

**Explaining Death:**  
**A Typology of Accounts of Parental Loss Experienced During**  
**Childhood and Early Adulthood**

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### **Explaining Death:**

## **A Typology of Accounts of Parental Loss Experienced During Childhood and Early Adulthood**

**Abstract:** This pilot study explores narratives of parental death shared by adults who were between the ages of four and 25 when they lost their own parents—often suddenly and unexpectedly. Drawing on data gathered through 21 semi-structured, in-depth interviews, four themes emerged in my analysis of the data: Losing a Loved One: Why Them?; Diverting Blame; Finding Purpose; and Learning in Advance. Although experiences of parental deaths were diverse, this research and the typology that it presents illustrates how participants used narrative accounts to explain or find meaning in their parent’s cause of death. Additionally, in some cases, I found that participants attempted to minimize the stigma associated with early death through managing the situation concerning parental loss. Through their accounts, or lack thereof, the participants offered essential insight into how parental death narratives are socially constructed and influenced by cultural norms and expectations of death.

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“People tell stories not just to work out their own changing identities, but also to guide others who follow them” (Frank 2013:17).

**Introduction**

Sitting at my desk, a “ding” alerted me to a scheduled Zoom meeting starting in ten minutes. Due to COVID-19 restrictions, what would have been an in-person interview was now being held in a virtual space. Right on time, the interviewee joined the call. McKinsey, now a college student, lost her mom to lung cancer at the age of seven. After a brief introduction to the study and a few minutes into the interview, I asked about her mother’s death. McKinsey took a deep breath and began to tell her story.

The death of a parent is traumatic, but parental death, experienced in childhood or early adulthood, is an incredibly challenging and deeply personal experience—carrying various layers of impact as bereavement is both complex and unique for every survivor (Ellis, Dowrick, and Lloyd-Williams 2013). At the same time, a large number of children in the United States will experience the death of a parent or sibling before they reach the age of 18. In fact, the Childhood Bereavement Estimation Model (CBEM) estimates that 1 in 14, or 5.3 million children in the United States, lose a parent or sibling before they reach adulthood. By the age of 25, that number more than doubles to 13.3 million. Moreover, with the ongoing COVID-19 pandemic, demographers estimate that 1 in every 500 children in the United States has lost a parent or primary caregiver (National Institutes of Health, 2021).

Parental death disrupts and disorders numerous aspects of a child or young adult's life as they are forced to learn to navigate a newly ascribed identity in an attempt to redefine a world that no longer includes the deceased parent (Farella Guzzo and Gobbi 2021). In the effort to bring order to and find meaning in a life that no longer resembles the one they knew, many use narrative strategies when talking about a parent's death (Gilbert 2002; Menig-Peterson and McCabe 1978). Although narratives are representational, they serve as a tool for coping with loss (Gilbert 2002).

The construction of death narratives does not happen in a vacuum but is deeply entrenched within a social and cultural context. Indeed, the social world in which death is experienced shapes the meaning given to death and informs what *should* be included or removed from the verbalized narrative (Charmaz 1980; Gilbert 2002). This paper examines narratives of parental death by analyzing a series of in-depth interviews with adults who were between the ages of four to 25 at the time they lost one of their parents. Specifically, it presents a novel typology of accounts of parental death, which was developed based on the collection of pilot data.

## **Literature Review**

“Narrative (stories) in the human sciences should be defined as discourses with a clear sequential order that connects events in a meaningful way for a definite audience and thus offers insights about the world and people's experiences of it” (Hinchman and Hinchman 1997: xvi).

Humans are driven to find order, meaning, and purpose not only in their own lives but in the lives of others (Orbuch 1997). How people make sense of their lived experiences has long been a focus of social science research as individuals recreate experiences through narratives that detail specific occurrences, arrange information, and ultimately construct meaning (Bruner 1991;

Clandinin and Connelly 1994; McAdams 2013; Orbuch 1997). Symbolic interactionism, in particular, provides a theoretical framework to address socially constructed meanings placed on objects, behaviors, and life events as individuals use language and act in ways that reflect subjective meaning (Goffman 1978). Stories, as a specific form of narrative, inform individual lives and shape the life of the storyteller (Moezzi and Peek 2021). As noted, the lived experiences recreated through storytelling are not siloed but embedded within a social and cultural context (Gilbert 2002).

Over the last several decades, sociologists have advanced narrative research as scholars have been encouraged to collect and analyze the stories people tell to make sense of and give meaning to their personal and professional experiences (Moezzi and Peek 2021; Orbuch 1997). Sociologist Arthur Frank, for example, details his lived experience of illness in his book *The Wounded Storyteller* but “widened the circle” to include the unique illness experiences of others as told through personal narrative (Frank 2013:xi).

Life experiences are narrated within a historical framework that governs shared information. Entrenched in social relationships and institutional structures, narratives are regulated by and within a specific culture that reflects social attitudes, beliefs, and norms (Ammerman 2010). Often, personal narratives, functioning to reconstruct past events, do not align with socially approved outcomes—thus taking the form of accounts. Accounts, which are often constructed to diminish blame, can reduce the effects of stigma (Irvine 2000).

Early research on accounts was based on Goffman’s (1959) theory that people are self-protective when presenting themselves to others, especially when attempting to manage an actual or potentially spoiled identity. The notion of the spoiled identity, which is often associated with deviant behavior, was addressed by Skyes and Matza’s (1957) seminal research. They

identified five techniques of neutralization used to justify behavior that violated social norms. Specifically, they found that people use *preemptive* accounts, which protected self-image and negated guilt. The five techniques of neutralization illuminated how individuals rationalize a deviant identity through denial of responsibility, denial of injury, denial of victim, the condemnation of the condemner, and appealing to higher loyalties. These preemptive techniques provided a framework to build narratives that would divert social disapproval of violated norms in advance of others' judgment (Sykes and Matza 1957).

Building on prior scholarship, Scott and Lyman (1968) defined *accounts* as “linguistic devices [that] explain unanticipated or untoward behavior” (p. 46). Accounts embedded within stories and narratives can diminish one's responsibility through excuses *or* assume personal responsibility for conduct through justifications (Irvine 2000; Scott and Lyman 1968). Although accounts are still often understood as a pathway to explain or justify deviance, scholars have broadened their focus to include “story-like” interpretations or explanations in the construction of accounts (Bruner 1990; Harvey, Orbuch, and Weber 1990; Maines 1993; McAdams 2013; Orbuch 1997; Surra 1987; Veroff et al. 1993).

Accounts, not limited to identity protection, are used in everyday narratives to make sense of social environments where stressful life events occur. Such accounts can validate and clarify past experiences (Sawicka 2017; Umphrey and Cacciatore 2011). Accounts provide a level of closure, establish order in relational experiences, and give hope to a personal and collective future (Orbuch 1997). Despite prior scholarship that identified account-making with deviance, complex situations are not required to tell a narrative—particularly in the context of a life narrative (Harvey et al. 1990; Orbuch 1997; Scott and Lyman 1968). Through the use of narrative accounts, the lived experience of the teller is understood (Richardson 1990).



## *Narrative Accounts of Death*

The experience of sickness and death is not siloed but instead intersects with a socially constructed understanding of *how* and *why* death occurs—shaping the meaning given to death and influencing how individuals respond to and talk about loss (Charmaz 1980). In the case of death, which can be temporarily or permanently disruptive, narratives can serve to create order where there is uncertainty, grief, and disorder and give meaning to a newly ascribed status as a bereaved person (Gilbert 2002). From a functionalist perspective, narratives are not given for the sole purpose of retelling events but instead serve a dual purpose. The first is to recount events in pursuance of their meaning and significance; the second is to verbally interpret the actions of others' responses to the retrospective retelling of a particular occurrence (Becker 1997).

