewise, the nature or tenor of the relationship—such as unresolved issues or prior stressors in the relationship—can affect how an individual will process and experience the loss. Those who were heavily dependent on the deceased can also experience a more difficult recovery process (Rando, 1991, p 113-114). In addition, the circumstances of the death—natural due to age or a young life cut short, accidental or self-inflicted, violent or peaceful—can each significantly influence the way survivors experience grief. This is especially true with regard to the willingness and ability of survivors to talk about their loss, which grief researchers and therapists agree is an integral part of how grief is experienced. Even with the support of family and friends, grief can be a lonely walk, as Clements et al. (2004) explain: "There is frequently discomfort and often an avoidance of discussing the pain and heartache that individual survivors experience in the shadow of a sudden and traumatic loss" (p. 149).

While most of the grief literature focuses on grief as an individual process, Breen et al. (2019) add an "invitation to grief in the family context," Breen et al. argue that the individual focus that "dominates" the literature neglects to consider grief that is experienced within a family unit, which they define broadly as "web of relationships that is individually experienced" (p. 173). Attig (1976) notes, "we grieve individually and collectively in complex and interdependent interactions with others in our families and communities. As with all families, this web or unit is fluid in nature, with dynamics that evolve and are defined and experienced individually" (p. 33). Because individuals grieve within the context of family, the grief experiences of family members can also be shaped by the dynamics of family structure, relationships, and expectations (Breen et al., 2019, p. 174).

Stigmatized Deaths

The death of a child is considered one of the most traumatizing events a person may experience in life, and when that death is particularly violent or gruesome, or is the result of drug abuse or suicide, the death is stigmatized. As a consequence, the parent's loss is often clouded by secrecy, shame, and denial (Weis et al. 2019). These factors can cause the survivor to withdraw from family and friends, and avoid discussing their child's death, placing them at even greater risk of mental health or grief problems.

Erving Goffman (1963) framed stigma as a condition or "mark" that leads to "spoiled identity." According to Goffman, the "manifest mark" of mental illness or drug addiction is an associated label, e.g., drug addict, crazy, bipolar, schizophrenic, junkie. While these terms are considered pejorative by today’s standards, and certainly by the mental health community, they are still widely used by the public and are most certainly labels that further sustain stigmatization. It is the fear of being labeled accordingly that often encourages the mentally ill or drug addicted patient to avoid seeking medical or mental healthcare that may save their lives.

There are many forms of stigmatization that lead to Goffman’s notion of spoiled identity. Stigmatized relationships may include those that involve extramarital affairs, where the relationship of the mourner is undervalued. But perhaps one of the loneliest and most devastating losses are those where the stigma devalues the deceased as a person, and where the loss itself is “socially recorded as illegitimate” (Fowlkes, 1990, p. 644). Examples of stigmatized, morally illegitimate losses may include the death of a convicted criminal, alcoholic, or drug user, death by suicide, or the death of mentally ill or incapacitated persons, all of which can cause mourner to experience a range of responses from indifference to condemnation. Some acts of stigmatization, such as blaming the parent or the deceased, are even more distressing to the survivors. Such blame is common in cases of suicide and/or substance abuse deaths. Suicide-bereaved parents are already inclined to blame themselves in the deaths of their children, so being or feeling blamed by family members or friends can be especially harmful. Feigelman et al. (2020) suggest that disenfranchising already marginalized people can negatively impact bereavement and hinder their healing period (p. 630-631).

Survivors of these types of losses are stigmatized in a number of ways, including three typical experiences: complete avoidance of discussion by significant others; absence of, or superficial, interest by others and unhelpful advice, such as encouraging them to move on. This kind of empathic failure among family and friends can force the bereaved to look for outside help among bereavement specialists or support groups (Feigelman et al., 2012, p. 54) which, though often productive and necessary, can cause its own layer of stigma. Corrigan & Nieweglowski (2018) reviewed the broader research literature regarding the stigma of behavioral health in an effort to identify the ways in which harmful stigma created barriers to understanding and addressing the opioid crisis in the United States. In this study, Goffman's work was extrapolated into a matrix defined by two dimensions: social cognitive constructs that cause stigma, and constructs that directly affect the person with the illness (p. 44). These constructs include stereotypes, prejudice, and discrimination. While stereotypes are learned from the culture in which one is raised, prejudice occurs when others agree with the stereotype, leading to emotional evaluation or judgment. This experience of social condemnation, or even the anticipation of it, can cause *self-stigma*, which occurs when someone accepts the social stigma and stereotypes assigned to them or their loved ones. Kauffman (2002) adds that self-disenfranchised grief can also be a psychological symptom where the bereaved disallows the recognition of grief without social influence (p. 61). In these cases, the survivor presumes a negative social reaction and will pre-emptively avoid interaction with others.

In addition, public and private stigma against people with a behavioral health disorder, including substance abuse disorder, often results in their refusing treatment in an effort to avoid the label (Corrigan, 2018, p. 45). Research shows denial of substance abuse is common among users and their families, who often feel a deep sense of shame and guilt. Whether these feelings are caused by actual condemnation or the anticipation of it, the result is the same: drug users and their families may avoid seeking the help they need, compounding the problem of drug-related deaths and unresolved grief.

The Rules and Rituals of Grief

There are societal norms that affect how people are expected to perform grief. Doka (1989) called these norms “grieving rules” through which a particular culture or society identifies who, when, how, where, how long, and for whom people should grieve. One such rule pertains to rituals. Grief literature has long upheld the importance of rituals as “socially approved means of expressing emotion associated with grief.” (Brabant, 2002 p. 31). In most cultures across the world, rituals are “highly symbolic acts that confer meaning or significance to certain life events” such as death. Death rituals provide both structure and opportunity to contain and express emotion in ways that allow communities, friends, loved ones to come together to witness and share in the grief of others (Doka, 2002, p. 135). Kessler (2019) argues that humans are born with a mirroring instinct that includes the need for grief to be witnessed, reflected, and acknowledged by someone who does not try to minimize the pain. This is exemplified in some of the indigenous villages of Australia. The villagers hold to custom in which, the night someone dies, all of the villagers move a piece of furniture or another object into their front yards. When the bereaved family wakes up the next day, they have a physical representation of the fact that everything has changed because their loved one died. In this way, the villagers symbolically witness and mirror the family’s loss so they know they are not alone, and that their loved one’s death mattered (Kessler, 2019, p.30). This particular ritual is an example of sacred symbolism, which consists of objects and actions with special meaning that set the ritual context apart from mundane events (Durkheim, 1912; Reeves, 2011 as cited in Sas & Coman, 2016).

The most common death ritual in the United States is the funeral, which allows for public mourning—the outward expression of grief. According to Doka (2002) the funeral ritual can serve a therapeutic role with a variety of benefits. The funeral affirms the reality of the death, providing social support while reaffirming their new identity within the community. For example, a married woman becomes a widow; or a child becomes an orphan. Funerals offer the structure and space to both express and contain grief, to facilitate recollections and to offer possible meanings for the loss. Doka adds that funerals offer structured activities at an otherwise disorganized time, allowing grievers to feel like they are “doing something” (p. 136). In noting the important function of funeral rites and mourning customs, Fowlkes (1990) expresses concern about the ways the “behavioral manifestations” of grief are socially regulated. When an individual mourner is denied access to traditional grief roles, the grief process can become prolonged and complicated.

There are times when grieving rules enforce an idea that some losses cannot be “openly acknowledged, socially validated or publicly observed,” resulting in what Doka (1999) and other researchers call “disenfranchised grief” (p. 37). This disenfranchisement can be implicit or explicit and takes many forms, but in general the outcome is the same: the bereaved are prevented from performing the culturally accepted rituals of grieving. Parents whose child committed suicide may be forbidden to hold a funeral in their home church; an unmarried partner may be excluded from the funeral completely or relegated to a non-familial role; family members who lose loved ones to a drug-related death may repeatedly hear the message that the deceased is better off dead. Neimeyer and Jordan (2002) call disenfranchised grief an empathic failure between the bereaved and their larger social network (as cited by Feigelman et. al., 2012, p. 43). Feelings of guilt and the expectation of judgments from others can force survivors into a “privatized and individualized mode of grieving” (Armour, 2007, p. 66). In essence, the mourner feels they are not entitled or allowed to grieve a loss; they are discouraged from talking about the loss or denied validation of and public witness to their grief, making that grief exceptionally complicated. The very nature of disenfranchised grief exacerbates grief (Doka, 2002 p. 17).

In many cases, some of the most common rituals of grief are avoided. A Brazilian study concluded, for example, that "overdose death is a highly stigmatized behavior because of the loved one's perceived immoral and/or criminal behavior" (Feigelman et al., 2012, p. 61). When illegal drug use is involved in the death, there is a challenge to the norms and values of society that opens a door for additional blame and fault-finding, while closing a door to "a comforting obituary that tells us of life achievements in which we can see merit and which enhances rather than destroys the persona of the dead" (Guy & Holloway, 2007, p. 91).

While beyond the scope of this study, it is important to recognize the affect the 2020 COVID-19 pandemic has had on the bereaved worldwide. On February 3, 2020, the United States government declared a public health emergency due to the coronavirus outbreak. On March 13th, a national emergency was declared making billions of dollars available to fight the spread of the disease. States began issuing stay-at-home orders to non-essential workers soon afterwards and millions of Americans began participating in quarantine precautions that are ongoing as of this writing. By May 2020, the death toll due to COVID-19 had reached over 100,000 in the United States (The Centers for Biosimilars, 2021, n.p.). Hospitals and morgues were overwhelmed, and funeral homes and churches across the nation were forced to delay, cancel, or limit funeral services. While it is too soon to have clear data on the experiences families and individuals who lost loved ones to the coronavirus, there is no doubt that impacts will be far-reaching for those who were denied the rituals that are essential to the grief process. It also remains to be seen, and warrants attention, if COVID deaths will be stigmatized by an increasingly polarized U.S. society to the extent that survivors feel marginalized.

Anticipatory Grief

Families experiencing loss due to mental health issues such as suicide, mental illness, and drug overdose have often been through extended periods of trauma related to the behavior of their loved ones. Many have spent entire life-savings, countless hours, and draining emotional energy on trying to prevent their family member's death. The burden of care for the mentally ill or drug addicted child almost always rests with the parents or other family members, creating a specialized version of what has been called anticipatory grief. The "successful" suicide is often not the first attempt; neither is the fatal dose of drugs the first serious overdose. The ups and downs of recovery and relapse, stabilization through medical care and mental health crises, successes, and failures—all take a toll on family life. One father described the complex roller coaster of emotions as "oscillating between exhaustion and optimism" (Titlestad, 2020, p. 5).

Losses experienced by the families of substance abusers begin with the development of behavioral, cognitive, and physiological phenomena. It can take some time for the family to recognize the problem, and often have the feeling that "something is not right." As family members try to understand and adjust to the discovery, they also begin the process of managing disclosure to the outside world. (Dyregrove et al., 2020, p. 416) With what Goffman (1963) calls the "discreditable person" the family must try to agree on a strategy of how to manage information and communication, both within the family and without (p. 4). As dependence to drugs increases, certain behaviors are almost inevitable. The user gives a higher priority to obtaining and using drugs and responsibilities to family and work suffer. As this progresses, close relatives often experience agitation, raised vigilance, heightened fears, and feelings of a lack of control over the situation. Behaviors that had been foreign before, such as violence and theft within the home, are often common and cause feelings of shame and guilt for family members, who believe they should be able to fix the problem (Dyregrov et al., 2020).

In this form of disenfranchised grief, families are locked in extended loss that they often cannot or will not talk about because of the shame, guilt, and anticipation of social condemnation they feel. One mother described her experience as twenty years of anticipatory grief where she lived in a “constant state of preparedness for her child to die” (Titlestad, 2020, p. 5). Death by drug overdose is difficult to compare to other deaths because it is generally an abrupt unnatural death that often follows years of anticipated grief and family dysfunction. It is not uncommon for the family unit to suffer as a result of the stressors, with estrangement among family members causing additional sorrow. Dion (2014) calls this the culmination of “a hundred little, a thousand little deaths.”

Further complicating the stigmatization of mental illness and drug abuse deaths is the rise in use and immediacy of social media and cell phone videos. What once might have remained private behavior can quickly become a very public spectacle when friends, family, or the general public post news or video to social media sites like Twitter, YouTube, or Facebook. Any public post can easily be shared, even by strangers, creating the snowball effect known as “going viral.” The more bizarre the behavior or sensational the news, the more likely it is to be widely disseminated. This trend towards sharing private experiences of death through the media is particularly significant when it comes to drug-related deaths (Guy & Holloway, p. 91). The anonymity of online discussion forums can wield their own brand of stigma. Attitudes toward drug use are reflected in judgmental and stigmatizing statements that are not in line with current healthcare best practices which treat addiction as an illness (Titlestad, 2020, p. 6). Statements that mock or blame the mentally ill or addicted reinforce the shame and guilt families often feel and complicate their grieving process.

A great deal of the existing bereavement literature refers to parental grief in the context of the death of a child. However, little information is available about the grief experienced by the parent who lives with a substance-abusing child. Because the child has not died, some may surmise a loss has not occurred; however, the parent does experience loss and grief. It is not uncommon for the family unit to suffer as a result of the stressors, with estrangement among family members causing additional sorrow.

The Case for More Research

In 1988, Therese A. Rando, Ph.D., first published her much quoted research on bereavement and grief *How to Go on Living When Someone You Love Dies*. In her chapter titled "Cause of Death," Dr. Rando lists five categories of death and discusses the specific issues with which the bereaved must contend. Those chapters are: Accident/Disaster, Homicide, Suicide, Acute Natural Causes, and Chronic and/or Terminal Illness. Among those five sections, there is no mention of drug overdose deaths and/or the grief that accompanies that type of loss, and to date this has not changed. While it is possible to glean some information from the section on suicide, death due to accidental overdose is quite different from the actual deliberate taking of one's own life. While there has been significant research related to suicide bereavement since Rando's work more than twenty years ago, little has been written specifically addressing drug overdose bereavement. This is where I believe research should focus.