Harvey, Stein, and Scott's (1995) seminal research documented the importance of narratives in their work with Normandy combat veterans who used stories as a way to navigate loss and trauma. The researchers found that the combat veterans talked about experiences with death in three primary ways: as a lifelong grieving process, as continual and compelling thoughts about the loss of their friends, or as memories of firsthand experiences and close encounters with death during the D-Day fighting. Just as the veterans used stories to understand their wartime experiences, bereaved individuals often recognize their losses through accounts or stories that put major life events into context (Bruner 1990; Coles 1989; Darden 1991; Folkman 1997; Harvey and Miller 1998).

Death, although inevitable, is one of the most avoided topics of conversation in our society (Sprang and McNeil 1995). Indeed, Elisabeth Kübler-Ross, a foremost expert on grief, wrote, "Dying is an integral part of life, as natural and predictable as being born. But whereas

birth is a cause for celebration, death has become a dreaded and unspeakable issue to be avoided by every means possible in our modern society” (Kubler-Ross 1988:5).

When a parent dies in the prime of their life, a cultural narrative of longevity is disrupted—leaving children to make sense of an untimely death. Deaths occurring “too soon” or as the result of a stigmatized cause or illness that does not align with an accepted norm of health and well-being deviates from established cultural expectations and can be more difficult to process (Fife and Wright 2000).

Prior research has established that various illnesses and causes of death are associated with stigma. Stigma, defined as an attribute that links an individual to an objectionable stereotype, sets those socially perceived as deviant apart from others (Goffman 1978). Disease-related stigma and perceived health-related stigma (PHS) are distinct and characterized by exclusion, rejection, blame, and devaluation as social judgment extends to the person or group that has been identified with a particular health problem (Wang et al. 2017).

Until very recently, cancer has been synonymous with death—a diagnosis and illness to be feared (Chapple, Ziebland, and Hawton 2015; Fife and Wright 2000). Specific cancers have been socially stigmatized due to their lethal nature and socially-suspect origins. Liver, lung, cervical, colorectal, and breast cancers, in particular, have been the focus of stigma-related social research (Wang et al. 2017). This research has shown that numerous factors determine why one type of cancer is stigmatized over another, including the actual or suspected cause of cancer (e.g., excessive smoking or drinking), the potential or available treatment for the cancer, and the possible lethal or non-lethal outcome of the cancer (Corrigan 2014).

Medical sociologists have extensively studied the stigmatizing nature of other diseases beyond cancer, such as HIV/AIDS, mental health disorders, and substance abuse (Doka 2014;

Fife and Wright 2000; Gilmore and Somerville 1994; Stahly 1988; Volinn 1989; Walkey, Taylor, and Green 1990; Weitz 1989). Additionally, causes of death that are violent, accidental, self-inflicted, or perceived as traumatic often bear the additional burden of social disapproval (Paul 2019). Murder, suicide, and motor vehicle fatalities are examples of these latter forms of death.

Cultural narratives attribute stigmatized illnesses and death to poor decision-making and flawed personal character. Prior research has found that specific diseases are socially considered controllable by personal choice and behavior (Stahly 1988). Persons diagnosed with a disease that could have been controlled (or is assumed to be able to be controlled) by “personal responsibility” often face a lack of sympathy and even blame. On the other hand, diseases that are understood to be out of a person’s direct control are typically met with compassion and understanding. Lung cancer, for example, continues to be a disease that has a strong behavioral link most often related to smoking and therefore is typically perceived as controllable (Corrigan 2014; Weiner 1993; Weiner, Perry, and Magnusson 1988). Of course, these assumptions are not static, and perceptions of illness and death can and do shift over time. This recognition further underscores the socially constructed nature of cultural narratives surrounding death.

During a particular historical moment, individuals living with or dying from a culturally stigmatized illness involuntarily become members of a social category that discounts their identity and further separates them from their healthy counterparts (Fife and Wright 2000). Stigmatized persons are marked with what Goffman (1963) termed a spoiled identity—a master status that places the sick and dying at fault (also see Becker 1963). Consequently, once assigned to the stigmatized individual, moral and social judgments may be transferred to the bereaved, resulting in “subjective awareness of other's stigmatizing attitudes” or perceived stigma (Pitman

et al. 2018:121). Committed to preserving a loved one's identity, diverting or neutralizing blame from the socially stigmatized to another—who might be complicit—serves to disrupt a marred identity defined by social constructs (Burke and Stets 2009; Hegtvedt and Johnson 2017; Sykes and Matza 1957).

### *Bereaved Children*

Children may be exposed to death even at early ages. This exposure may be in the form of viewing children's movies, losing a pet, or hearing about the tragic loss of life on the nightly news. Although children are often exposed to death and dying in less distressing ways than their own parent's death, talking about loss with children often makes parents uncomfortable—a difficult subject locked in “silence and tension” (Doka and Hospice Foundation of America 2000:6).

In helping bereaved children cope with unexpected loss, research supports the importance of open and honest communication with children about death (Monroe and Kraus 2005; Paul 2019; Silverman 2000). Although developmental psychology has been dominant in academic and medical realms in terms of defining how children understand and process death, the social aspects of childhood experience should not be overlooked as they shape a child's understanding of *and* response to death and other forms of loss (Christ 2000; Fothergill and Peek 2015).

Studies have found that children who are told about their parent's illness have better mental health outcomes than children who lack adequate and age-appropriate information (Welch, Wadsworth, and Compas 1996). Finding the balance between truth-telling and protecting children is difficult as the desire to shield children from pain is a powerful instinct. Studies have shown that parents find it difficult to openly communicate with their children about their illness for fear of frightening them or taking away any hope of recovery (Meriggi et al. 2017).

Understanding how they make sense of this is especially important when a child or young adult's parent has died due to a socially stigmatized reason—for example, cancer, suicide, or drug overdose.

The limited literature available on this topic indicates that well-intentioned adults often shield bereaved children from the harsh reality of suffering and death. In trying to protect children, information about a person's illness is withheld, which often “fosters confusion and increased anxiety in children” (Hunter and Smith 2008:149). In these instances, in particular, discussions of death continue to be socially undesirable and, therefore, typically avoided (MacPherson 2005). In the end, adults' discomfort with death may inform their conversations with children, resulting in adverse bereavement experiences and outcomes (Hunter and Smith 2008; Paul 2019; Silverman 2000).

To date, there has been limited sociological research in the U.S. on young people who have lost a parent abruptly or unexpectedly during childhood or early adulthood. Past research has primarily focused on the long-term impacts of parental death on the life course or health outcomes (Ellis et al. 2013; Feigelman et al. 2017; Jacobs and Bovasso 2009). One study by Menig-Peterson and McCabe (1978) analyzed the death narratives of 96 children between three-and-one-half and nine-and one-half years of age. Children told various stories of death, but only five of the 96 children in the study had experienced the death of an immediate family member. Two of the five talked about the death of a sibling, and three described the deaths of a parent. Each narrative provided chronological accounts of the deaths but was devoid of evaluation—meaning that children did not communicate how they felt about the death or the events leading up to the death. The researchers found a lack of emotional response in the death

narratives of the children who had confronted death—indicating the importance of collecting narratives of loss from adult parentally bereaved children (Menig-Peterson and McCabe 1978).