Those who lose loved ones in deaths related directly or indirectly to drug abuse suffer a form of disenfranchised grief that is often more difficult to navigate than death due to more natural causes. It is a facet of grief that noted researchers recognize is understudied and underreported. Drug overdose deaths have been routinely categorized as “unintentional poisoning” by the CDC, which can include drug abuse or misuse, or accidental overdose of a drug prescribed for medical reasons. Likewise, on death certificates there are only four possible categories: natural, homicide, suicide, and accident, the latter of which include drug overdose deaths. There is a significant difference in the causal factors of death due to accidental overdose of a prescription drug and death due to the recreational or addictive use of illegal street drugs. And though suicide has received a reasonable amount of attention from researchers, suicide specifically related to drug abuse has not. Sometimes and the category of unintentional poisoning does not provide a unique designation to isolate and study the issue of drug abuse separately.

The second reason that drug overdose deaths are understudied is because the bereaved population has long been considered fragile for purposes of research. Consequently, many bereavement specialists have shied away from such studies. Feigelman et al., (2012) take issue with this notion in their research on drug overdose deaths as a particular phenomenon with specific and distinct consequences for the bereaved. “We have yet to see any persuasive empirical evidence that supports the exclusion of the bereaved from research participation based on their presumed fragility (Feigelman et al., 2012, p. 296).”

Throughout this literature review, the common declaration in many articles was a reference to a lack of research into bereavement specific to drug overdose death. Dion (2014) stated, “Little has been written about the parents of adult substance-using children despite this increasingly common role in society (p. 397).” Likewise, Valentine (2016) noted, “Bereavement following a drug- or alcohol-related death has been largely neglected in research and service provision, despite its global prevalence and potentially devastating consequences for those concerned.” According to Feigelman et al. (2012), “although the subject of overdose deaths appear to attract substantial attention among the public at large, in the media, and from epidemiologists, surprisingly, it has sparked scant interest among bereavement researchers. Little has appeared in print on this neglected subject in the research journals" (p. 61). While bereavement related to suicide has been individually studied, the book *Devastating Losses: How Parents Cope with the Death of a Child to Suicide or Drugs* by Feigelman et al. (2012) was the first project of this magnitude with the inclusion of bereavement unique to drug abuse deaths.

Though my initial plans were to attempt to fill some of the gaps in literature with regard to drug overdose deaths, I found the task a bit daunting. I hope that this work inspires more experienced researchers than myself to take on the daunting task of exploring the processing of grief that is unique to loss due to drug abuse. In the next chapter, I explain this study including the catalysts that led to me to inquire into how others experienced disenfranchised grief.

Chapter 3. Methods

I came to this project as someone who has been coping with stigmatized grief for over five years now. I lost my sister, niece, nephew, and stepdaughter to drug overdoses, and my mother from complications of complex and disenfranchised grief. This experience left me with a desire to understand how other people communicate with family and friends after the loss of a loved one to socially stigmatized deaths. As an author, storyteller, and advocate for social change, I know well the power of story to reveal unknown truths and elicit empathy and compassion. In her work on symbolic interaction, Arlene Stein (2009) notes that to tell a story, one needs an audience who is willing to listen. “But in the aftermath of trauma, potential storytellers are often hesitant and the audiences ambivalent, at best” (p. 47). My main goal as a researcher was to be a willing, compassionate, and non-judgmental audience for stories that are difficult to tell.

I used a qualitative method of inquiry in an attempt to understand the experience of disenfranchised grief from the participants’ point of view. Denzin and Giardina (2012) note that qualitative inquiry “refines understanding of social inquiry,” and that its potential benefit to both the researcher and society is, at the very least, empathy and a better understanding of the plight of others (p. 55). Using a qualitative approach allowed me to use open-ended questions that encouraged participants to share their individual stories which, as I illustrate in subsequent chapters, the participants made clear they were not just willing, but anxious, to tell the stories “the world did not particularly want to hear” (Stein, 2009, p. 46).

As these bereaved individuals likely are compelled to use self-silencing as a strategy for avoiding stigmatizing behavior from relational others, it is useful to think of these individuals as a “muted group” (Kramarae, 2005; West & Turner, 2018, pp. 495-499). The concept of muted groups originally was developed to help explain feminist concern about the social muting of women’s experiences generally. However, it also provides a useful framework for examining other disempowered groups and how dominant language practices mute their experiences and the language they might employ in making sense of those experiences. Survivors of stigmatized death represent one such disempowered group, as the social focus on casting blame upon the deceased disenfranchises the survivor’s grief, thus impeding or blocking their ability to talk about and make sense of it.

The study explored how traumatic grief impacts the lives of close relational others, including: a) how such grief experiences differ from grief over losses that might be considered more acceptable or “natural.” b) how the bereaved make sense of, or meaning from, the death; ; c) how their lives or behaviors might be changed by the loss; d) how their internal dialogue or personal beliefs might impact their interactions or communication with others; and e) how others’ social reactions influence the bereaved person’s communication of grief.

Participants

The participants for this study were volunteers who self-identified as meeting the criteria of: 1) being an adult over the age of 18; 2) having lost a loved one due to a stigmatized death; and 3) being willing to discuss a sensitive topic that might cause emotional distress. I included in my criteria a broad view of death due to stigmatized behaviors, which helped avoid limiting interviews to any one population and offered a more inclusive approach to the research.

My recruitment efforts focused mainly on social media platforms Facebook and Instagram, where I shared recruitment flyers (see Appendices A through D) as posts to my personal and professional pages and requested that viewers and potential participants share my posts either globally on their own pages, or individually with potential participants they knew. I also contacted moderators of grief support groups on Facebook with information about the study. I asked them to share the flyer either as a post on their group page, or with individuals who they thought might be interested. My recruitment efforts were almost immediately successful; and I reached my goal of eight participants within two weeks.

Everyone who volunteered and met the criteria were invited to participate in the study. The participants were a group comprising two men and six women ranging in age from late twenties to early sixties. All were born in the U.S. and six of the eight were raised in the South. One had a parent who was a foreign citizen living in the U.S. All but one had at least an undergraduate degree. All but one were employed and working outside the home, with the exception being a retired registered nurse. Most had experienced the most recent loss more than five years prior to the interview.

Two participants were recruited through my personal Facebook page, two referred by friends, two referred by business acquaintances, and two former or current college students. Of the eight participants interviewed, four lost close family members who committed suicide after years of drug abuse, one lost a spouse to complications of alcoholism, one lost a sibling to a drug overdose, and two experienced multiple losses including to suicide, violent murder, and/or lung cancer due to tobacco use.

Data Collection

Data collection took place through one-on-one interviews, which were conducted via Zoom video-conference meetings due to the contact restrictions associated with the COVID-19 pandemic of 2020 and imposed by my university. I chose this type of intensive interview because it provided an “interactional space” (Charmaz, 2014, p. 57) in which participants might feel inclined to share stories about themselves. I felt it was important to make the interviews feel conversational, but I also wanted to leave room for reflexive narrative that might reveal deeper truths about the participants' experiences. This individual format allowed me to facilitate the nature and sensitivity of the subject matter, with adequate time and focus to build a rapport that might inspire reflection and candor from the participants (Berg, 2009, p. 104).

My goal was to learn about each participant's experience of grief within their community: how they talked about their loss with family members, friends, church family, and others. I wanted to know if they had experienced stigmatization from others and, if so, how it affected their grief process and the way they communicated with others. I wanted to know if they felt supported and encouraged by others to talk about their loss, or if they experienced any responses that caused them to remain silent.

In planning the interviews, I was mindful of the power of story and how it is organized by the human mind. McAdams (1993) suggested that, as natural storytellers, human beings instinctively organize information into a story format, which is then used to express themselves, their experiences, and their world to others (p. 27). According to Denzin (2003) "the interview is both an active text where meaning is created and performed," and an interpretive practice with a shared experience between storyteller and audience (p. 81). Referring to Madison (2014), I structured open-ended interview questions designed to elicit experiential and behavioral responses in the form of personal stories (p. 29). I organized the questions systematically leaving room for the freedom to digress but including follow up questions to assist in probing deeper if necessary (Berg, 2007, P. 107).

Due to the personal and potentially emotional nature of their experiences with stigmatized loss, it was important to make sure the participants felt comfortable and at ease during the interview. I knew the necessity of virtual meetings might add some stress to the situation, so I discussed this ahead of time with each participant to make sure they had a comfortable and private place at home to conduct the meeting. The issue of privacy was simplified by the online format of the interviews, since participants maintained control of their setting. On my end, I conducted interviews only when I was alone in my home.

Each interview was arranged for a time most convenient to the participants according to their schedule. Study participants were prepared to spend about an hour during the video- and audio-recorded interview and understood that I might contact them later to ask additional questions. Informed consent documents were emailed to potential participants and verbal consent was obtained prior to the start of the interviews.

Herbert Blumer (1969) held that social scientists should establish intimate familiarity with their studied phenomenon (as cited by Charmaz, 2004, p. 984). When I chose this research, I knew I had intimate familiarity with the subject of stigmatized grief—not because I studied it, but because I lived it. Following Carolyn Ellis's (2014) focus on compassionate interviewing, I took into account the "social and dialogical nature of communication and our connections with events and persons we study" (p. 94). I considered carefully whether I could be the kind of creative interviewer Douglas (1985) describes, capable of displaying my own feelings while at the same time drawing meaningful information from the participants (as cited in Berg, 2009, pp. 103-104). My goal then became to not only establish a comfortable rapport born of common experience with the participants, but to also provide compassionate support and ample space in which to tell their stories.

Each meeting with participants began with a brief introduction to the study in which I attempted to explain what I hoped to discover from our interviews. I identified myself as having personally experienced the loss of family members to drug overdoses with the hope that it would establish some common ground and inspire candid responses, and it did have the desired effect.

In my first few interviews, I stuck fairly closely to the questions in the interview schedule (see Appendix D). I soon realized, however, that the participants had come prepared to tell their stories in narrative fashion and that, if I simply suggested they tell their story, they would answer most of my questions without my specifically asking them. I then used the interview questions when necessary to augment what they provided on their own. I was careful, however, not to jump in too soon, but to leave space for the "uncomfortable silence," a technique suggested by Berg (2009). This worked well in several instances where the participant volunteered information I had not thought to ask.

There were times throughout the interviews, especially as participants recalled the immense pain of their loss, that I found it difficult to maintain my composure. I knew it was important to be an objective researcher, but I also experienced a visceral reaction to their stories. I found myself having to self-censor on several occasions, whether it was the urge to cry or to share my own story. The experience that made me a compassionate audience, was the same experience that made me recognize the potential for compassion from my subjects. When you find someone who understands like others do not—who will join you in making sense of the death without drawing into awkward silence or offering trite and superficial advice (Neimeyer, 2019, p. 84)—it is difficult not to take advantage of the opportunity. This was a balancing act for me. I managed it by following Ellis' (2014) guide to compassionate listening; and I discovered that sometimes a simple "I feel you" allowed me to echo their grief without shifting the focus to myself (Berg, 2009, pp. 141-142).

Data Analysis

Following each interview, I journaled brief notes about the experience in a notebook. I wanted to highlight some of the thoughts I had about the interview process, and the unspoken meaning I ascribed to some of the exchanges. This helped me when it came time to code the data.

I transcribed the audio recordings verbatim using the transcript generated by recording the Zoom meeting. The transcript was copied into a Word file, and manually stripped of time signatures. Afterwards, I listened to each recorded interview and manually edited the text to ensure accuracy in the transcript. I assigned pseudonyms to each participant and changed other identifiers that might reveal their identities, including in some cases changing the relationship or choosing androgynous names and pronouns to avoid gender identification.

Once the transcript was satisfactorily accurate, I transferred the data from each interview to an Excel spreadsheet for coding. I drew from Charmaz (2014) for grounded theory coding, planning both initial and focused coding accordingly, and opting to assign actions to the data using “gerund” coding for my initial round. Coding for actions via gerund coding is a heuristic device that helps to define implicit meanings and helps guide the researcher in new directions to explore (pp. 121-122). I also drew from Saldaña (2016) for guidance in developing themes and recognizing data that lent itself to “versus” coding. Versus coding acknowledges that humans are frequently in conflict—within themselves, between them and others, between people and policies or practices. The codes help identify which individuals, groups, or systems are struggling for power (p. 124). In this case, the coding helped me identify conflicting emotions that could influence how some participants avoided talking about their losses, as well as how dominant narratives of grieving were in conflict with the stories participants wanted to tell or felt safe to tell. The more conflicted the participants were over certain feelings and narratives, the more likely they were to avoid talking about their loss outside of their own trusted circle.

In addition, while I did not do a specific round of *in vivo* or versus coding, I made notes on my initial coding when data stood out, as Charmaz (2014) suggests (p. 134). For example, one participant who is a professional storyteller said, “Why is this a story I cannot tell?” This quote illustrates a type of *in vivo* code that “crystallizes participants’ actions or concerns.” Another participant made the statement, “I’m so tired of being the not normal girl,” which is an innovative term that describes her experience in the way she is viewed by dating partners. The *in vivo* coding keeps the data rooted in the participant’s own language and allows for coding specific to not just the words themselves, but the context of the words and the perspective of the participant (Saldaña, 2018, p. 71). Charmaz (2014) calls these symbolic markers of participants’ speech and meaning (p. 134).

Once I completed the initial coding, I compiled the coded data within one Excel file. I then sorted the data alphabetically by codes and by interviews. This allowed me to see patterns across the data, and group similarly coded data into more consistent codes, which became part of my focused coding process.

After spending many hours analyzing the data for common themes and organizing those themes in sections on the spreadsheet, I worked with my advisor to identify three primary themes emerging from data. Focusing on what the participants did and how they behaved after their loss revealed common strategies for managing grief. In the next chapter, I discuss these themes and strategies.

Chapter 4. Findings

My brother stood on the upper level of our deck overlooking the Suwannee River in North Florida, his head dropped slightly forward, his back and shoulders shaking with barely contained sorrow. We'd been talking about his son Nick when he started to cry and walked away from me, perhaps trying to spare me his sorrow, I don't know. I just remember how excruciating it was to see him in so much pain. I approached him and put my hand on his back, trying to think of something that might make him feel better. "Bean," I said, using the nickname I gave him years ago, "Nick is still with us. We know this. And honestly, he would hate to see you hurting like this. You have got to find a way to move on." I meant well I think. But in hindsight, knowing now what I know now of grief, my words were as much about me as they were about him. I could not bear his pain. And my words were anything but helpful. I wonder, even today, how it has been for him, losing his twenty-year-old son, his firstborn child. It will be twelve years this Thanksgiving.

I did not interview him for this study. I did not ask, and he did not offer, though I'm certain he saw my call for participants. We have spoken very little of his grief over the years, but we do talk about Nick sometimes. We tell and retell the stories of his youth, how funny and brave he was, how he charmed us all. We talk about all the things friends and family members have lost and then found after calling on Nicholas to guide us. I dedicated my first book in his memory: *For Nicholas, lighter of candles and finder of lost things.* I've told stories about him on The Moth stage in Asheville. But I have not talked to my brother about how he feels, or how he has dealt with the loss of his beautiful boy. I don't know how.

***

Through trial and error, instinct and experience, the bereaved often develop strategies for managing complex, stigmatized, or disenfranchised grief. Experts agree that talking about the experience of losing a loved one is an important part of the grieving process, but the participants in this study reported challenges to effective communication caused by the lack of suitable witnesses they could be certain would reflect their grief without judgment (Kessler, 2019).

Careful analysis of the data revealed similar strategies in the way participants managed their grief process. First was the way they talked about their grief, including the stories they told and the way they managed disclosure of private information with others. Second were the conflicting emotions that created challenges to processing their grief. Third was how they found ways to move forward in a world that was forever changed—and how they managed the resulting changes in relationships. These factors helped identify what I called "strategies of grief management," which included managing communication, conflicting emotions, and the grief process itself. I explore each of these components and how participants navigated them below.

Managing Communication

In my work as an author speaking with writers groups and book clubs, I often mention the fact that I have lost four family members to drug overdoses, and the reactions are a mixed bag of horror, sympathy, and dead silence. But it is rare that I sit face-to-face with anyone and actually talk about my grief, or even tell much more than a cursory version of the story of their deaths. And not once has my revelation made anyone urge me to continue. I wondered if participants in this study would reveal similar experiences, but I also had real concerns about whether I would even find enough participants who wanted to sit down with a stranger and talk about their traumatic loss like the ones I experienced. I needn't have worried; every single one expressed gratitude for the opportunity to share their story, especially if it helped others understand what they were going through.

Because I posted the request for participants on my own social media pages, my close friends knew my story and shared the posts immediately. The first two interviews were with women I knew from high school, but with whom I had only infrequent contact on social media in recent years. When we first talked, going over the criteria for inclusion and the consent document and what I hoped to learn from the study, both women mentioned without prompting that they were grateful for the opportunity to tell their story to someone they knew and trusted. And both also acknowledged that, knowing we had been through similar experiences, they thought the project was important and wanted to help me.

People who struggle with a traumatic loss feel compelled to tell their story and to find someone who is willing to listen without judgment, even when the story is difficult to hear. They need someone who can help them make sense of the death without withdrawing into silence or offering unhelpful advice (Neimeyer, 2019, p. 84). But this can be tricky when the loss is socially stigmatized. In the case of drug overdose or suicide, there is often blame assigned by family members or friends (Feigelman et al., 2011) making it difficult to speak candidly about the loss with the very people who would normally be a source of great support. So as a rule, the traumatically bereaved must be strategic in what they tell and to whom.

In reflection, I found the matter of who did *not* respond to be significant. Every single respondent was either someone who knew me personally or was referred to the study by someone who knows me. Though I do not have a close personal relationship with any of the participants, those who knew me, knew I was someone who would understand. Those who didn’t know me were referred by a mutual friend or colleague who could assure them I was worthy of their trust. So even the choice of these participants to join this study was made from the standpoint of managing communication; in this case, with whom they were willing to risk sharing their story. It is worth noting that every single one *wanted* to tell their story. They simply had to make sure it was *safe* to do so.

Coordinated Management of Meaning (CMM) is a communication theory introduced by Barnett Pearce and Vernon Cronen which was initially developed as practical approach to interpreting context within interpersonal conversation (Pearce & Pearce, 2000, p. 405). Rooted in social constructionism, CMM holds that social reality or meaning is co-created by humans through face-to-face interactions. It further suggests that people communicate based on particular rules: *constitutive* which reveal what certain types of behavior mean within a given context, or *regulative*, which communicate what happens next in a conversation. According to CMM, participants in conversation coordinate and control conversations by managing meanings that change with varying interactions (Griffin, 2009, p. 68).

CMM highlights several types of stories used in communication including stories lived, stories told, and stories untold, which I use in this analysis. S*tories lived* are “incidents, situations, or interactions that can be described or observed” (Montgomery, 2004, p. 367), and *stories told* are developed from the meaning one gives to those lived stories. They are the way these meanings form unique stories that can be told. The relationship between stories lived and stories told is recursive, or circular, and incoherence between the two can result in conflicts (Montgomery, 2004, p. 367). It helps to think of stories lived as what actually happens, the actions performed and words spoken, the event itself without interpretation. Stories told, then, describe stories lived from unique perspectives and thus may be different from one interactant to another. That is, two people may have experienced the same story lived, but their individual stories told about it are likely to be different. Further, the effort to coordinate meaning may be obscured when interpretations of actions and words are at odds or misunderstood by interactants. According to CMM, meaning is more effectively communicated when interactants ask themselves the question: “What meaning are we making together?” (West & Turner, 2018, pp. 84-86). *Stories untold* are what is *not* said (Griffin, 2018, p.68). Sometimes stories are not told because they are too painful for everyday conversation, or because the teller does not yet have a reflective grasp on the experience. Often they are still living in the chaos of the loss, which “makes reflection, and consequently storytelling, impossible” (Frank, 2013, p. 98). Other times they believe that others should be, or expect to be, protected from stories that might cause emotional trauma, so they self-silence. One example of this is the relatively new social expectation of “trigger warnings.” When the story is traumatic, mourners may tell a story that has been edited, whether to avoid a stigmatized response or to protect themselves or the listener.

Extending Pearce and Cronen’s initial work, I additionally examine what I have called *stories revealed,* which refers to one’s own story that is divulged by someone else. Both CMM and Communication Privacy Management (CPM) are helpful here for understanding an aspect of communication that occurs when personal information becomes public knowledge.

In this study, CMM is applied to conversational interactions between myself and participants in interviews, as well as conversation between participants and others, as the former describes them. In the next sections, I employ CMM as a conceptual frame to reveal how different types of stories are used to manage interaction. In the following, I highlight similarities across the early choices made by the participants in how they told their story in the interview.

Stories Told: It's zombie-like, the shock of death . . .

I opened each interview asking participants to share the story of the loved one they lost. With little exception, each remembered specific details about the time period leading up to learning of their loved one's death. Some filled in background details first; others wove them in later for clarity as needed. This cognitive process of going over events that occurred before and at the time of death, and its focus on memories is part of *grief work* that helps the bereaved come to terms with loss (Stroebe & Schut, 2010, p. 275). What might have been unremarkable on any other day was amplified in the telling of the story on that day, in hindsight. David remembered the last words he spoke to his sibling—"S'up?"—three days before her death from a heroin overdose. Mika recalled the odd behavior of her brother the night before he committed a carefully planned suicide. Suzanne outlined innocuous conversations and preparations for a party she attended just before learning her loved one had died. Many people remember vividly what they were doing at the time they learned of events such as the assassination of John F. Kennedy, the terrorist attack on September 11, 2001. In fact, JFK's assassination was instrumental in highlighting the phenomenon of enhanced awareness surrounding significant life events. Brown and Kulik are credited with coining the term "flashbulb memories" to explain how certain emotionally charged events lead to an enhanced memory of personal circumstances surrounding the event, including seemingly incidental details (Bremner et al., 1997, p. 63). Where were you when you got the news? The answer is often a catalyst for a story, or at least the beginning of one.

The stories flowed with little effort from participants who seemed at once eager to share their story with someone who would listen, and reticent to reveal certain details. However, as they reached the point in the story where they learned of the death, participants' recall became less clear, more hesitant. Most of the participants paused at this point in their story, as if either weighing what they were going to say next or trying to formulate the story. Through the lens of CMM, life experiences are described as “undirected theatre” where actors rely on past experiences or *life scripts* to achieve meaning (West & Turner, 1980, p. 91-92). I imagined their hesitations as attempts to coordinate meaning with me—a pause to gauge my reaction—to ask the unspoken questions: *Are we speaking the same language? Are we using the same script?* I used the empathy I felt to encourage them to keep going, and most did.

Further research on this common phenomenon amongst participants, where recall was clear until the moment they learned of the death, revealed information on trauma-related memory disruption. While Post-traumatic Stress Syndrome was not within the scope of this study, it is important to note that researchers recognize the effect of emotional arousal on the accuracy of memory (Bremner et al., 1997, p. 63). Some of those who participated in this study identified their hesitation as confusion. When discussing the aftermath of learning of his mother’s unexpected death, Shane noted:

> It’s funny, but I remember very vivid parts of it, but then it’s all just kind of a mishmash where I know what happened and I can tell you certain things, but I couldn’t . . . you know, it’s all just a big blur in my head.

While most participants could describe where they were days later, some did not remember exactly how they got there. Jill got confused recalling the time period between the funeral and when the room in which her husband killed himself was cleaned so she could return home. She remembered spending considerable time at her parents’ house but couldn’t recall how her belongings ended up there with her or how long she stayed.

There is another element at play that may explain the sharp clarity and recall of actions before and the foggy details afterwards, and it is that these deaths especially are life-altering experiences. In most cases, there *is* no script for surviving a loved one's traumatic death. There is no playbook for how such conversations go. These stories reflect the confusion felt when the social script is abruptly altered, and the retelling in the context of this episode feels like *unpacking* the story as a way of making meaning (Neimeyer, 2019, p. 84).

During the interviews, I noted that some participants were processing details as they spoke them aloud. Recalling moments in their stories, certain pre-death details came more into focus and seemed to take on greater meaning in hindsight. For example, Mika recalled the last time she saw her brother Terry alive, which was during a visit to his house the day before he committed suicide:

> At one point, we went out [of the room] and then we came back and he was laying on his back on the kitchen floor, staring at the ceiling. It's almost like . . . I don't know whether he was . . . had himself in repose or what, but it's like he was planning all this. Of course, we couldn't know that at the time. But, the next morning, with some time throughout the middle of the night, he killed himself.

Jill recalled her husband pausing to watch their daughter play before leaving that morning. "He watched Janie run around in her little witch costume, and he was headed to the doctor that day because he'd had a bad cold and so, I didn't think . . . That's last time I saw him." He killed himself later that day. And Shane remarked on his mother's instructions five days before her death:

> She said, Look, here's the deal. When I die, this is who I want to do my funeral. These are the songs I want played, and I don't want an autopsy done. And we were like, okay

> those are weird things you want right there but okay, and then five days later she was dead.

Participants also expressed a compulsion to cling to normalcy by sticking to daily routines or scheduled events, especially between learning of the death and attending the funeral. In some ways it was simply finding a distraction that allowed time to adjust to the circumstances. Suzanne said:

> I couldn't just sit in the house and we couldn't just get in the car and go. And so, we went and we bought car seats and we did the things that we had to do that day and just, it was phone call after phone call throughout that day as we're trying to figure out the pieces . . .

Maeve remembered feeling compelled to "do something" after learning of her father's death, so she went to the mall and got her nails done. "It's zombie like, the shock of death. It's like, you will just walk through life like . . . and do really normal things that you wouldn't think you'd do."

Within minutes of learning of the death of his mother, Shane took it upon himself to notify the family. "I just immediately went into *everybody needs to know*. So, I called all my uncles; I went and saw my aunt—like I was just trying to make sure everybody knew what was happening." He said it was good for him to stay busy those first few days, but then he retreated into himself afterwards. "Just because, you know, your world turns upside down. And you've got more questions than answers, and now you can't answer those questions and you're trying to figure out what to do." And then, four days after the funeral, he kept a speaking engagement he'd had on his calendar for months, which he said was a mistake; he said he was thinking: "I've got to go jump into work and try to, you know, make sense of the world again." I asked him if he thought he was trying to distract himself and he responded, “It was more of like I gotta get back to my sense of normalcy.”

The stories participants choose to tell illustrate their effort to tap into a “life script” to help guide them through a traumatic event. Afterwards, as they demonstrated in the interviews, the effort is to assemble the details into a coherent story that makes sense of what has happened (Pearce & Cronen, 2014, pp. 69-70). While telling the story is an effective way of processing the event, retelling it many times is a necessary way of working through the grief. Neimeyer (2019) advocates for “narrative retelling” as a treatment approach to grief therapy (p. 84). One participant found a unique way to manage when and to whom he told the story of his sister’s drug-related death. During the interview, David pointed to a chain he wears around his neck which bears a set of metal plates with commemorative information about his sister. He noted that he takes them everywhere he goes whether he wears them or not. He also said he sometimes wears them inside his shirt and sometimes out and that, though they could become a source of “privacy invasion,” he said he still chooses certain times to display the chain because doing so:

> …allowed me to let [people] know that my sister passed away. Sometimes they would ask how and sometimes they wouldn't, but I would always be truthful about it. I wouldn't try to steer clear of the conversation, because I think people need to talk about it more. The more we talk about it, the more normal it becomes.

When asked if he selectively used them as a conversation starter he said:

> Now that you mentioned it, I did used to wear it outside my shirt as a way to like, if someone did ask about it, I had to have talked about it. I also have a memorial tattooed on my back shoulder for my sister as well. So, it makes it very easy when people, over the summertime, or when I was playing [sports] in my undergrad, I would walk around

> without a shirt afterwards, and then people would be like, ‘Oh, I didn't know you had a tattoo.’ And I'll be like, ‘Oh, funny story about that.’

In some ways, this strategy forces him to do what he believes is necessary for healing, and he employs it when he is open to the conversation. However, by wearing the chain inside his shirt, or not exposing the tattoo on his back, he is able to better manage when he chooses to talk about it and when he would rather not.