This study attempts to build on the limited available research through learning directly from young and middle-aged adults about how they made sense of the loss of a parent during their own childhood or into early adulthood. Extensive research has been conducted to understand the long-term impacts of parental death in childhood in the U.K. However, there is a lack of sociological research that directly aims to examine the impact of parental loss experienced in childhood or early adulthood through narrative research—particularly in the U.S. (Ellis et al. 2013; MacPherson 2005).

## **Methods**

This pilot research for my dissertation draws on 21 semi-structured, in-depth interviews conducted between July 2021 and January 2022 with adults who, during their childhood or early adulthood years, experienced the death of a parent. This research, which is both sensitive in nature and involves a potentially vulnerable population group, required human subjects' approval. All work proceeded as proposed in my IRB application, which was approved on June 28, 2021 (#IRB Protocol: 21-0276). Per the IRB protocol, all participant names included throughout the paper are pseudonyms.

Participants were four to 25 at the time of parental loss. I recruited participants through various social media platforms like Facebook, Instagram, and Reddit. I also contacted national grief organizations for references to potential participants and drew on personal contacts in my social and academic networks. My dissertation committee members and other acquaintances also

shared my recruitment materials through their own social media accounts and personal and professional networks.

The primary criterion for recruitment for this study was the death of a parent when the participant was a child or in the early years of adulthood. In addition, I pre-screened all potential participants via a brief online questionnaire to determine research eligibility before scheduling or conducting interviews. Specifically, the pre-screen questionnaire asked individuals their age and school grade (kindergarten through college) when their parent died, participant's current age, and if they currently resided within the United States (see Appendix A).

Once I had determined that a potential participant was eligible for inclusion in the study, I collected additional data via a second online questionnaire and through open-ended, in-depth interviews conducted via the virtual platform Zoom. At the outset of each interview, I asked all participants to complete a second questionnaire that asked about demographic information, including age, gender, race, and level of education. I also collected data on the demographic characteristics of the deceased parent, including asking the study participant about the parent's age when the death occurred and the cause of death (see Appendix B).

Once the participant had finished the questionnaire, I began the semi-structured interviews, which lasted approximately one hour each. The open-ended interview questions were designed to understand each unique experience of parental death and encourage in-depth discussions. After introducing myself, I then asked participants to take as much time as they needed to (1) chronicle their life before and after their parent's death, (2) recount the story of their parent's death, and (3) summarize how the death of their mother or father had impacted their life (see Appendix C). Because of the emotionally challenging nature of this research project and my own commitment to ethically-grounded research, the interview guide did not

probe for the deceased parent's medical history or lifestyle choices. However, if the respondent volunteered this information, it became part of the interview data.

I used a grounded theory approach for the analysis of participant interviews (Charmaz and Mitchell 2001). Shortly after each interview was conducted, the audio recordings were professionally transcribed (I did not keep the video recordings). I then loaded the transcribed interviews into Atlas.ti and coded each interview twice. In the first round of inductive coding, I identified broad meaning-making themes that were then narrowed down into sub-themes that reflected socially constructed ideologies of illness, death, and grief. Themes were identified based on my review and analysis of the data rather than from a predetermined hypothesis. Patterns within participants' narrative accounts were analyzed to make sense of how historical and sociocultural factors were represented in the meaning-making account process. For this paper, I focused on the data relevant to the typology of accounts of parental death.

#### *A Note on Positionality*

My recruitment materials and introduction to each interview emphasized my strong connection to the research topic (see Appendix D). When my sons were seven and ten years old, their father died suddenly and unexpectedly in a car accident. Although my parents are still living, meaning that I have not personally experienced parental death in childhood or early adulthood, I have firsthand experience raising parentally bereaved children.

Qualitative researchers are not separate from the study but instead essential to it (Dwyer and Buckle 2009). Yet, sociologists have long debated the benefits and challenges of researchers who hold an insider identity with the communities they study. On the one hand, it has been argued that an insider status may limit objectivity. On the other hand, researchers who share an



“identity, language, and experiential base” with study participants may benefit from a level of trust that otherwise might not be afforded to a researcher on the outside (Asselin 2003; Dwyer and Buckle 2009:58). I shared my positionality as an “insider” with participants by telling my story of sudden loss and of my children’s grief. My interviewees seemed to view me as an ally and perhaps even a trusted insider, given my experience with and awareness of the complexities of death and grief. My children’s story of parental loss granted me a certain amount of legitimacy as participants entrusted me with their stories—each expressing their gratitude for the research I was engaged in. In addition to being a researcher, I am a white female and mother—statuses that I believe positively influenced interviewees’ willingness to share their stories with me (Fothergill and Peek 2015).

#### *Sample Population and Description of Decedents*

As previously noted, I interviewed 21 adults who experienced the premature death of a parent. Interviewees’ age at the time of the interview ranged from 18 to 48, and most experienced their parent’s death during their teenage years. Seventeen participants were female, two male, one non-binary, and one transgender person. All but three participants were white; the other three self-identified as Black (see Table 1).

Table 1. Demographic Characteristics of Participants

Age at Time of Parental Death	
4-9	3
10-14	8
15-18	7
19-25	3
Gender	
Woman	17
Man	2
Non-Binary	1
Transgender	1
Self-Described Race	
White	18
Black	3
Highest Level of Education	
High school diploma or equivalent	2
Some college	10
Bachelor's degree	5
Master's degree or higher	4
Region of Residence	
Northeast	4
Southeast	4
West	6
Midwest	7

In terms of the deceased parents, 12 of the 21 were mothers; nine were fathers. At the time of their death, parents ranged in age from 29 to 80. There were seven sudden or unexpected deaths (at least from the perspective of the participant), three of those being accidental, one suicide, and three heart attacks. The other 14 (anticipated) deaths were from disease (i.e., cancer, autoimmune disease, and organ failure).

### **Explaining Death: A Typology of Accounts**

Although experiences of parental death were diverse, participant narratives were embedded within a larger social context and upheld socially constructed death norms. Meaning, that as life expectancy has increased, it is most typical for individuals to experience parental death during middle adulthood rather than in childhood or in early adulthood (Charmaz 1980; Marks, Jun, and Song 2007). Even though death is a biological fact, symbolic interactionism informs how conceptions of sickness, death, and dying are socially constructed. Additionally, the

manner in which death occurs is understood and framed through socially accepted norms and values (Goffman 1978).

How death is viewed and conceptualized has shifted over time as the decline in mortality has been significant in the past century (Seale and Addington-Hall 1995). Most deaths now occur among the elderly population—in contrast to deaths among the young. As a result, death is understood as an irreversible fate, *but* one that is often deferred until later in life. Extended life expectancy rates have given new meaning to how loss is understood both socially and individually—as “on-time deaths” have become the cultural norm (Riley Jr 1983: 195).

Americans put a high value on living a long life with the idealized notion of a good death as being one that is without agony, pain, or delay (Cottrell and Duggleby 2016). In the *Social Reality of Death*, Kathy Charmaz notes that “death is typically assumed to occur at the ‘correct’ time, old age” (Charmaz 1980:70). When children die, the loss is significant as their contribution to their family and society has been prematurely halted. In contrast, when death comes for the elderly, the expectation is that their lifelong contribution has been met. When individuals die in the middle of their life course, death is often met with disbelief as their contribution to families, occupations, and society is at their greatest (Glaser and Strauss 1964).