Maeve recounted a time when she experienced a clear shift in her ability and willingness to talk to others about her experience. She reached a turning point when she met people who did not judge her experience and were willing to listen to and reflect and honor her experience. When asked if there was anyone in particular that she was able to talk to about her experience, she responded this way:

> Honestly, [college] was a big part of that for me and it was the first time in my life that I felt like I could be radically honest about what I've been through. Because before, it was like when I would tell somebody my sister was murdered or my dad died of cancer, it was like, ‘Oh, I'm so sorry. That sounds awful.’ And then awkward silence.

Applying constitutive rules to sudden silence, Maeve interpreted this recurring response as *this is not something I’m comfortable talking about,* and she began to self-censor with people she did not know. Maeve’s experience at an ultra-liberal college was a turning point for her. There, she found an audience who did not look away, who engaged her with interest and empathy, a vast change from her prior experience which pushed her repeatedly up against a wall of silence that shut conversations down. Her instructors also encouraged complete candor in her writing and she felt validated “for the first time.” This opened new avenues for choosing when to tell and when not to tell her stories.

Stories Untold: I just didn’t talk about it . . .

> *Life gives us pain. Our job is to experience it when it gets handed to us. Avoidance of loss has a cost. Having our pain seen and seeing pain in others is a wonderful medicine for both body and soul* (Kessler, 2019, p. 34).

Grief can be avoided or postponed, but nothing heals like going through it. The initial goal of this research was to understand how people communicated grief after the stigmatized death of a loved one. The somewhat unexpected result was the significant avoidance of communication by some participants. What stood out was not what they said; it was what they did not say, how they avoided discussing the loss and for what reasons. In communication, there is a term that expresses silence caused by taboo topics or the politically motivated muting of certain groups. The term *przemilczec* also refers to the silence learned through family policies (spoken or unspoken) regarding issues such as who one can marry, how much anger can be expressed and by whom, which topics (such as sex and death) are taboo, and when silence is required as a matter of respect (Book, 1996, p. 324-325). These are the untold stories, the things not said.

One interview illustrated avoidance from the perspective of societal taboos. In the initial participation and consent phone call with Gabriella, she mentioned her husband had died of complications from alcoholism and she wasn’t sure if she was eligible to participate. I assured her she was and we had a brief discussion of what constituted stigmatized death so that she would understand what my goals were in the study. A week later, during the interview, I asked her to tell me about the loved one she lost. This is an excerpt from her response:

> So, the thing with the alcoholism: it's—and I didn't think about this until after I talked to you—people that knew us knew Jay drank too much—knew how much he drank. He

> drank every day. And he had to basically to keep himself going. Anyhow, if they'd asked me how he died or anything I'd say, well you know the alcoholism and liver failure. But people that I didn't know, I would say he had liver failure or multiple system failure. I didn't say alcoholic, you know, and I have never thought about that. And I guess you just don't want to delve into, you don't want to delve into . . . You know what the first thing somebody asked me? ‘Was he abusive?’

Gabriella’s reaction to this question highlights one of the reasons mourners might avoid certain disclosure as a strategy for communication management. Gabriella seemed to be framing her story around the brief conversation we had about the study itself. She had been thinking about the issue of stigmatization and how she dealt with that. And she is saying, in essence: *I hadn’t thought about it before we talked, but I realize now that I told different stories to different people.* Those who already knew Jay drank excessively were “safe” to tell the truth. Those who did not got a clinical answer that was technically true but was constructed to avoid uncomfortable responses or questions. But, as she was telling me this and searching for a reason *why* she made that choice, she suddenly remembered a question someone asked: *Was he abusive?* CMM offers insight into how the question functioned as an act of stigmatization.

CMM defines a *speech act* as actions we perform by speaking. They indicate the intentions of the speaker but are also interpreted by the listener. For Gabriella, “Was he abusive?” was a loaded question. It implied a presumed correlation between alcoholism and abuse, which she found offensive. Jay had been a lively, gregarious man and a loving partner. This question, whether well-intentioned or not, became part of what she instinctively believed was a necessary strategy to control disclosure of her husband’s cause of death, so as not to cast him in a bad light or feel judged.

Mika chose an even more narrow sphere of disclosure than Gabriella. When asked if she were able to talk with people about her brother's suicide, Mika replied:

> I always felt I could with my family. I feel like I probably could have tried to talk to people outside of family, but I didn't feel like it was going to be accepted very well. So, I avoided talking to anybody that wasn't an immediate family, or a very close friend. I guess probably for fear [of] how they may react with that . . . the old, you know, 'He killed himself. He took his own life.' [But] I can't say I experienced it because I avoided it.

I pushed a little further on this, wanting to know specifically what she was afraid would happen. So I asked Mika to imagine how she might have felt if she had encountered those kinds of comments and she replied,

> My deep feelings would have been, it would have been very heartbreaking and hurtful to have somebody respond that way. Because I sure wouldn't do somebody's family that way, whether I knew him or not, you know? I'm not going to say, 'well, he shouldn't have killed himself. He shouldn't have been doing drugs.' I would never do that to somebody else. Yeah. Much less want to have it done to me.

Mika's comment that she just didn't feel like it would be "accepted very well" illustrates the fact that stigma is often so entrenched in society that it becomes generally accepted as truth. Before I began to study disenfranchised grief, I believed that suicide was somehow a punishment inflicted on the family by the deceased. I'm not sure how I came to believe this, other than it was what I'd always heard. Of course, I know better now, but still, it is easy to imagine how survivors of suicide might anticipate stigmatization. Doka (2002) notes survivors may "self-disenfranchise" or experience feelings of “isolation, embarrassment, or low self-esteem and inadequacy” (p. 327).

After her husband’s suicide, Jill adopted an avoidance strategy to protect her own emotional state and her relationship with others. She remembered one of the catalysts for avoiding the discussion being the reaction of the first stranger she encountered who recognized who she was:

> It’s not that it was embarrassing to have to admit to someone that he died by suicide, but it was that I just knew it was going to get a reaction. And I didn't look forward to that reaction—like the pity, the sympathy, the look in their eye, *you poor thing*, and just the shock.

Later, she admitted that reactions like this still affect her. Jill worried about being known as “that young mother who was widowed” and it pained her to be pitied. She said:

> There have been times when I have, if I'm just running over the course of my life, that I just simply say I was widowed at a young age. And yeah, I do not include [details]. For one thing, I don't want to complicate, like if I'm just trying to tell a simple story, but also I just, I don't want that whole sympathy, the whole horror, and it's easier to just say I was widowed. If anybody really talks to me about it or somebody who matters, I will tell them, but yeah—in general, I just say that I was widowed.

She also admitted hiding how incredibly angry she was at her spouse for leaving his family. She did not want anyone to see the way she sometimes screamed and cursed and pounded the air with her fists. It bothered her to see someone else feel bad for her.

> I think it’s like I gave myself the stigma. I think I felt guilty for feeling angry, not consciously, but I think probably subconsciously. Yeah, like I shouldn't be. Especially

> because I was surrounded by his family and, I mean, I just didn’t want them to know how mad I am . . . because they were so broken-hearted.

When asked if she ever talked to them about it, she said “Never. [I talked] to my best friend. She was there for me and we talked about how furious we were, but only with my very best friend.” Jill’s experience highlight the tendency of some disenfranchised mourners to self-censor and to protect both her own feelings and those of others.

David claimed it was just a normal part of their family dynamic not to talk much about their loss but, when pressed, he was not certain whether they avoid it because it is too difficult or because they are all “okay” where they are. When asked if his mother talks about the loss, David answered:

> Not really. I think the most that we've ever talked about it is within my research, but that is more about the concept of grief. But I've never, I don't know why . . . I think it's just because it's normal . . . it's our normalcy, not to talk about it in a way. I think we understand that if we want to, we can talk about it with each other. I can talk about it with my brother, but I've never had an open conversation with my mother about everything, because I don't know how it would . . . One, I don't know how the reactions would go, and two, I think we're all pretty okay with our grief and our coping mechanisms on it.

It is the last line that suggests this might be an avoidance strategy to protect the family’s somewhat fragile emotional state. Don’t rock the boat; we are safe where we are. Outside the family, however, David realizes avoidance may cause more harm than good, as he learned early in his college experience:

> I think I probably failed a total of five classes in two or three semesters, because I wouldn't go to those professors and talk about things. Because my mindset is, and this in

> itself is a stigmatization . . . *Why should they care? It's not their life*. And I still do it in some respects [and] I have to hit myself on the hand and tell myself, ‘No, you have to be able to talk about this because it’s going to be more trouble than [if you don’t].’

Sometimes avoidance is a self-protective strategy and sometimes it is a calculated choice.

Maeve’s avoidance strategy at first seems like the most extreme example, but it is actually carefully considered and has garnered good results for her. Essentially orphaned while still a teenager, Maeve was forced to grow up quickly and make adult decisions before she was equipped to do so. So, life after the traumatic deaths of her father and sibling was difficult to navigate. She professed to having been in several toxic relationships over the years and making some choices that, while they got her through difficult times, were socially stigmatized in themselves. Finding ways to talk candidly about her experiences, and to develop new and healthy relationships, was a challenge for her.

Maeve found the greatest communication challenges for her took place in new relationships. She felt like it was almost always necessary to weigh how much she divulged about her past in small increments. She found it frustrating that she always felt judged and ostracized in new relationships when she would give details of her losses.

> Why does it have to be taboo? ... I feel like in dating. Every time I meet somebody in dating, I have to be like “I have a disclaimer here. I happen to have lost a father to cancer.” And then the little red flag goes up that *Ooh, she's got daddy issues*. And then I have another disclaimer of “My sister got murdered.” And he's like: *Oh, there's another issue.* And he's like, *I don't even want to get into that because I don't even know what comes of that.*

So, she took a year off from dating, putting herself into a self-imposed moratorium which was to have ended just as the COVID-19 pandemic hit in early 2020, when everyone went into quarantine. Though this extended her time alone, she recently began dating again and found that avoiding a monogamous relationship was rewarding for her. She said the time spent alone allowed her to get to know herself, and to learn to be comfortable being alone. Managing communication by limiting exposure to difficult conversations gave her the opportunity to protect both her self-image and social-image—gave her time to think about who she is and what she wants, and to be able to articulate that clearly going forward.

The COVID-19 pandemic brought up some issues for Suzanne as well, one being the estrangement with her parents. She said she worries about their health, as they are elderly and susceptible to complications or death if they contract the corona virus. Even if they avoid the virus, she knows there will come a day when she and her sibling may have to manage their care. She said she has reached out to her mother before, setting clear boundaries and stipulations for rekindling their relationship, including getting professional help to address the familial dysfunction, but that those stipulations have not been met. In discussing the issue of her parents' health going forward, Suzanne said:

> All of us want our families. Even if they were never who they were supposed to be. We want that chance that they could be. Like, I understand in so many ways why my parents are who they are. That doesn't make it okay and I can't let that destroy me. But I sympathize with it and I feel it. But part of my feeling is that it *could* destroy me. Even in this time of COVID, I was like, do I write my parents a letter or not? And so, I wrote them a letter saying, *this doesn't mean we're okay. We're not going back to life as normal, but I need to know if you're okay.*

There is much packed into this statement. COVID has created issues the likes of which people young enough to have elderly parents still living have never experienced. In the past year COVID deaths have topped over half a million and serious illnesses over 28 million. Funerals are being postponed or limited, the elderly are dying or suffering alone in nursing homes because family members cannot visit. In Suzanne's case, there is the very real possibility that her parents could contract the virus and die without ever having resolved their issues.

There is almost always a tension between our stories told and stories lived. This is what communication scholars Pearce and Cronen call *coordinating our patterns of action* (Griffin, 2009, p. 70). Each person has their own lived story, which is separate from and yet complicated by the lived story of another. The stories told are crafted by either side to be coherent but may or may not reflect the other's lived experience. This is not to say that the stories told are necessarily true or untrue; it simply means that they reflect the perspective of the teller. When the stories lived coordinate well, patterns of action are relatively easy to decide. When they do not, choices are less clear. Suzanne and her sister are working to create some new possibility for a relationship in the future as they discuss what actions they may have to take as their parents age. It is a tenuous position that causes Suzanne great concern as she balances her desire for self-protection against the desire to feel like she has done all she can to be compassionate and kind.

In the situations described above, privacy is managed by disclosure choices of individuals in personal conversations. In what follows, Sandra Petronio's Communication Privacy Management is used to examine issues surrounding the complex negotiation between privacy and disclosure of personal information by others (West & Turner, 2018, p. 205).

Stories Revealed: Oh, that's you . . .

Grief, and the way people achieve some sort of coordination of the process, is often a subjective experience, however Breen et al. argue that, because death usually takes place within a family, the setting for grief is often a "family affair." Different families have different rules with different stressors, demands and histories (Breen et al., 2019, p. 173). Predetermined expectations and experiences can influence communication within the family as well as outside of it. Matters of privacy become much less manageable when information is "co-owned" as is the case with most stigmatized deaths (West & Turner, 2018, p. 213).

While it was expected the study would uncover matters of privacy as they relate to social media, further research revealed that suicide and drug overdose deaths have long been sensationalized in the media. In general, most media platforms have certain guidelines regarding privacy to which they adhere, though they vary between platforms. With the 21st century phenomenon of social media, managing which information becomes public and which remains private is almost impossible. There is very little regulation of privacy on most social media sites which results in widespread misinformation. For the bereaved, social media presents a tremendous challenge to identifying and managing private information. In addition, regulative and constitutive rules that apply to in-person interactions can be lost in translation on social media due to a lack of context, which can inhibit the ability to coordinate meaning.

Communication Privacy Management Theory (CPM) outlines the ownership, boundaries, and rules people assume regarding what they consider to be private information. CPM is a communication process that includes multiple levels ranging from self- to group-disclosure (West & Turner, 2018, pp. 208-209). Determining who owns the information regarding the death of another human being is complicated. Public dissemination of private information has long been an issue, and the accessibility of social media adds another level of stress to those in grieving their loss.

As a young teenager, Natalie lost a close family member to suicide in the late 1970s. She recalled a local newspaper printing an article that incorrectly named the deceased's *sister* as having committed suicide, and the next day burying a tiny correction among other news stories. Her small town's "social media" at the time may have lacked the technology and rapid rate of proliferation we see today, but its local gossip achieved a similar type of damage. As if it were not difficult enough dealing with the death itself, the family had to manage the spread of misinformation along with the unwanted divulgence of information that they felt should have been private. Natalie recounted the difficulty of returning to school where most of her friends knew what had happened, but simply did not know how to respond. She said she faced stigmatization from schoolmates that bordered on bullying. At one point she wrote a rather pointed poem about her family member's suicide and read it in her English class. She remembers seeing the entire class responding with a "deer in the headlights" look.

> I think they just didn't know how to react to that, so they didn't. Over the next few years, it was . . . when people had asked me how my [family member] died, there was always this pause [to consider]: *Will this person understand, or is this person going to judge?*

Like partial disclosure, full disclosure can be a form of self-protection, too, as Natalie's story illustrates. In some ways, Natalie's poem was preemptive, a way of saying, *if you're going to talk, I'll direct the narrative.* Likewise, answering insensitive questions like "How did she die?" required a certain exercise of restraint. Her early experience with stigma at school, and the very public attention the death received, led her to develop specific strategies for how she answered the question when it was asked. She readily admitted that, as a defense, she weaponized some of her answers. She said there were “seven different ways” she could describe how her family member died. And “which one I choose depends on whether I like you or not.”

An important element of CPM is the concept of *coordinating boundaries* around information that is co-owned, such as is often the case with the *collective boundaries* of information relating to multiple family members. How and when it is shared can be difficult to negotiate, especially in conversations over social media. Suzanne revealed an issue she had regarding a family member and social media. Because there is very little that Suzanne considers public information about her family and her loss, she is guarded in what she shares, and only does so with a limited number of trusted friends. Further, she is careful to whom she allows access on her social media accounts. As a rule she monitors her own social media closely to discourage public discussion of family matters, especially with regard to her loss or to her family estrangements. When one family member asked repeated questions about her family on a social media page, she adopted more restrictive measures:

> The one and only time I have in my life blocked someone [on social media] without explanation, was that moment, which is very *not me*. And I still keep going back to that decision, like, do I need to . . . am I healed enough now to contact [them] and say this is why? I didn't even have the ability at that moment to communicate with you. I didn't have the language.

Boundary turbulence is said to occur when the rules are unclear or when “expectations for privacy management are unfulfilled” (West & Turner, 2018, p. 214) Respecting privacy entails understanding the implicit privacy norms about what, why, and to whom information is shared within specific relationships (Martin, 2016, p. 551). While social media offers some methods of privacy management, it is often impossible to control what others deem to be co-owned information and can cause distress when privacy norms are ignored and personal information is disseminated indiscriminately. Social media can be an amplified version of gossip that invites public participation in private matters, or worse simply broadcasts information for entertainment purposes. The more sensationalized the story, or lurid the details, the more likely social media posts are to "go viral." For Suzanne, the only way to deal with a conversation she was not ready to have privately, much less publicly, was to shut it down completely. She said she manages her privacy by being selective about who she trusts with personal information, but that she has a network of good friends with whom she can safely share her story. One of those trusted friends is who forwarded my information to her for this study.

Jill recalls the first time she realized how quickly word had spread of her husband's suicide. She'd gone to the Emergency Room for a badly cut finger and, checking in, gave her age as twenty-five and her marital status as "widowed." When the attendant looked confused, Jill knew why:

> And I said, yeah, my husband died by suicide and then her face got really worried because, this is a small town, right? It's just like: *I know about this,* like*, oh, that's you.* So there it was. It was harsh. It was just, it was unbelievable.

For Jill, this became a disturbing label for her that was difficult to reconcile. And not knowing who knew her story made it even more traumatic. And yet, no one asked about it. They would simply look horrified and go quiet, unable to find words or express sympathy. I asked how she handled situations like that and she said she always ended up trying to comfort them. I found it ironic that the story everyone was telling behind her back was the one she could not talk about to them. So the question becomes, is the story one they do not want to hear, or do they not know how to respond to it? This is an important question and one that bears discovery.

CPM has been useful in understanding the process of disclosure and concealment that people regularly perform within relationships. CPM remains a valuable framework for communication as technology advances and coordination becomes complex, such as shown here with social media interactions. In the next section I explore how conflicting emotions affect the grieving process itself, as well as the way survivors talk about their grief.

Managing Conflicting Emotions

The conflicting emotions resulting from stigmatized losses can make an already difficult situation almost impossible to navigate. The bereaved survivors are in uncharted territory. It is important to point out, however, that in many cases of stigmatized grief, the family has already endured a “roller coaster of emotions” (Titlestad, 2020) dealing with issues related to substance abuse, mental illness, or family dysfunction—sometimes over a period of many years. Researchers call this anticipated grief; but it also commonly known as “waiting for the call.” And when the call comes, whether they are cognizant of it or not, they are often immediately affected by the stigma attached to what society deems a self-inflicted death. They are already considering to whom they want to speak and what they will say about the death—how they will explain it, and even how they will defend or blame the deceased. These are instinctive reactions and reflections that are rarely topics of consideration in natural deaths; but when a loved one has committed suicide, or died of an illicit drug overdose, there are questions to be answered and decisions to be made. And they must be made in the midst of a fog of emotions that would be difficult to process in the best of circumstances. What often comes out of this experience is, first, a flurry of activity as distraction, and then self-imposed silence, censorship, or selective disclosure.

The three sets of conflicting emotions emerging from the data were, guilt and relief, anger and regret, and sadness and acceptance. These seemed to arise loosely in that order within the grieving process as recounted by participants, but all were ongoing in some ways.

Guilt and Relief

Some participants felt guilt from the moment they learned of the death; the emotions come hard and fast. *This is real. This is awful. Is this my fault? Could I have changed this?* And with the guilt, some experienced a simultaneous or fleeting sense of relief. *The worst has happened, which means I can stop worrying about the worst happening. I don't have to feel obligated or responsible or afraid anymore.* Mika and her family hoped the autopsy would provide some explanation of her brother's seemingly bizarre behavior. He had been an occasional marijuana user before he lost an infant child, but afterwards seemed to turn to increasingly to harder drugs as a response to emotional pain. When the report came back negative for drugs, Mika immediately felt guilty, questioning how she and her family had handled the situation.

> They did not find any drugs in his system, which was very hard to deal with. Because we first thought, okay, this all happened because of drugs. And then we started feeling bad. Was he so sad, was he so depressed, that we didn't see this? But it's just one of those situations where . . . what if I'd said something? What if I've asked him before I left, you know, Terry--are you okay? But I never did. I never thought about it.

Mika said she mostly talks with her sister about their loss because they both feel the same way, not so much angry as just feelings of guilt and regret, wondering if there was anything they might have done to save his life. She put it this way: "So, there's all these things that you still think—is that one little thing that could have been different? Your mind kind of just spins around, you know?” And yet she seems to console herself by pointing out the deliberation he clearly made planning his death, setting out pictures of the child he lost. “A lot of people say that's a very selfish thing to do. And yeah, it is selfish. But you know, he's got to be in a lot of pain to do it.” CMM holds that meaning is co-created in conversation. I distinctly remember hearing Mika say these words and interpreting them as relief, not that her brother was dead, but that he was no longer in pain.

For others, the relief was immediate, though not without accompanying feelings of guilt. Gabriella lost her husband to alcoholism after having been his parents’ caretaker before they died, and then his sole caretaker through a long steady decline that was physically and emotionally taxing.

> I’ve got some guilt feelings, too. Because when Jay was really sick, I got to the point of really tired of taking care of him. And I can remember thinking, *God I wish this was over*, which I know has nothing to do with why he passed away. I don’t feel bad about that now, because it was killing me.

She said that she attends a 12-step program for families of alcoholics, not so much to work the steps as to have a place she can go and be candid. In this way, Gabriella manages these conflicting feelings by talking about them in a safe space.

For Maeve, the feelings were complex. Her father, dying of lung cancer, was angry and sad and lashed out often. At age fifteen, she moved with him to his hometown and tried to keep up some sense of normalcy attending high school every day. But toward the end, the pressure was too much and she moved in with a friend’s family. Maeve professed feelings of guilt for leaving him when he was dying, yet relief that she had extricated herself from the family dysfunction. She expressed anger at her father for not trying to fight the disease and regret for not being able to understand at the time. She confessed that she still feels angry at her family for abandoning and rejecting her when she was still a child but feels regret for what she said to them when her father was dying. She put this rather eloquently:

> I don't know what it would have looked like had I stayed, but I learned a really valuable lesson about what happens when you put words out into the world. You know, at this very crucial time in my life I had to learn a very, very hard lesson. You just can't take things back once you've done them and you can't go back; like you can't crack glass and then just expect that glass to come back together.

When her father died, Maeve was just turning eighteen. She was candid about how it felt to deal with the finality of that death and what it meant for her, that she was completely on her own at barely the age of adulthood and making choices she feels a certain amount of guilt and regret over today. And yet, she said she feels confident those choices taught her lessons she might not have learned otherwise and made her stronger. Suzanne admitted feeling guilty that her estrangement from her parents keeps her children from their grandparents but expressed relief that they will not grow up with the dysfunction she experienced.

> It has changed their lives. It is not fair. It's not fair that they don't get to have a relationship with their mother’s grandparents, their mother's parents. That has been one of the burning issues, that they don't get that. But I'm also trying to save them from that. And so the complexity’s there . . .

Anger and Regret

Each set of conflicting emotions seemed nuanced among the participants, who came from a variety of backgrounds. Suzanne talked about her struggles with issues of family dysfunction and enforced silence that spanned generations. Estranged from her parents and therefore much of the rest of her family, she has dealt with a myriad of emotions that could feel overwhelming at times. She expressed anger at the responsibility put on her as a child, which included, in many ways, being a surrogate mother to her sibling. She said she faults the behavior and secrecy within the elder generation of her family for her loved one's suicide, but also said she regrets not being able to save them. When Suzanne's family member, Sam, committed suicide, her thoughts went to a text she had recently received from them:

> I hadn't responded right away. And so, whenever I heard [about the final suicide], that feeling came back, like, what if I had responded? Should I have responded sooner? In the midst of all these pieces of life that are hard for me. Is it my fault that I didn't help?

Suzanne acknowledged that these conflicting emotions continue to trouble her and are part of the decisions she makes about disclosure going forward.

Maeve oscillated between anger and self-recrimination for years, and the circumstances surrounding her father's death made her worry about how she would be viewed by others. Her father's diagnosis of terminal cancer coincided with ongoing marital stress that caused him to leave his wife and mover closer to his family for his final months. Maeve had to beg him to take her with him, and he reluctantly agreed. But the transition was tough. She was a teenager, trying to attend high school and maintain some sense order in a world that was falling apart, and she ended up leaving her father before his death and moving in with her boyfriend, something she says fills her with regret. I asked if her feelings of regret had anything to do with how people viewed her and this was her response:

> I think I'm always scared [my story] will impact how people see me. And you know, when my dad was sick, I did everything I could to be the perfect daughter, and it was a lot of pressure to be as perfect as you can for somebody when they're sick. So I really

> leaned into all the societal norms of: get good grades and don't do anything you're not supposed to. Like, walk on eggshells, be the most feminine version of yourself that you can. And essentially, I just cracked and I left and I didn't look back and I ended up moving in with my boyfriend at the time. I've given myself blame for years and years and years of, you were a bad daughter, you didn't stick by him. *It's your fault you didn't get to say goodbye to him. You should have kept your mouth shut and been the bigger person*. But I was 17 years old and he wasn't perfect and I wasn't perfect. And I just, and I wish I could take it back. But I can't.

Maeve said some of her regret has been a catalyst for change in her life and hopes this research will inspire change in the way certain deaths are stigmatized:

> You know, they say the definition of insanity is doing the same thing over and over again, but it's like you're chugging down the road, and you're like gosh, I'm not getting anywhere and this hurts and it's uncomfortable and I'm tired and I need some type of resolution here. I'm so tired of it not being normal to have lost a dad to cancer and to have a sister murdered. I'm so tired of being the not-normal girl. It's exhausting. I don't want to be the difficult girl, or the not-easy girl, or the girl that comes with baggage anymore. I want to be the girl who's lived a very interesting life. And I'll be damned if like it's going to label me in some way that I'm [somehow] damaged.

The discomfort Maeve feels with these conflicting emotions push her to do the work, make changes, and move on. She takes responsibility for, and thus charge of, her future, rather than sit in emotions that make her feel bad about herself. In essence, she uses anger and regret to make meaning of her loss and articulates this clearly: she wants her story to help create change.

Shane talked at length about what it was like to live with a mother who was charming and gregarious and beloved at their church, but who placed his life in danger many times without consequences. The conflict is demonstrated in the way he speaks of her:

> Because the thing about it is, I grew up a mama's boy. It was me and her through thick and thin, you know… Well, I mean, I've got, I've got horror stories from when I was a kid about some of the stuff that we went through. You know, one of the one of the worst days of my life was when I realized that this addiction that she had was just gonna...it wasn't more important than me, but it felt like it was more important than me.

Throughout the interview, Shane's love for his mother is evident, as is his effort to portray her in a positive light. But I found it difficult to imagine that his experiences with his mother had *not* creating feelings of anger from him. In many ways, he seems to deal with these emotions by managing his attitude about them.

Sadness and Acceptance

In this third set of conflicting emotions, the participants noted how they struggled from day to day trying to find a balance between missing their loved one and making efforts accept their loss and move on. Gabriella admitted still alternating between the sadness of missing Jay and the acceptance that he is gone. She spoke of grief as coming in waves—more like "tsunamis"—where the smallest thing can sweep her off her feet. She said that Jay usually did all the cooking, so now when she is in the kitchen alone, she sometimes forgets that he is not there. "I'll be making something and, it's so weird, I'll look back and see if Jay's there and ask him what [to do] and he's not there." And yet, she has moved on. She bought a house that is all her own, the first that he had nothing to do with. I asked if moving into the house made her feel like she had lost him all over again. She replied, "I want to feel like I'm starting a new chapter." But, in the next breath she said, “But I'm telling you, it's just hard at night, it really is, I mean, just to have somebody’s foot touch your foot gives you, gives you like a secure feeling.” Gabriella admitted those feelings are often in opposition to each other and that she sometimes feels like she compartmentalizes or postpones dealing with them just to maintain her equilibrium. Near the end of the interview she mentioned that she had been thinking of contacting her grief counselor again to deal with some unfinished business the interview may have brought up. Gabriella is the only participant to be in a relatively early stage of grief having lost her husband less than two years prior to this interview, but she seems to have a clear perspective on her experience. Her pragmatic approach to grieving may come from her background as a nurse; she has seen death and understands it as part of human existence. When she is sad, she takes steps to move her back to a place of acceptance, so in that way, sadness helps propel her through grief in a healthy way.