As indicated previously, I did *not* ask participants about their parent’s medical history or health lifestyles. Instead, I invited participants to “share as much or as little about their parent’s death as they felt comfortable.” For a few, the narratives of parental death detailed a chronic illness that led to the anticipated end of life. For most others, parental death was sudden, unexpected, and occurred with no warning. All retrospective participant experiences employed accounts—without my prompting—to explain, or find meaning in, their parent’s cause of death.

Some of the narratives offered by the participants reflected a tension between their own personal experience of parental death and the social expectations of how, when, and why people die. Employing a narrative approach to data analysis requires the researcher to search for deeper meaning as narrative accounts are not only about *what* is said but *how* and *why* it is said by the teller (Gilbert 2002). These accounts became the object of my analysis and offered essential insight into how parental death narratives are socially constructed and influenced (Zussman 2000, Irvine 2013).

My research with the parentally bereaved identified four distinct themes which I include in the typology described here. Typologies are most often used as a way to classify people, things, or ideas into groups based on shared characteristics. As such, this typology of accounts provided a framework to organize and analyze the narrative accounts that captured how interviewees explained their parent's causes of death.

- *Losing a Loved One: Why Them?* aimed to make sense of a death that occurred in a parent's prime of life or understand a cause of death that did not align with the prevailing science around health and longevity.
- *Diverting Blame* focused on shifting responsibility away from a parent's stigmatized cause of death and placing the blame elsewhere.
- *Finding Purpose* emphasized turning the experience of parental loss into a life purpose.
- *Knowing in Advance* demonstrated advanced knowledge of a parent's terminal diagnosis and impending death.

While the participants' stories sometimes touched on elements of more than one theme, typology placement was designated based on the predominant theme that ran through the narrative account. Table 2 summarizes the dominant category for each of the gathered accounts.

In addition, I include several other key variables in the table that likely influenced the accounts offered.

Table 2: A Typology of Accounts, by Participant

Participant Pseudonym	Participant Gender	Participant Race	Participant Highest Level of Education	Participant Age (current)	Participant Age (when parent died)	Expected or Unexpected Parental Death	Deceased (mother = M; father = F; grandmother = GM)	Deceased's Age at the Time of Death	Cause of Parental Death (stigmatized causes are <b>bolded</b> )	Typology 1: Losing a Loved One: Why Them?	Typology 2: Diverting Blame	Typology 3: Finding Purpose	Typology 4: Learning in Advance	No Account Given
1. McKinsey	Female	White	Some College	19	7	Expected	M	44	<b>Lung Cancer *</b>	X				
2. Ainsley	Female	White	Bachelor's Degree	25	13	Expected	M	44	<b>Breast Cancer *</b>	X				
3. Elizabeth	Female	Black	Some College	21	16	Unexpected	GM	70	<b>Heart Attack **</b>					X
4. Payton	Female	White	Bachelor's Degree	31	13	Unexpected	M	49	<b>Suicide/Overdose</b>		X			
5. Amy	Female	White	Some College	46	15	Unexpected	F	32	<b>Heart Attack **</b>	X				
6. Charlotte	Female	White	High School Diploma	24	13	Expected	M	39	Stomach Cancer				X	
7. Keith	Male	White	Some College	21	10	Expected	M	39	Stomach Cancer				X	
8. Molly	Female	White	Some College	21	19	Unexpected	F	56	<b>Alcohol Related Fall</b>		X			
9. Bailey	Female	White	Doctoral Degree	29	17	Expected	F	45	<b>Intestinal Cancer *</b>				X	
10. Aiden	Male	Black	Some College	22	16	Expected	F	80	Bone Cancer				X	
11. Mia	Female	White	Some College	20	5	Expected	M	47	<b>Ovarian Cancer *</b>		X			
12. Grace	Female	White	Some College	21	17	Unexpected	M	53	<b>Colon Cancer *</b>				X	
13. Alex	Non-Binary	White	Some College	18	14	Expected	F	42	Gallbladder Cancer				X	
14. Melanie	Female	White	Some College	19	13	Unexpected	F	51	<b>Alcohol Related Fall</b>		X			
15. Megan	Female	White	Some College	18	12	Unexpected	F	56	<b>Car Accident</b>		X			
16. Maggie	Female	White	Bachelor's Degree	34	10	Unexpected	M	42	<b>Heart Attack **</b>			X		
17. Vivian	Female	White	Bachelor's Degree	48	16	Unexpected	M	42	Organ Failure			X		
18. Quinn	Female	White	Bachelor's Degree	23	17	Expected	F	55	<b>Cirrhosis of the Liver *</b>		X			
19. Elana	Female	White	<i>Bachelor's Degree</i>	31	21	Expected	M	55	<b>Breast Cancer *</b>				X	
20. Leigh	Female	Black	Master's Degree	28	4	Expected	M	29	Lupus			X		
21. Hannah	Female	White	Master's Degree	26	15	Expected	F	60	<b>Lung Cancer *</b>	X				

\* Many cancer treatments take a heavy physical toll on the body. Treatments can change a patient's appearance through hair loss, weight loss, and even physical deformities—which may be stigmatizing. Not all cancers carry a stigmatized label, as noted by the non-bolded causes of cancer deaths. However, despite increasing breast cancer awareness and social support, breast cancer patients face social stigma following a mastectomy as breast removal is seen as disfiguring and deviates from the feminine norm (Else-Quest and Jackson 2014). Additionally, lung, intestinal, ovarian, and liver cancers are stigmatized. (see Else-Quest and Jackson 2014).

\*\* Socially stigmatized, heart disease is often attributed to an unhealthy diet and lack of physical exercise (Clarke 1992).

### *Losing a Loved One: Why Them?*

Some causes of death do not conform to loss rationales (Glaser and Strauss 1964). For example, a loss rationale might be that a parent who exercises faithfully and never smoked should not die of lung cancer. Socially, health and wellness are valued, and illnesses that arise in spite of adherence to healthy lifestyles violate the expected norm that death comes in old age.

For example, sociologist Peter Kaufman died from lung cancer on November 19, 2018.

Documenting his experience with cancer that did not align with his healthy lifestyle, Kaufman wrote this in a blog post: “I have never smoked or tried illegal drugs, and I’ve never even been drunk. I’ve pursued clean living, good nutrition, and regular exercise in part to avoid the sort of medical misfortune that I am now experiencing... I was incredibly healthy until I wasn’t”

(Kaufman 2018). Kaufman's death at the age of 51 disrupted social death norms and cultural expectations of a good death. When a chronic illness disrupts the death norm, there is a social expectation that one can overcome an illness—achieving “victory over death” (Exley 2004:14). Using this framework, death can become the ultimate failure leaving the bereaved to question *why them?* (Charmaz 1980).

Three participants in this study accounted for their parent's cause of death by offering narratives that emphasized the shock of a life gone too soon. Left to grapple with a cause of death that did not align with prevailing science around health and longevity, these participants attempted to minimize the stigma associated not only with their parent's early death but with their cause of death. When I interviewed McKinsey, now 19, it was evident that she struggled to make sense of her mother's death. Only seven at the time of her mother's lung cancer diagnosis, she did not understand how her once healthy and vibrant parent was suddenly in and out of the hospital. Her mother had never smoked, and she was physically fit and active until cancer left her unable to adhere to her previously healthy lifestyle. McKinsey's eyes filled with tears as she talked about her mother's diagnosis.