Jill was a young mother when her husband committed suicide. After the fog of disbelief and confusion over her loss, she turned her attention to her children. “I thought, my God, I am going to rebuild my life. I have to. I have to rebuild my life.” She remarried less than two years after her husband’s death feeling sure she was doing the right thing for her children moving on with her life. As happy as she was to have found a man she was deeply in love with, Jill had not given herself enough time to grieve her loss. She recalls a time when she was grieving her loss and it did not sit well with her new husband, to whom she had been married about a year:

> The trouble was that, of course, I was still grieving, you know. One time I remember I was crying and grieving after we got married, and I was just grieving for Jack, and I remember Joseph just picked up a newspaper, [and] he wouldn't comfort me and he just ignored me. I'm sure he was mad that I was grieving for this other man, you know? But

> anyway, so that grief process was ongoing. Even though, on paper, it looked like I had built my life nice and neatly.

In this case, Jill’s commitment to moving forward for the sake of her children proved difficult for her. The emotions that accompany grief work together and cannot be ignored. They will make themselves known eventually.

For Mika, the sadness was more inferred than implied. It was the tone in her voice as she spoke of her loved ones, rather than any outward declaration of sadness. She is a private person and protects herself and her family this way. She talked about how she found joy and comfort gathering with family to look through photos and tell stories about the ones who are no longer with them. I asked what the most effective thing was she had done to process her grief and come to some kind of acceptance. Knowing that I’m a writer, she laughed when she said this:

> Well, you can relate to this, I write things down, you know, I write stories or I'll write a poem or something. Matter of fact, when my dad passed away, my sister wrote a poem which we had framed. It's on the wall, but yeah, we kind of do that. We have some way of expressing, and usually for me it's writing.

These emotions punctuate almost everything in the grieving process, and survivors continually play a balancing act with them. They exist simultaneously, but they also sometimes function as a catalyst to move from one to the other. The duality of these emotions and how they function are similar to the way Stroebe and Schut’s Dual Process Model of Coping with Grief concepts help us understand how the bereaved come to terms with their loss and move forward.

Managing the Grief Process

The participants in this study suffered multiple traumatic losses in their lives resulting in dramatic paradigm shifts that often changed their relational worlds. Their concepts of self-identity, their relationships with others, and their ability to communicate in ways that made sense of their loss were negatively affected by the social stigma associated with the deaths. While this study is not focused on bereavement outcomes specifically, but rather on the way in which the process itself is managed by the bereaved, the data called sufficient attention to the ways the participants overcame their challenges to warrant inclusion here. According Stroebe and Schut (1999) their Dual Process Model of Coping (DPM) can best be understood as a classification that describes the ways in which people come to terms with loss. Its main parameters of loss-orientation and restoration-orientation are related to bereavement outcomes. DPM is one of the few theories that provides a framework for understanding forms of *complicated grief*, where those who suffer a form of traumatic bereavement might be expected to have trouble alternating smoothly between loss- and restoration-orientation methods of coping with grief. This type of *oscillation* between confronting aspects of the loss and avoiding them is necessary for adaptive coping, though care should be taken not to dwell in one or the other too long (p. 278). *Loss-orientation* denotes a concentration or focus on the loss itself. *Restoration-orientation* reflects the attempt to reorient oneself in a new life without the deceased. Both are necessary components of the coping process and are considered *stressors* that can also function as catalysts for change.

Loss-Oriented Approach to Grieving

According to DPM, a loss-oriented approach to grieving includes frequent rumination and wishful thinking, unconstructive goals, and negative interpretation of events (Stroebe & Schut, 1999, p. 281). Shane’s experience with an unreliable mother and an absentee father took a toll on him in many ways:

> If I'm being honest, I don't think I really truly processed her death until probably a year, year-and-a-half later. Because at the time, I was in my senior year in high school. And so,

> I was always on the go with something because I was a part of every social group and every after-school activity and drama club and all that stuff. So, there was always something in my mind to do. And then you're sitting in an empty apartment, in college, away from everybody and all of a sudden it just kicks in. And so, I think that was where a lot of the healing started to take place for me . . . was trying to figure out, *was my mother a bad person? What was the reasoning behind why she did the things that she did?*

Shane eventually reached a turning point in his life when he knew he needed to change the way he viewed the world. He had lost his job when the business he managed suddenly closed its doors and found himself blaming everyone he could for the situation he was in. He said:

> And so through that, I started to victim blame, you know? And I just remember one day, I looked in the mirror and I went, dude, you're becoming your mother. You can't do this. And so that started a process for me that I guess kept going on to the last five years where I'm really just starting to flesh out all the stuff that happened to me as a kid and trying to flesh out the things that had happened with her.

Though it was not overnight, Shane began to reframe the way he remembered and felt about his mother. He acknowledged the pain she must have been in to choose to drugs over the welfare of the son she loved, and he forgave her. He turned his attention to creating a new life with purpose. He started a public blog where he writes about his mother’s experiences, as well as his own. He believes it has helped him make sense of even his worst experiences, and hopes it helps others going through similar grief.

Losing a sibling to a violent murder after losing her father shook Maeve’s world in ways that left lasting effects. For a time, she lost her sense of security in the world. She spoke of sleeping with a knife or scissors under her pillow, when she could sleep at all, and feeling so afraid of being alone that it caused her to stay in relationships that were volatile and in themselves unsafe.

> Even today, I have a really hard time feeling safe living alone or going places at night because I think the one thing about trauma that's really significant to me . . . is that it's like . . . life is a hallway. And on either side of you are just doors and as you walk through life, you're opening doors, you're opening windows, and it's letting light in and it's showing you different things and different avenues. And then once the doors are open, you cannot close them. Like you're aware [now]; knowledge has been given to you in those ways. And for me, I had this awareness all of a sudden that murder actually happens. And I was also in these toxic relationships and there were times where I was scared that it would happen to me, or times where I felt like, what if I'm doomed to the same fate?

This loss-oriented focus resulted in ongoing anger and regret that affected Maeve’s life in multiple ways, including how she saw herself and how she interacted with others. Loss-orientation implements some concepts from Cognitive Stress Theory to help guide future actions. Identifying emotion-focused or problem-focused coping mechanisms can help the bereaved make choices that helps them move out of loss-orientation and restore a sense of vitality or purpose to their lives. Focusing on her loss and fear kept Maeve in a cycle of bad relationships for several years, but taking steps to increase her marketable skills and working on creating a positive relationship with herself has increased her confidence and self-image and helped her move the focus away from her loss and toward new relationships.

Restoration-Oriented Approach to Grieving

> *Rethinking and replanning one's life in the face of bereavement, a part of DPM's restoration orientation, can also be regarded an essential component of grieving*. (Stroebe & Schut, 1999, p. 277).

Shane's coping process when he gets stuck in loss-orientation is to reach out to friends for support. If he is feeling isolated or if he is struggling with thoughts of his mother, he has friends he can call to talk about his troubles or just to hang out with for their company. This tactic always seems to help him work through his grief when it comes up. He has learned which friends he can count on to help him co-create a positive meaning that motivates and reassures him that he is supported and loved. He writes a blog and to make connections with and encourage as many people as he can, and in this way he makes meaning from his experience.

Maeve credited her drive for education and passion for writing to her father's expression of regrets on his deathbed. He had always wanted to go to college but took a different job to support his family. She completed her undergraduate degree and started applying to graduate schools soon afterwards. She was living alone, confident, self-sufficient, and proud of her accomplishments. She said that the way she lives her life now is in tribute to the family members she lost.

> I honor them in my relationships; I honor them in the way that I treat myself; because there was a point in time where I was just not good to myself. I think just constant self-improvement, writing, having a passionate and working towards it, not giving up and trying to do the things that they couldn't, and trying to honor them in the best ways possible, I think that those are the biggest things [I do].

For Suzanne, what has changed most is how she mothers her children. She said she is determined to do a better job than was modeled in her own family. Her daughter was born a few months after Sam died, and she recalled:

> I remember sitting up in those dark hours when you're nursing and trying to figure out this whole motherhood thing. And just realizing how much I loved [this baby]. And making promises to her and God that I would not let her generational story be the same. [I] know that was a pivotal point in my life. It changed me. It changed what I was willing to do, even if it took years afterwards. [It] changed what I was willing to stand for.

She said it also changed the trajectory of her work, and she alluded here to conflicting feelings about the experience:

> And there's a part of me that much of the work that I do will always be dedicated to Sam, whether I put it on a page or not. Because knowing that some of us are given eyes to see things that other people [are not] . . . It's a terrible burden and it's a great gift.

Suzanne noted that working through her grief with this kind of purpose is an ongoing process, and part of managing her identity includes managing who she allows into her circle.

Natalie seemed to attach a good bit of her identity to career choices. She said she initially chose social work as a college major based on her family member’s suicide.

> The argument I told myself, was that if I could prevent one person from [committing suicide], then it's all worth it. Because I had observed the devastation within [her] parents. So yeah, and that had a significant impact on my life, and with my Social Work degree I went into community mental health, [where I] lost several clients in the program to suicides. Sucker for punishment.

Natalie has since gone back to school and devoted her life to a completely different career that suits her well and fulfills the desire to have a positive impact on others without exposing herself to further trauma. This restoration-oriented approach helped direct Natalie's career in a way that increases her self-esteem and confidence. In many ways, she is still processing her grief through the stories she tells as a performer, as well as helping others tell their stories.

David based his choice of a graduate program on the work he was doing on the subject of grief, and his experience losing his sister to a drug overdose. He professed a similar desire as Maeve, to "normalize" the conversation, to remove taboos and stigmas that make some survivors feel unwarranted shame:

> I talk about her everywhere I go. In undergrad I started an autoethnographic response to death. It is [based] solely around my experiences and everything after her passing away. So, everything I do within academia is practically around her. And I hope to one day be able to help someone that was in my situation to be able to understand a little more why things are the way that they are.

When a close friend of Shane's family recently died of complications from the corona virus, he had to carry on as normal for a few days but took the first opportunity to do what he needed to do to grieve. Shane tells it this way:

> So he passed away and I was pretty upset about that on Saturday, but I had two shows and couldn't really do anything about it. So yesterday morning, I got up early. I was the only person in the gym and I was there for two and a half hours just...music cranking just as hard as I could. My whole body cries, instead of just my eyes.

CMM claims that we create social worlds through our patterns of communication. In this way, we "get what we make" (Griffin, 2009, p. 73). DPM's classification of loss-oriented and restoration-oriented grieving help us understand how participants managed their grief processes in ways that improved their outcomes and helped them make meaning in the contributions they make to others like themselves.

Conclusion

Despite the fact that storytelling today is accepted as an important function for working through traumatic experiences, there are still some stories that are not well-received in our society. The study findings support existing literature that establishes disenfranchised grief as a significant issue related to stigmatized death. They also reveal challenges the traumatically bereaved face in managing communication, conflicting emotions, and the grief process itself. The findings suggest the way participants communicate after the loss of a loved one to a socially stigmatized death is affected by both actual and anticipated stigma. Disclosure of some details of the death are withheld unless the bereaved are comfortable they have a compassionate audience. This self-imposed silence can function as pre-emptive protection against emotional upset but can also be encouraged by a lack of inquiry from others. If attempts made at conversation are met by a “blank stare” or “wall of silence” the bereaved stop trying to tell their story no matter how much they may benefit from sharing it.

When a loved one is lost to a death that is deemed discreditable, survivors are often made to feel as though their grief is unwarranted, like they have no right to grieve the loss. This can exacerbate the grief process causing complicated or prolonged grief. In these cases, mourners sometimes compartmentalize or avoid certain aspects of their grief so as not to bring shame upon themselves or the deceased. The emotional cost of avoidance can be devastating.

Survivors also face conflicting emotions that are ongoing and simultaneous, which affect how they are able to process or communicate their grief. These emotions can serve as stressors and as catalysts for change. By managing these components of grief, the bereaved can find ways to work through grief and move forward in their lives over time. Failure to manage the communication and conflicting emotions inherent in the grief process can lead to further emotional trauma.

Chapter 5. Discussion

Through this project, I sought to understand how individuals manage the narratives that accompany a socially stigmatized death. Having lost four family members to drug overdoses, I recognized how difficult it is to talk about grief, or to tell the stories of a loved ones' death when the social response is not always supportive or welcoming. I also knew firsthand the complexity of the experience and how it changed who I am and how I felt about myself. This study aspired to analyze how survivors of stigmatized deaths managed their grief from a communication standpoint. More specifically, it sought to uncover how they talked about the loss(es) and with whom, what strategies they used to manage those conversations and relationships, and how their sense of self and their relationship to others was affected by the social stigma. The primary goals were to shed light on a subject that has gotten relatively little attention from communication and/or grief researchers, and to determine how communication and storytelling studies might expand our understanding of stigmatized death and the resulting disenfranchised grief.

Implications

Disenfranchised grief has a profound effect on how survivors talk about their loss, causing them to develop strategies of silence or limited disclosure to protect themselves from additional pain and/or to manage their relationships and sense of identity. The process of communicating about a stigmatized loss is often highly individual and subjective. What the bereaved share with others is what they believe is *safe* to share, and changes depending upon the audience. Managing conversations is the way in which they cope with the expectation and experience of stigmatized reactions from friends and acquaintances. In some cases, disenfranchised grief can lead to traumatic or complicated and prolonged grief with emotional and physical ramifications. Because of this, and the limited current research on the topic, there are several implications for future research directions.

Coordinated Management of Meaning (CMM) is a useful framework for evaluating how the traumatically bereaved manage communication about grief because of its emphasis on assigning meaning to interpersonal conversations through the use of constitutive and regulative rules, which dictate interpretation of meaning and course of action respectively. In addition, using CMM's hierarchy of meaning to look at the influence of cultural patterns or archetypes on seeking professional counseling might open up additional avenues for continuing to develop our understanding of grief.

When meaning is not coordinated during social interactions due to a discrepancy in how the rules are understood, participants must decide what course of action to take going forward. The findings in this study indicate that the course of action for those suffering from stigmatized grief may be to disengage from conversation entirely. The study highlights stigmatized grief as a taboo topic worthy of study along with other social taboos and forbidden conversational subject matter. It demonstrates the ways in which social silencing or muting is internalized by grievers of complicated deaths and creates barriers to healing. Findings suggest that the available cultural narratives for social and personal grieving are inadequate means for managing stigmatized grief and illuminates the need for new grief narratives that speak to the stickiness of this kind of grief experience.

Storytellers could be instrumental in constructing such narratives. By examining the social and cultural influences on the current narratives, or stories told (Griffin as cited by CMM Institute, n.d., pp. 68-70,) and the effect of silencing stories that should be told, or stories that are untold, unheard, or untellable (p. 70), storytellers could work with the traumatically bereaved to create workshops and story events with recognizably safe space for the telling of difficult stories. They can also help them craft those stories in a way that makes meaning of their loss and guides them toward healing rather than keeping them stuck in grief. In addition, they can amplify a cultural narrative that welcomes grief stories and fosters compassionate responses so that audiences are willing to hold space for the stories of the traumatically bereaved. What I hope they take from this study is that the term "therapy on stage," while useful for identifying unprocessed stories told by experienced storytellers, can silence novice tellers looking for a place they can share their stories. While there are certainly reasons for storytellers to be mindful of the purpose of their stories and potential impact to the audience, it is incumbent upon the storytelling community to be cognizant of the way the term is used outside of the curated performance.

For psychologists, grief therapists, and counselors, this research supports the call from noted grief researchers like Kenneth J. Doka, and psychiatrist Dr. Colin Murray Parkes who argue that survivors of disenfranchised grief often cannot rely on their families for emotional support and need counselors who understand the significance of this type of grief (Parkes, 2002, p. 381). It also highlights the need for greater encouragement for, and access to, grief counseling geared specifically to those dealing with disenfranchised or traumatized grief. The literature indicated that many grief counselors are not prepared for grief that does not fit the assumption that grief follows a known set of stages. Grief counselors and psychologists and their clients can benefit from the development of new techniques that acknowledge and maximize the usefulness of storytelling in creating meaning and navigating grief. More specifically, study findings support Neimeyer's (2019) push for "restorative retelling," a therapeutic procedure in which trained professionals encourage bereaved clients not to avoid the story, but to tell it in the safe and supportive space of therapy (p. 84).

There are also implications for clinicians using Victor Frankl’s logotherapy with bereaved patients, the tenets of which focus on the human being’s search for meaning. Studies have shown that meaning is important to the human condition and is associated with a range of positive outcomes including mood stability and improved social behaviors and attitudes toward life. The concepts in logotherapy are of particular interest to those professionals who are striving to help clients find ways to create meaning of socially stigmatized losses (Schulenberg et al., 2008, p. 448).

Because one of the main sources of stigmatization comes from social and cultural beliefs and practices themselves, the implications for religious leaders, hospital chaplains, and schoolteachers include the ability to be a source of information for the public and support for the bereaved. It is important that survivors have individuals they can turn to who understand the need for a non-judgmental audience who will listen without offering trite and unhelpful advice. Such professionals can instead provide comfort and understanding and a place where these survivors can be candid about how they feel. Religious counselors can learn to listen with recognition that prayer alone is insufficient for responding to the kind of grief with which these survivors suffer.

Limitations

Quarantine conditions in the U.S. presented several limitations in this study. First was the exclusion of potential participants without access to the technologies used to both advertise the study, and to complete the interviews. Advertisement was limited to online sources, which ended up being almost exclusively social media. In addition, as advertised, one-on-one interviews were conducted via video conferencing technology. While the video chat appointments had certain benefits, such as better control of privacy and personal comfort, the use of this technology likely prevented a more diverse participant pool in the long run.

The unique nature of the topic also makes for its own set of limitations. In this study, I am asking participants to talk about a subject that is socially taboo—one they may have avoided talking about except to their closest friends and family members. As I considered study limitations, I realized that every single participant who contacted me either knew me or was referred by someone who knew me personally. One participant saw the advertisement and took two steps before deciding to reach out to me. The first step was to contact the mutual colleague who had shared the study details with her to ask about me personally, specifically if I was trustworthy. The second step she took was to purchase my novel and read it. She made a point of telling me this in the interview. She wanted to be clear that this was a personal story she did not normally tell. Explaining why reading my book influenced her decision to talk with me, she said,

> I believe [we all] put a lot of ourselves into our writing and even if we don't tell our personal stories, they influence the stories that we do tell and so I felt like I knew certain things about you [and that] you would be someone trustworthy to hopefully help other people with this research.

These limitations may explain why this subject has not received more attention in the literature. Almost as a rule, the traumatically bereaved only talk about their loss with those they know for certain they can trust to be a compassionate and non-judgmental audience. That this is a limitation is all the more reason these studies need to be done and highlights the fact that researchers will need identify new ways that participants can feel safe enough in the research context to tell their stories of bereavement.

While I was more than pleased at the results of the study and the contributions of my participants who graciously shared their time and their stories, the study might have benefitted from a more diverse pool of participants. With the majority of the participants representing white Anglo-Saxon individuals having lived most of their lives in the U.S. South, it is difficult to determine if the strategies employed to manage grief were influenced by geographically-bound cultural practices or if they could be applied broadly to mourners in other regions of the U.S. or cultures beyond it.

Also of note is that the interview schedule was designed to cover a broad range of stigmatized deaths. A focus on drug-related deaths in recruitment and interviewing would have allowed me to ask deeper, more specific questions. For example, I might have learned more about how such participants experienced anticipatory grief and how management of that communication compared to or influenced how they communicated after the loss. There is much to be learned about this phenomenon of grief and many reasons for future research which I will discuss below.

Future Directions

The participants in this study demonstrated the difficulty they faced communicating with others about losses due to suicide and drug overdose deaths (DOD). This study reveals a need for future research directed specifically to DOD. Addiction has been the subject of much research, but the stigmatized grief that survivors experience after a DOD is understudied in current literature. Going forward, grief researchers from a variety of disciplines could do focused studies on both the anticipatory grief and disenfranchised grief related to DOD. Such work could inform new therapies to address the specific issues these mourners face. As noted previously, the grief of addiction begins long before the death occurs. Family members need access to support and adequate information to help them navigate this specific type of grief, and to be encouraged to talk about it in healthy and restorative ways.

There is much to be discovered about how stigmatizing certain types of death leads to prolonged and complicated grief for the survivors and how crucial it is for survivors to have meaningful conversations that provide compassion and support. There is a critical need for religious leaders, grief counselors, social justice advocates, hospital chaplains, and educators at all academic levels, especially in Communication and Storytelling studies, to take leading roles in education and advocacy for learning to talk about traumatic loss. Specific exploration of stigmatized grief through the lens of Narrative Paradigm, Muted Group, and Coordinated Management of Meaning could develop new ways of training professionals not only to be compassionate listeners, but also to position themselves to be *recognized* as trustworthy by these mourners in particular. There are many people in positions of trust who enjoy a generally accepted ethos of being seen as safe, however, there is an entire population of individuals whose experience prevents them from having confidence in anyone they are not certain will respond appropriately.

Storytellers could create opportunities for the traumatically bereaved to learn to process stories in a way that creates healing for themselves or inspiration for others. The Health Story Collaborative in Massachusetts offers good models for this type of project through several of its programs, including Healing Story Sessions, The Opioid Project, and Coping with COVID-19 as examples of working with the bereaved to tell healing stories (http://healthstorycollaborative.org).

In addition to this work with storytelling performances, storytellers could collaborate with therapists and counselors to develop narrative therapies specifically for survivors dealing with disenfranchised grief. Communication scholars have long recognized the ability of storytelling to change minds and inspire social change. In addition, courses in applied storytelling could develop introductions to narrative grief therapy as a further application specifically designed to work with those experiencing disenfranchised grief.

Studies like this can also inform and promote future work in the area of Forensic Experiential Traumatic Interview, which is a science-informed interviewing framework designed to help interviewers (especially within law enforcement) collect and accurately document an individual's high stress or traumatic experience in a neutral and fair manner. Science has shown that high stress events and emotionally traumatic experiences can interfere with the ability to process and remember details. Understanding how to conduct thorough and compassionate interviews can alleviate some stress and increase the accuracy of the information gained from people who have been traumatized (CertifiedFETI, 2021).

There is also a new form of stigmatized death that will need attention in the future. While the current study did not address this specifically, I would be remiss if I failed to forewarn of the potentially widespread disenfranchised grief associate with the COVID-19 pandemic. The experience of traumatic grief has risen exponentially with the opioid crisis, and I expect to see it rise even further due to the current pandemic. When I started the literature review for this thesis, the COVID-19 pandemic caused by the novel coronavirus SARS-CoV-2 was just beginning. Classes were halted abruptly in March 2020 and those of us who could went into quarantine in our homes. At the time of this writing, the CDC data tracker notes 503,587 deaths in the U.S. alone, with a slowly declining average of approximately 2000 deaths per day (CDC, March 2, 2021). While this research was begun to learn about stigmatized death and disenfranchised grief due mostly to suicide and drug overdose, the pandemic has set in motion an entirely new wave of survivors with stigma to face that may prove equally complex. It is likely too soon for research on the stigma attached to COVID to have even been completed as of this writing. But there are social stigmas attached to politicized safety precautions, such as the wearing of masks, as well as the complexity of grief and stigma related to being the source of exposure to a loved one who subsequently died. These factor increase the likelihood of a new wave of survivors dealing with stigma and traumatic grief.

With all the U.S. political turmoil of the past several years, and the rise in divisive discourse, topics like this are easily buried by headlines. The focus has been on the immediate needs of the public: food, education, jobs, and healthcare. But the consequences of not addressing the emotional needs of the traumatically bereaved are potentially disastrous. We are in the process of sending millions of children back to school when we have little idea how their experience during the COVID-19 shutdowns will affect them or what kinds of trauma they have endured. As vaccinations accelerate under the Biden administration, the nation will begin to return to work in what will feel like more “normal” circumstances. This may mean millions of survivors of stigmatized grief will be returning to work outside of quarantine while working through and adapting to what has become a “new normal” that resembles nothing they have known before. This study can provide a window into what needs may have to be addressed, and what issues the bereaved may face.

Research Reflections

I did not enter grad school expecting to work through grief over the loss of my mother. In fact, I thought I would eventually work on a thesis involving the issue of race relations in America, a theme that has been prevalent in the four novels I have written in the past twenty years. I chose that theme in my first class in Qualitative Research Methods in Communication and did my first ever research on black history as taught in American public schools. But in the next semester I took a class in Issues in Communication and Culture and, just to take a break from the other subject, I decided to write a paper about Broken Heart Syndrome (BHS). My brothers and I had long been saying our mother had died of a broken heart. I wanted to know if that was even possible. The more I learned about the complications of grief that caused Takotsubo Syndrome, the technical name for BHS, the more I realized how much I had failed Mom. First by blaming her for years for enabling my sister's drug addiction, and then for not talking to her about Petey's death, or more specifically not *knowing how* to talk to her about it. I also began to realize how much I had avoided talking about the series of losses I had experienced in the past few years. I was not sure I wanted to sit with the kind of emotional energy I knew it would require taking on such a heavy topic, but as I said in the introduction to this thesis, I thought I was ready. So when the time came to identify a focus for my master's thesis, I chose to study disenfranchised grief because that is what I believe killed my mother. It is not that I thought I would work through my own grief, though I have. It was the idea that, if I could save someone the same experience of deep grief and regret, it would be worth going through what I knew I would endure with this project.

When the pandemic hit and we went into lockdown, the stress was overwhelming at times. I spent the summer alternately making masks for ETSU's medical center (a distraction, but a need I knew I was meeting) and printing out literature on stigmatized death and disenfranchised grief. Reading the material gave me even more insight, and as a consequence, more regret. Early on, there were times I simply wanted to walk away from it. It was too much. But I kept going, reminding myself it was an important contribution and an accomplishment of which I would be proud.

Still, the solitude of quarantine affected me profoundly in many ways. Part of what gave me the courage to face this subject was the fact that I had such a strong support system within my cohort at ETSU. The sudden move to online classes had a rather abrupt effect on my sense of security. It was as if a set of tethered balloons had been released by cutting them above the knot. We just drifted away. I felt unsteady and weightless with no place to land. I felt frequently lost with a perpetual sense of spaciness, like a helium rush, pun intended but not for a laugh. I lost confidence and focus and I believe the study itself suffered.

I found myself frustrated at the lack of literature on the subject. Every single article I chose made note of the "paucity of information" on stigmatized grief, especially related to drug overdose deaths. Even after eventually locating more literature, I still found it largely failed to address the angle from which I'd like to approach the subject. Having lost four family members to drug overdoses, I intended to narrow my thesis to the stigma attached to that cause of death. But the scarcity of literature on drug overdose deaths worried me, and as a novice researcher I had doubts about my ability to find the number of participants I sought. So I opened the study up to any form of stigmatized death, and I accepted participants in the order that they applied. A stronger focus on drug overdose and a more selective process might have had a more desired effect on the data, as well as have allowed me to reference more of my experience in the analysis. Moving forward, my intentions are to write about my personal experience with stigmatized grief with a focus on the issues inherent with and specific to drug-related deaths. I hope this graduate project inspires other researchers to take a more focused look at the complex grief experienced by families of drug-addicted loved ones.

I came to this program as a published author seeking new ways of communicating using story to encourage social change. I currently speak with an average of one book club a week about the issues my novels raise, and I wanted to be able to better-facilitate conversations that must accommodate different perspectives. The stories I write illustrate a variety of social issues prevalent in the Southern culture. And though the topic of my thesis changed, the knowledge I gained applying Coordinated Management of Meaning especially will be invaluable to me. Understanding that everyone comes to a conversation with the rules as they understand them, will allow me to foster conversations that co-create new meaning with broader interpretations and understandings of cultural norms.