*It was metastatic lung cancer. She wasn't a smoker or anything. She was super healthy, super active, but it [cancer] started in her lungs.*

Throughout the entirety of her mother's treatment, McKinsey's parents never disclosed the gravity of her illness in an effort to shield McKinsey and her siblings from the harsh reality of imminent death. Even as her mother entered hospice, the assurances that she was “*fighting and was going to get better*” continued. Prevailing promises of recovery were consistent with the belief that her once healthy mom would return home cancer-free. At the age of 44, McKinsey's mother died from an illness that did not align with the belief that a healthy lifestyle is equivalent to a long life—leaving McKinsey and her family to wonder, “*why her?*”

Ainsley’s mother died of breast cancer. Like McKinsey, she described her mother as a person who was “extremely in shape” and “very healthy.” She reminisced about her mother’s involvement in her life and the life of her younger siblings—something that was taken away too soon.

*My mom was super involved in our lives. She would go above and beyond to get involved in our school stuff. We were happy and spent lots of time together as a family. Up until she got sick, we had a very happy childhood.*

Ainsley’s mother’s cancer diagnosis was unexpected and disrupted their families’ belief that a healthy diet and exercise would be rewarded with a life that extended well into old age.

For McKinsey and Ainsley, the loss of their mothers in their mid 40’s contradicted the expectation that death occurs in old age. Although cancer is the leading cause of death in women between the ages of 45 and 64, the life expectancy of non-Hispanic white females in 2019, as reported by the Centers for Disease Control and Prevention (CDC), was 81.4 years. When death does occur, particularly when someone is socially considered to be young, their death is often viewed as tragic (Hilliker 2013; Walter 2007).

When Hannah was 15 years old, her dad died of lung cancer at the age of 60. Hannah described her life before his death as somewhat unconventional but happy. Despite her father’s stage four cancer diagnosis, the truth of his illness was kept from her and her siblings. They were told he was sick and taking some time off from work—never that he had cancer *or* was dying.

*We were operating under the assumption that he was sick, not that he was dying. They told us he would be okay. He took a turn for the worse about a week before he died, and it all happened really quick. Because we really didn’t know the severity of his illness, when he died, it was harsh.*

Hannah’s narrative focused more on her father’s sudden death than his cause of death. Hannah never expected that her father would die while she was in high school. His death

opposed her understanding that he was not only going to get better but that he would live a long life.

### *Diversion of Blame*

As previously described, cultural narratives often attribute stigmatized illnesses such as alcoholism, drug addiction, HIV/AIDS, and certain cancers to poor decision-making and flawed personal character (Volkow 2020). These beliefs place the sick and dead at fault—leaving the bereaved to navigate stigma from others. In an attempt to manage an anticipated spoiled identity, six participants diverted blame from their parents' actions to other potential causes when accounting for their parent's death.

Amy, for example, whose father died unexpectedly of a heart attack, blamed his decline in health and negligent self-care on her stepmother. As she discussed his untimely death at the age of 32, she emphasized how he had long struggled with poor health, including juvenile diabetes, which Amy felt was heightened later in life due to his tumultuous relationship with his ex-wife:

*My dad was a juvenile diabetic, which caused his heart disease. He had kidney failure, and his health conditions caused issues within his marriage. His second wife divorced and left him—taking my younger sister with her. Because my dad was depressed, he started to take even worse care of himself. He didn't monitor his diabetes. He got gangrene on one of his feet, and they amputated his leg. He had a massive heart attack when he was in the hospital recuperating. Like I said, his health got increasingly worse after his wife left.*

Similarly, Melanie, whose father died from an alcohol-related fall when she was only 13 years old, blamed his addiction and inadequate treatment on her family. In particular, she emphasized during the interview that her grandparents “could have done more” to try to save her father:



*I was young and thought his drinking was normal. Once alcohol consumption gets to that level, it's a disease—it's not a choice anymore. So, I don't necessarily blame him at all. I blame my other family members who didn't step in to help. My grandparents did not put him into any sort of treatment program. They could have done more.*

Suicide is socially recognized as an incredibly stigmatizing form of sudden death that profoundly affects bereaved family members (Abrutyn and Mueller 2018; Durkheim 2005). Often, survivors face stereotypes that negatively label and threaten the deceased's character, which can leave the living in the position of trying to save face for those who are gone. Bailey was 13 when her mother died by suicide of an intentional overdose. She described her life as “*normal, with unconditionally loving and safe parents.*” Her mother had, however, lost a son when he was only 15. Explaining her mom's death by suicide as one that resulted from a “broken heart,” Bailey rationalized her mother's death and diverted any blame from her mother for taking her own life. Several times she referenced the death of her brother and that her mother always talked about wanting to be with him. Conversations about death were prevalent in their home, and her mother never hid the fact that she wished for her own death. Since these conversations typically happened when her mother was drinking, her desire for death never felt like a dominant suicide threat. The night Bailey's mom died, she had been drinking and decided to drink her husband's methadone. Her death was ruled an overdose.

Bailey was aware of a strong cultural narrative surrounding what it means to be a “bad mother” defined her parent as selfish and *unloving* for committing suicide when her daughter was only 13. Her account, therefore, focused on redeeming her mother's identity by emphasizing her devotion:

*In the end, my mom was very loving. She was so protective, maternal, and amazing. But, I had always known that she wanted to be with my brother after he passed away.*

Bailey's story included narrative statements that both rationalized and redeemed her mother's decision to take her own life. These accounts justified a decision that would be widely considered deviant. Providing context for her mother's cause of death helped Bailey to neutralize internalized social judgments by deflecting in advance presumed judgment (Sykes and Matza 1957).

Stigmatized deaths added a layer of complexity to participants' lived experiences and sometimes forced them to hide the actual cause of death. Quinn's story was illustrative of this observation. She was a senior in high school when her dad was diagnosed with cirrhosis of the liver. Acutely aware that the origin of his cancer would be viewed as "socially undesirable," she rarely offered details of her father's cause of death:

*I thought it was stigmatizing and I didn't want people to know. My dad was an alcoholic, and because of that, he was dying. I didn't want the kind of attention that would come from people knowing it was more than 'just cancer.' I just didn't want to have to lead the conversation about my dad being dead with the fact that he was an alcoholic, and because of that, he died from cancer that could have been prevented.*

Quinn's story exemplified the social understanding of perceived stigma as her account displayed her strong understanding of how her father's terminal diagnosis would be socially recognized as one advanced by poor decision-making and flawed personal character (Stahly 1988). Quinn kept her father's diagnosis, and the eventual cause of death, secret.

Traumatic and accidental deaths, most often unexpected, leave those left behind to search for answers that may never be found (Farella Guzzo and Gobbi 2021). For example, the death of a father killed in a car accident is understood as senseless, and the impact is ergo greater (Glaser and Strauss 1964). Although Megan understood the circumstances leading up to her father's death, her narrative illuminated her struggle to accept that he could be solely responsible for the car accident that took his life. She questioned whether a different outcome might have been

possible if he had been driving his own car and diverted the blame from her father to another driver for causing his death. Years later, she was still searching for answers:

*My dad was a big football fan and was driving to see his favorite team play. I guess he missed a stop sign and got into a minor car accident with a truck. He was still alive at this point. Then someone else failed to stop. They hit his car and killed him. There were two other people in the car with my dad, but they both lived. Even though he was driving, it wasn't his car. If he had been driving his car, he probably would have survived. The vehicle he was driving was old and not safe. That is why he died.*

Bereaved children whose parents died from socially stigmatized causes are often aware of how the “outside world” views their parents. This social awareness dictates the narrative accounts given to explain a parent’s cause of death, as exemplified in the participant’s accounts above. In the end, the participants whom I interviewed were often trying to reframe their parents as a “good mother” or “good father.”

### *Finding Purpose*

For many, a person's relationship with their parent is one of the most important relationships they will ever have. When a parent dies, that death is life-changing. Although each experience of parental death in childhood and early adulthood is unique to each person, for some, turning a tragedy into a life purpose creates meaning—enabling the person to live with and survive the loss in a way that benefits others (Lawrence et al. 2006; Tyson 2011).

Positive reinterpretation and growth are ways that those who have experienced the disruption of death manage loss. Finding meaning in aspects of a negative situation can turn adverse circumstances into something regarded as favorable (Carver, Scheier, and Weintraub 1989). By reinterpreting the loss, death has been given new meaning (Tyson 2011). For example, my children found meaning in the car accident that caused their father’s death by reinterpreting his loss of life into one that *saved* others. If their father had been situated in the traffic differently,

the four teenagers in the truck behind him would have died instead. My children view their father as a hero who, in losing his own life, saved the lives of others.

Determined to turn a tragedy into more than a defining moment, four participants credited their chosen profession to their experience of parental death in childhood or early adulthood. In accounting for their parent's death, each offered narratives connecting the pain of loss associated with a parent gone too soon to their own purpose-driven life.

Vivian's mother died from organ failure at the age of 42. As we started our interview, she held up a brightly colored children's book for me to see. This book was special. A few years before her mother died, a family friend died in a car accident. Determined to comfort the six-year-old left behind, her mother wrote a book to help the little boy understand his father's death. Years after *her* mother died, Vivian published the book—launching a series of life-altering events. Vivian left her “well-paying” corporate job to start a non-profit organization for teens who have lost a parent, sibling, or close friend. During our interview together, she highlighted the lack of support she felt after her mother's death. This became the catalyst for her career change and for finding her own life's purpose. Her organization now offers support groups and access to counseling, which has allowed Vivian to give children “*what she wished she had had when her mother died*” and use what she has learned through her experience of loss to help others.

For Vivian, publishing her mother's book gave meaning to her mother's death two-fold. First, in publishing the book, her mother's love and compassion for others would be publicly known, and second, her mother's written words would help others experiencing loss and grief. Through positive reinterpretation, Vivian turned her negative experience of being a teenager who

lacked support following her mother's death into an organization that connects bereaved children to resources that otherwise would not be at their disposal.

Several participants talked about not wanting their parent's death to "define them" but instead used their experience to help others. Maggie was ten years old when her mother died of a massive heart attack. Her mother, a registered nurse, was 42 at the time of her death. She shared that for a long time she felt like her mother's death was a "death sentence for *her* life." Maggie's experience of loss became a passion for helping others. In adulthood, Maggie opened a thriving yoga studio and extended her yoga practice to include grief work. During our interview, she reflected on the local grief groups she facilitated and her plan to re-enter academia to pursue a degree in social work.

Interviewees' life paths did not all lead to engagement in a "helping field," but those who fit this category in the typology credited their experience of parental death for "making them who they are today." For example, Mia, who was five when she lost her mother, emphasized how that loss had defined her entire life. While she was only 19 at the time I interviewed her and hence had not yet identified her own career path, she underscored how her mom's death shaped what she would likely do.

*I'm still sad all the time, but I think that I wouldn't be who I am if my mom hadn't died. I have thought about going into some therapy or social work. I'm always the person that helps everyone work through stuff. What I am best at is understanding people's emotions and understanding trauma.*

For four of the interviewees in this study, the intimate understanding of parental death drove their passion to "give back" in ways that would help others in a similar situation of loss. In doing so, participants felt a sense of validation in their ability to turn their pain into a life purpose (see Talbot 2002).

## *Learning in Advance*

Culturally, children are often shielded from death. However, as noted, research has demonstrated that children who face parental bereavement need clear and easily understood information based on their developmental stage (MacPherson 2005). Equipped with an early understanding of their parent's terminal diagnosis, eight participants accounted for their parent's cause of death through narratives that demonstrated knowledge and even acceptance that death was inevitable.

When Keith was ten-years-old, his mother died of stomach cancer at the age of 39. She had been suffering from stomach pains and was diagnosed with stage four cancer following an appointment with her doctor. Keith shared how he learned about his mother's illness:

*My mom went to the hospital because she thought she had a stomach problem, and she was there for a couple of days. My dad brought my siblings and me to the hospital and took us individually into her room. They told us what was going on.*

Although Keith was young when his mother was first diagnosed, and he didn't always understand the complexities of her diagnosis and treatment, his father kept him updated.

Charlotte, Keith's sister, shared similar memories of the experience:

*My dad made sure that I was in the know about what was happening. He was transparent, knowing that her death was imminent. He explained the risks and benefits of any procedures. I don't think he sugar-coated anything. He just made sure I knew what needed to be known. I never felt like he kept me out of the loop. I learned early on that she might not live a year, and she didn't. If I had expected her to live a year or longer, that would have been even more traumatic than it was.*

Like Keith and Charlotte, other interviewees conveyed the importance of knowing the truth about their parent's illnesses. Although many expressed their parent's determination to live, they were given accurate and up-to-date information throughout the diagnosis, treatment, and death.

When Elana was a freshman in college, her mother died of breast cancer. Ten years earlier, Elana first realized that her mother might die.

*My mom was diagnosed with breast cancer when I was ten years old. It was minor at the time—I think like stage zero. She didn't go through chemo, only radiation, but it was always in the back of my mind that she might die. Almost exactly ten years later, she came to visit me in college. That evening we met at her hotel, and she told me that she needed to tell me something. I knew what it was immediately. I asked her if her cancer was back, and she said yes.*

When Elana returned home from college, she learned for certain that her mother was dying. Despite aggressive chemotherapy, her cancer had spread. Elana's story continued:

*My mom's doctors were pretty clear that she would be lucky to live a year at this point—although she was determined to live longer. She wasn't ready to go. Although we never talked directly about her death, we did plan what songs she wanted at her funeral. My mom wasn't blind to the fact that she was dying, but she also wasn't having end-of-life-type conversations. Instead, she talked about booking hotels for my college graduation. She wasn't in denial, but she just wasn't willing to give up.*

Each detailed narrative of parental death included stories of visits to the hospital and, for some, Hospice care. Grace's mother, diagnosed with stage three colon cancer, spent eight months in the hospital before moving to Hospice. Grace shared her experience:

*I remember my mom complaining a lot about stomach issues, and she went to get it checked out. My twin sister and I were sitting in our bedroom when she came home from the hospital, and she was like, 'I need to tell you something.' It was stage three when she was first diagnosed, but the doctors were hopeful. They told us that they thought they got most of the cancer. It wasn't as scary at first, but then she was in and out of the hospital all the time. We had to move her to Hospice eventually.*

Like other interviewees, Alex spent a considerable amount of time at the hospital before their father's death. Sadly, their father died only two months after being diagnosed with bile duct cancer. Although their parents were clear "and realistic" in explaining the magnitude of the terminal diagnosis, his sudden death was unexpected.

The accounts above illustrate that providing clear information about a parent's terminal diagnosis and encouraging open conversations allowed children the time and space to process a parent's death. Similar stories of knowing in advance were given throughout the participant's narratives, showcasing that in putting their discomfort in talking about death illness aside, parents' honest and accurate communication with their children allowed for a greater understanding and acceptance of a parent's death.