This project also brought to light some personal issues I'm having that impacted my ability as a researcher. For many years, I have worked around a profound attention deficit with a sharp memory and organizational tools such as a planner and a big white board to keep everything where I can see the "big picture." I found it difficult, even with these tools, to process complex material and remember it from one day to the next. It just seems like my short-term memory is increasingly deficient, which may be a simple fact of aging. As with many people who struggle with attention deficit, I find I need to physically see the information I have or I will forget that I have it. This meant stacks of literature I would organize alphabetically on my desk so that the information would be at my fingertips. Once again, the pandemic had an effect on this process. Working from home, I did not have physical access to the ETSU library or its staff, which was crucial for me in earlier graduate projects when I could go sit with a researcher or tutor and get the help I needed or pull the books from the shelf for immediate access.

Despite these struggles I found that I thoroughly enjoyed the process of research. The interviews were interesting and enlightening, and the experiences of the participants reinforced and validated my own experiences. As I mentioned in Chapter Three on my research methods, it was difficult sometimes not to react emotionally to the stories, but I also learned the valuable lesson that I could control my emotions without being unemotional. I could exhibit compassion and concern that inspired trust and allowed the participants to be candid without turning the interview into a dialogue. I could be the kind of audience with whom these mourners—these fellow mourners—felt safe to tell the story they wanted to tell. The participants exhibited the kind of courage I aspire to, and I was honored to be the recipient of their stories. I hope I have done them justice.

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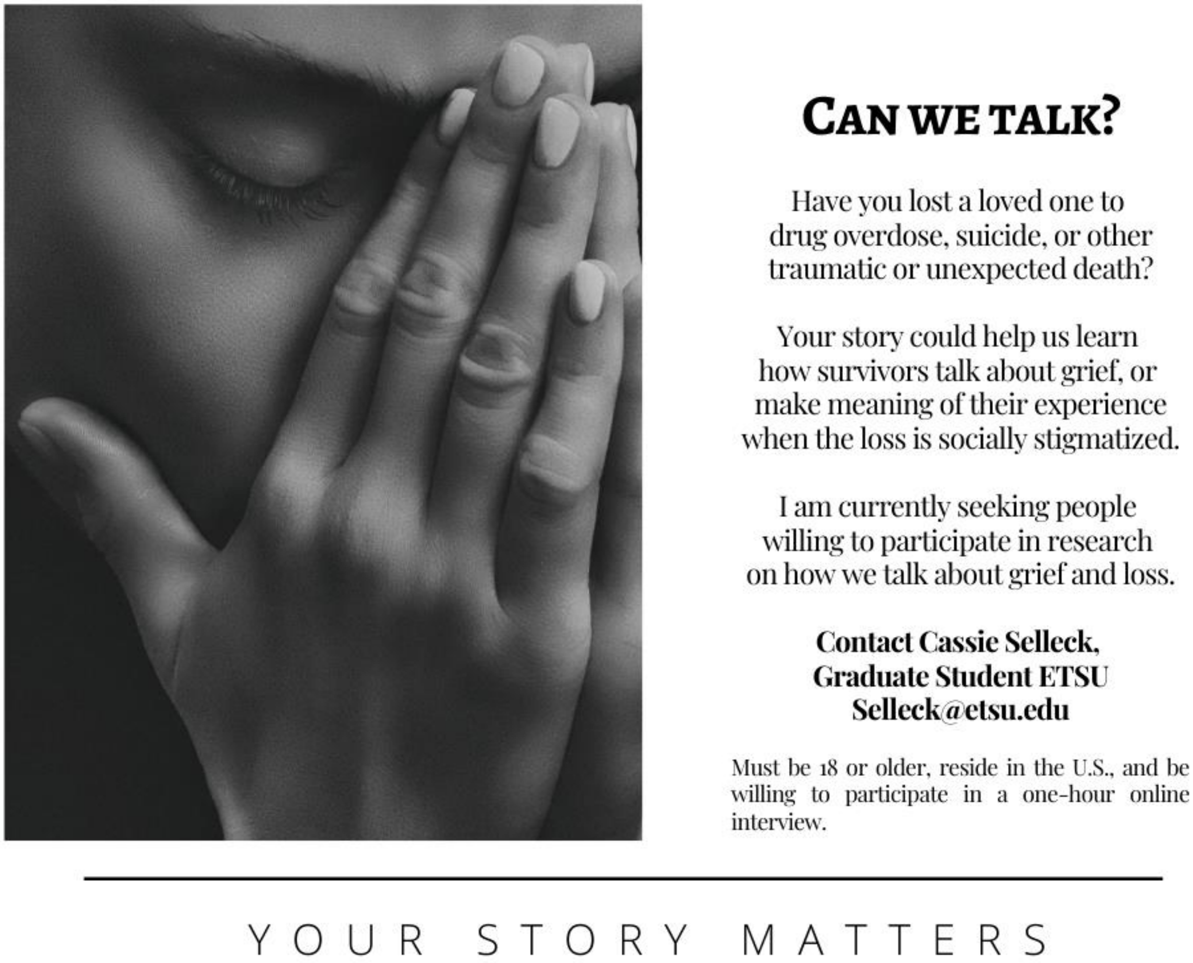
APPENDICES

Appendix A: Flyer



CAN WE TALK?

Have you lost a loved one to
drug overdose, suicide, or other
traumatic or unexpected death?

Your story could help us learn
how survivors talk about grief, or
make meaning of their experience
when the loss is socially stigmatized.

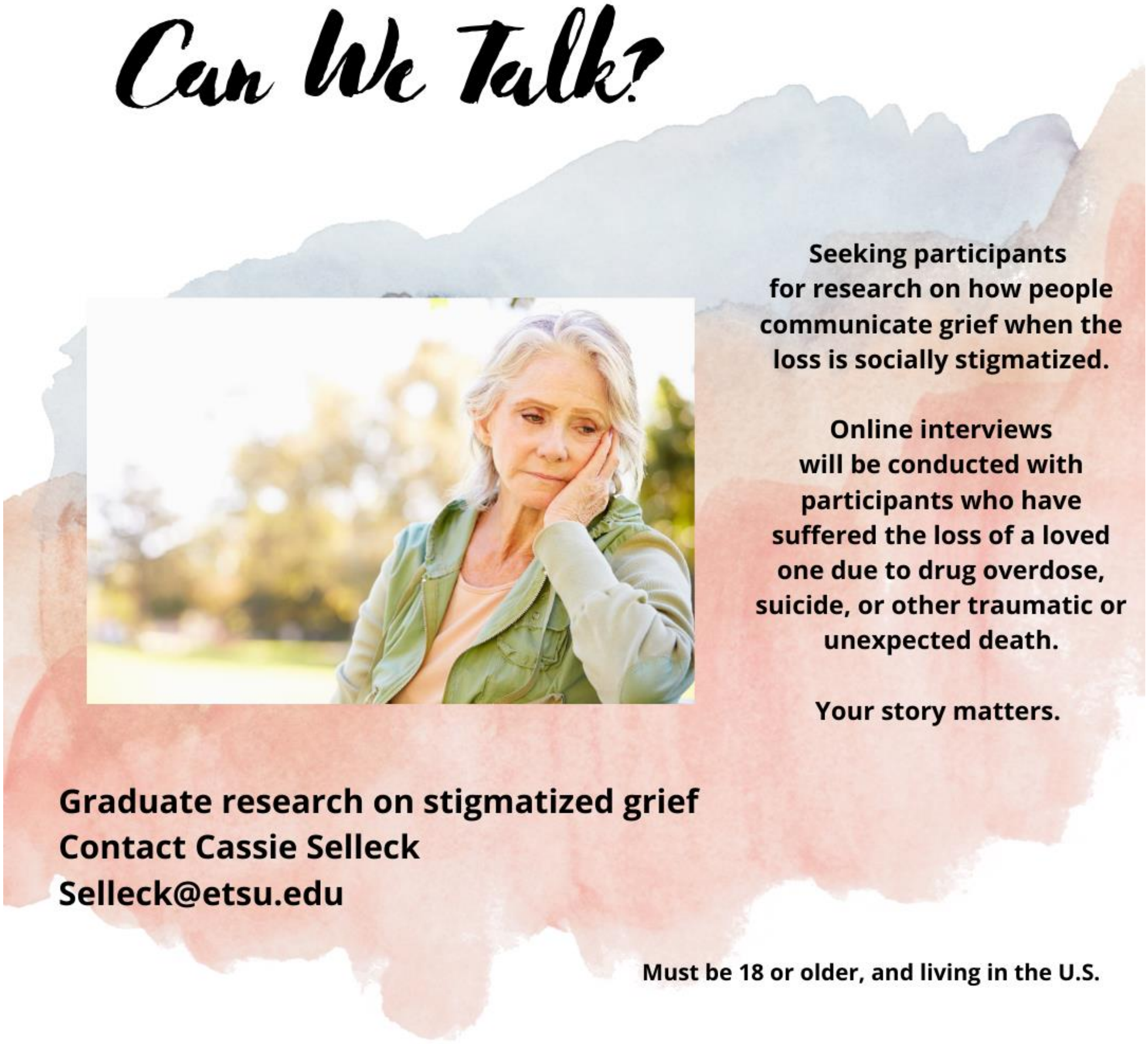
I am currently seeking people
willing to participate in research
on how we talk about grief and loss.

Contact Cassie Selleck,
Graduate Student ETSU
Selleck@etsu.edu

Must be 18 or older, reside in the U.S., and be willing to participate in a one-hour online interview.

YOUR STORY MATTERS

Appendix B: Social Media Announcement



Can We Talk?

Seeking participants
for research on how people communicate grief when the loss is socially stigmatized.

Online interviews will be conducted with participants who have suffered the loss of a loved one due to drug overdose, suicide, or other traumatic or unexpected death.

Your story matters.

Graduate research on stigmatized grief
Contact Cassie Selleck
Selleck@etsu.edu

Must be 18 or older, and living in the U.S.

Appendix C: Online Post

Online posts:

Seeking participants for my graduate research involving stigmatized grief. If you have lost a loved one to drug overdose, suicide, or other traumatic and unexpected death, and are willing to share your story by participating in a one-hour interview, your input is valued. For more information on the project, please contact Cassie Selleck by email at Selleck@etsu.edu.

Appendix D: Interview Schedule

1. Could you tell me a little about the loved one you have lost?

   Possible prompts

   - What is your relationship to them?
   - How would you describe your relationship?

2. Is there anything you feel comfortable sharing about their death? (We can skip this and come back or skip it entirely.)

   Possible prompts

   - Was it completely unexpected?
   - How has death affected you or impacted your life?

3. Where would you say you are in the grieving process?

   Possible prompts

   - Do you feel like you have had a chance to heal at all?
   - Do you feel like you have had support through this process? How much or how little?
   - Who has been your biggest support? What were some of the most helpful things they did?
   - Whose reactions have surprised you the most? Can you elaborate?

4. What was the support like from your friends and family during your time of loss?

   Possible prompts

   - Did you feel like people responded differently to this loss than others you have experienced?

        - If so, what were those differences?
        - How did that impact your ability to cope with the loss, or heal?

5. Did the responses or reactions of family and friends influence what you did?

    Possible prompts:

    - At home?
    - At family gatherings?
    - With your personal care?
    - In your social life?

6. Was there anything that made it easier to talk about your loved one? Anything that made it more difficult?
7. Did you ever seek help outside of the family?

    Possible prompts:

    - If so, what kind of help?
        - Religious?
        - Counseling?
        - Meditation?
        - Support group?
    - Can you tell me how this went for you?
    - Was there one particular friend who played a big part in your grief? If so, what were some of the ways they helped?
    - Do you feel like you wanted help but didn't know how to go about finding it?
    - Did you find the effort to seek help was beneficial to you? If so, in what ways?

8. How have you communicated with others about this loss and your grief?

    Possible prompts:

    - Have you talked with family or friends about your loss?
        - If yes, have they been willing to talk openly with you?
        - If no, could you share some of the reasons you don't?
    - Is it helpful for you to talk about your loss and how you are feeling about it?

9. What, if any, are the barriers you have faced in talking about your loved one's death?

    Possible prompts

    - Have you felt like you were able to discuss the circumstances openly?
        - Walk me through any situations where you felt like you were encouraged not to share when you wanted to.
        - Have there been times when others wanted to talk, but didn't feel comfortable speaking to them? Can you share more about this?
    - Was there anyone you felt like you couldn't talk freely with?
        - If yes, what kind of information did you feel like you had to avoid, and why?
        - Have you avoided the discussion with anyone because it was difficult to be honest about the circumstances or how you feel?
    - Have you ever felt blamed by anyone for the death, either verbally, implied, or insinuated?
    - Have you felt like you needed to withhold or change details about your loss with anyone? If so, what led you to feel like this was necessary?

Alternate question for anyone experiencing a stigmatized death during the pandemic:

10. How has the pandemic/quarantine impacted your ability to grieve?

    Possible prompts

    - Were you able to hold a funeral?
    - Gather with family and friends?
    - How has the lack of social contact affected your ability to talk with others about your loss?
    - What are the challenges to seeking outside help, if any?
    - Have you felt like some people have used the quarantine as a way to avoid talking about the loss?
    - What, if any, are some of the ways friends and family have gone out of their way to reach out to you with limited contact?

11. So many times, we hear that time heals all wounds. From my own experience, I might disagree. Time has helped me process the pain, but it does not go away. What do you think about this?

    Possible prompts

    - Can you describe how time has affected your ability to speak openly about your loss?
    - Has the passing of time helped you process the loss in a way that taught you something you didn't know before?

12. What are the ways, if any, you have tried to make meaning from your loss?

    Possible prompts:

- What are some of the stories you like to tell about your loved one to honor the good times and good memories you have of them?
- These can include focusing on the good times you had, or the qualities and accomplishments of your loved one.
- Is there anything specific you have done to reach out to others?
  - To share your story?
  - To honor their memory?
  - To volunteer or donate with other organizations?
- Do you feel like these things have helped you through your grief? If so, in what ways?

13. If you could only share one thing with me, so that I would know who your loved one was and why they were important to you, what would that be?

VITA

CLAIRE “CASSIE” DANDRIDGE SELLECK

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Publications:	Novels of Southern fiction: *The Pecan Man, The Truth About Grace, What Matters in Mayhew, The Mayhew Junction Historical Society*