## **Discussion and Conclusion**

“Narrative is the best way to understand the human experience because it is the way humans understand their own lives... if we wish to understand the deepest and most universal of human experiences, if we wish our work to be faithful to the lived experiences of people, if we wish for a union between poetics and science, if we wish to reach a variety of readers, or if we wish to use our privileges and skills to empower the people we study, then we need to foreground, not suppress, the narrative within the human sciences” (Richardson, 1990:65).

This pilot research for my dissertation analyzed 21 semi-structured, in-depth interviews and developed a new typology that helps to shed light on how those who experienced the loss of a parent during childhood or early adulthood account for their parent's cause of death. In the first theme—*Losing a Loved One: Why Them?*—participant narratives indicated a disconnect between their parent's prior health history and their sudden and untimely cause of death. Participants who fit this category were shocked by the loss of their parent. They were also often denied the possibility of saying goodbye as their parent or other caregiver engaged in a form of death denialism—assuring children that their sick parent would get better. In the second theme—*Diverting Blame*—participants offered narrative accounts that focused on other persons or outside determinants that they deemed complicit in or even responsible for their parent's death. This allowed these participants to shift responsibility from their parent and to relocate that blame elsewhere (also see Richardson 1990). This narrative strategy was especially likely to be applied



when a parent's identity was in social jeopardy from a stigmatized illness or cause of death. The third theme that emerged from my data—*Finding Purpose*—emphasized narrative accounts of turning the pain of loss into a life purpose. For these participants, a deeply intimate understanding of parental death and the grief that followed became the catalyst for helping others navigate a disrupted childhood or early adulthood. The final theme—*Learning in Advance*—demonstrated the importance of honest and truthful communication. Participants who knew about their parent's terminal illness, stigmatized or not, were allowed the opportunity to ask questions, communicate freely, and even say goodbye before their parent's death. Those young people who lost a parent suddenly and unexpectedly did not have the option of learning in advance and thus did not find the same kind of closure as those who fell into this final category in the typology.

From a theoretical standpoint, narratives are central to how individuals make sense of their lived experiences. Building on prior narrative research, this study expands the scope of analysis to include narratives of bereaved adults who lost one of their parents to death during childhood or early adulthood—a population that has been greatly understudied, especially in light of the small but substantial portion of young people in the U.S. who lose their parents prematurely. Although it is not “common” to lose a parent as a child, the COVID-19 pandemic has drastically increased the number of parentally bereaved children. From April 1, 2020, through June 30, 2021, more than 140,000 children under the age of 18 in the U.S. have experienced COVID-19-associated deaths of one or both parents or the deaths of custodial and co-residing grandparents (National Institutes of Health, 2021). This is an important group to learn from because there is an expectation of a “distance phenomenon” as the time elapsed between the experience of death and one's current placement in their life course gives new

meaning to their experience (Menig-Peterson and McCabe 1978:316). Adults' understanding of death admittedly differs from children's concepts of death which is critical in understanding how meaning-making following a parent's death ebbs and flows over time but does so in the social context in which the experience is told.

Further, these findings shed light on stigmatized causes of death that dehumanize the deceased—labeling them as deviant. These evaluations, often misplaced, leave the bereaved to manage a loved one's spoiled identity (Goffman 2009). Usually, the stigma associated with deaths that do not align with socially accepted lifestyles or behaviors does not “expire” with a person's last breath. Instead, it has far-reaching implications for those left behind—which, in this study, are children and young adults (Paul 2019). Understanding the ways socially constructed beliefs about death and dying amplify existing stigma can inform processes to dismantle long-standing systems of discrimination that are detrimental to individuals and society (Wang et al. 2017).

This research also demonstrates how social and cultural death norms inform how parental death is explained and understood through a typology of narrative accounts. In particular, this work advances how retrospective experiences of childhood loss are viewed through a socially constructed lens—experiences that inform the narratives given well beyond one's childhood and early adulthood. For example, how the bereaved reconstructed their accounts of a parent's stigmatized cause of death may provide insight into how perceived stigma becomes embedded into how death is understood and even explained intergenerationally.

There are some limitations to the study, including a small sample size and a lack of gender and racial diversity as the majority of the participants were female and white. Participant recruitment proved to be challenging as this is a challenging population to access due to the

sensitive nature of the research topic. Although this research is limited by participant size, the findings from this study provide initial evidence on the importance of examining the sociological connection between a parent's cause of death and how the experience of death is narrated (Charmaz 1980).

In addition, because this research was launched as a pilot study for my dissertation, it has not yet accounted for other variables that might influence the narrative accounts, such as time elapsed since parental death, educational attainment of the bereaved, or other key demographic characteristics. It is important to note that participants' narratives were not only influenced by their values, perspectives, and attitudes but also undoubtedly by numerous other factors like race and ethnicity, age, gender, socioeconomic status, family size, and structure (Harvey and Chavis 2006). While chosen purposefully and through the use of a screener questionnaire, the sample is not large or diverse enough to draw firm conclusions from. My intent is to continue to collect data in this realm to better test the strength and veracity of the typology presented in this article. In addition, I intend to further focus my sample as I proceed, ensuring that participants are of a more similar age cohort and that they share more in common regarding the death experience in that it was expected or unexpected.

Despite the study's limitations, the narratives gathered in this preliminary study give voice to those often overlooked in sociological research on death—parentally bereaved children beyond the first several years following the death. Sociological literature has primarily focused on the well-being and health lifestyles outcomes of adults who lost a parent in childhood or early adulthood. Narrative research with this population is scarce within the U.S. Journalist Hope Edelman, for instance has been a significant contributor to the conversation of parental loss—specifically, the experience of maternal loss in childhood. In Edelman's book *Motherless*

*Daughters*, she draws on interviews with over 92 women who experienced the death of their mother before the age of 18, capturing her participants' perceived experiences of parental death in childhood through narrative accounts (Edelman 1994). Her critical work highlights the need for continued and more expansive rigorous social science research with those who were parentally bereaved in childhood or early adulthood.

The shared experience of parental loss, expressed through narratives, points to the challenges of child bereavement as embodied social and cultural narratives of health, illness, and longevity become embedded into the narratives of adults whose parents died when they were children. This is not to say that all socially constructed health, illness, and longevity norms are damaging. Instead, this research sought to understand the process of how socially constructed beliefs are transmitted through narrative accounts of parental death experienced in childhood and early adulthood. This research provides a next step in understanding the role of parental death narratives through a typology of accounts that allowed participants to verbally express their parent's cause of death and, for some, how that death had influenced and shaped their lives. By integrating narratives into social expectations of death, a strong understanding of how meaning is constructed is formed. Additionally, this research also supports previous findings of the importance of communicating with children about death (Eklund et al. 2021; Hilliker 2013; Schonfeld 1993).

The field of sociology has been remiss in studying this vital population as psychology has had the prevailing voice in clinical participant research on the experiences of death and grief. This study, still in its infancy, can serve as a foundation for future research with adults who experienced the death of a parent during their childhood or early adulthood. Additional research should expand the sociological understanding as to why narratives of parental death, told

retrospectively, continue to normalize and maintain death norms and expectations. Further research should attempt to identify how a child's account of parental death (collected shortly after the death when ethically feasible) aligns with or challenges their primary caregiver's account of the death. Additionally, narratives should be collected longitudinally to classify how accounts of parental death change over time and if narrative accounts are intergenerationally transmitted.

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## APPENDIX A

### Interviewee Pre-Screen Questionnaire

1. During your childhood, did you experience the death of a parent?

- Yes
- No

2. Please briefly describe your parent's cause of death.

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3. Are you currently between the ages of 18 and 35?

- Yes
- No

4. What is your current age? \_\_\_\_\_

5. What grade were you in when your parent died?

- Kindergarten
- 1st - 3rd grade
- 4th - 6th grade
- 7th - 12th grade
- Other: \_\_\_\_\_

6. If you are eligible for this research study, are you interested in participating in a one-hour Zoom interview with the researcher?

- Yes
- No

7. If you answered YES to the question above, what is your name?

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8. What is your email address?

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## APPENDIX B

### Interviewee Demographic Information Survey

First name \_\_\_\_\_ Current age \_\_\_\_\_

#### Gender

- Male
- Female
- Some other gender identity (specify) \_\_\_\_\_
- I prefer not to say

#### Race/Ethnicity

- White
- Hispanic or Latino
- Black or African American
- Native American or American Indian
- Asian / Asian American / Pacific Islander
- Other
- Some other racial or ethnic identity (specify) \_\_\_\_\_
- I prefer not to say

How old were you at the time of your parent's death? \_\_\_\_\_

What grade were you in when your parent died?

- Pre-Kindergarten
- 1st grade
- 2nd grade
- 3rd grade
- 4th grade
- 5th grade
- 6th grade
- 7th grade
- 8th grade
- 9th grade
- 10th grade
- 11th grade
- 12th grade
- Freshman in college

- Sophomore in college
- Junior in college
- Senior in college
- Other \_\_\_\_\_

Was it your mother or father who died? \_\_\_\_\_

Briefly, will you please describe the cause of death?

\_\_\_\_\_

Where were you living at the time of your parent's death? (city, state)

\_\_\_\_\_

What is your religious affiliation?

- Catholic
- Protestant
- Mormon
- Unitarian Universalist
- Muslim
- Jewish
- Atheist
- Agnostic
- Other (Specify) \_\_\_\_\_
- I prefer not to say

How religious/spiritual are you?

- Very religious/spiritual
- Religious (neutral)
- Somewhat religious/spiritual
- Not at all religious/spiritual
- I prefer not to say

Education: What is the highest degree or level of school you have completed?

- Some high school, no diploma
- High school diploma or the equivalent (for example, GED)
- Trade school
- Some college (including Associates degree)
- Bachelor's degree
- Master's degree

Doctoral level degree

What is your current occupation? \_\_\_\_\_

Marital Status: What is your current marital status?

- Single, never married
- Married or domestic partnership
- Widowed
- Divorced
- Separated
- I prefer not to say

***These final questions are focused on your parent, who died when you were a child. Please answer these questions to the best of your ability.***

Parent's first name \_\_\_\_\_

Your parent's age at the time of death \_\_\_\_\_

Parent's gender

- Male
- Female
- Some other gender identity (specify) \_\_\_\_\_
- I prefer not to say

Race/Ethnicity

- White
- Hispanic or Latino
- Black or African American
- Native American or American Indian
- Asian / Asian American / Pacific Islander
- Other
- Some other racial or ethnic identity (specify) \_\_\_\_\_
- I prefer not to say

Your parent's religious affiliation?

Catholic

- Protestant
- Mormon
- Unitarian Universalist

- Muslim
- Jewish
- Atheist
- Agnostic
- Other (Specify) \_\_\_\_\_
- I prefer not to say

How religious/spiritual was your parent?

- Very religious/spiritual
- Religious (neutral)
- Somewhat religious/spiritual
- Not at all religious/spiritual
- I prefer not to say

Education: What is the highest level of degree or level of school your parent completed?

- Some high school, no diploma
- High school diploma or the equivalent (for example, GED)
- Trade school
- Some college (including Associates degree)
- Bachelor's degree
- Master's degree
- Doctoral level degree

What was your parent's occupation at the time of their death? \_\_\_\_\_

At the time of your parent's death did you rent or own your home?

- Own
- Rent
- Unsure

Marital Status: What was your parent's marital status at the time of their death?

- Single, never married
- Married or domestic partnership
- Widowed
- Divorced
- Separated
- I prefer not to say
- Unsure / Don't know

## APPENDIX C

### Interview Guide

Will you tell me about your life prior to your parent's death?

- Where did you live?
- Who did you live with?
- How many family members?
- How would you describe your relationship with your deceased parent?

Can you tell me the story of your [mother's/father's] death?

- How did you learn about their death? How were you told about your parent's death? Who told you?
- Was the death explained to you in a way that you understood?
- Did you attend the funeral? What do you remember from that day?

What was it like in your household after your parent passed away?

- Did you feel like you could talk about your [mother/father] openly in your household?
- How did your relationship change with your other family members?
- Did your family experience any financial difficulties as a result of your parent's death? In retrospect, how did that impact not only your family but you?

Will you tell me about the support you received following your parent's death?

- Did you receive counseling following your parent's death? If yes, what type of counseling (private, school, etc.) and for how long? If not, can you talk more about the decision to not receive counseling?
- Did you receive social support from individuals outside of your family? For example, support from religious affiliation, community support, etc.?
- Did your family receive monetary support? (i.e., GoFundMe, community fundraisers, etc.?)



- What “messages” did you receive from the adults around you about grief?

Can you tell me how the death of your [mother/father] impacted your life?

- Were there any other stressors in your life at the time of your parent’s death?
- In retrospect, were there any unexpected bright spots that emerged in the aftermath of the death - here I mean, new lessons you learned, the growth you might have experienced, and so forth?

Can you tell me about your school experience after your [mother/father] died?

- Was your school a safe place to grieve?
- How did your peers interact with you following the death?
- How did your teachers interact with you following the death?
- In what ways did your [mother’s/father] death impact your education?

What was the one thing you needed following the death of your parent?

Do you know anyone else that might be interested in participating in this research?

Would you be willing for me to follow up with you in the future?

## APPENDIX D

### Recruitment Materials

My name is Theresa Edwards-Capen, and I am a doctoral student at the University of Colorado Boulder. My research aims to understand childhood grief and trauma. **If you are between the ages of 18 and 35 and experienced the death of a parent during childhood, I invite you to be a part of this important research.**

My research asks individuals to share their stories with me. I want to recognize this and share a part of my own story that helps explain my passion and drive behind this research.

On October 23, 2008, I faced the unthinkable. My children's father was killed in a car accident. With as much composure as I could muster, I sat down with my seven and 10-year-old sons, both already suspicious that something was wrong. Although I had a robust support system, no one I knew had experienced a similar type of loss. Those first few months following the accident were challenging as we grieved collectively and individually. My children's experience became the catalyst for my research—research that seeks to understand grief, trauma, and how we can best support young people who, like you, have experienced a tremendous loss.

#### **YOUR STORY MATTERS.**

Collective stories give voice to shared experiences, influence policies, and can become the catalyst for change. Your story can make a difference. **If you are between the ages of 18 and 35 and experienced the death of a parent during childhood, please complete the following survey.** If you are eligible for this research study, you will receive a follow-up email to schedule your Zoom interview. If you are not eligible to participate in this study but know someone who might be interested, please feel free to share this information.

I appreciate your interest in being a research participant. If you have any questions you would like addressed before or after completing this questionnaire; please contact me at [theresa.edwards.capen@colorado.edu](mailto:theresa.edwards.capen@colorado.edu).