

Exploring the Experiences of Bereaved Parents Who Have Created Digital Memorials

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Dedication

This dissertation is dedicated to Dr. Gloria Williams. Your insight changed how I think. Your support has been a lasting inspiration. Thank you.

Abstract

The project described in this document seeks to understand the experiences of bereaved parents ($N=8$) who have used digital media to memorialize their deceased children. The project considers how these bereaved parents have used digital media to create memorials, what their experiences have been, as well as why they have done so. The document includes a literature review to establish a foundation for understanding contemporary ideas and practices related to digital memorialization. This review addresses key ideas related to bereavement studies, provides an understanding of interaction design as a disciplinary context, and considers the ways bereavement-related ideas are being incorporated into research within this discipline. The document also contains a discussion of the phenomenological methodology used in the project. This discussion describes the historical development, philosophical basis, and practical methods of the methodology. The document proceeds with an explanation of the study's findings. These findings are presented as the master themes that were identified through our analysis of the participants' interviews. These themes address the technology and media types participants have used to memorialize their children, the ordinary and extraordinary experiences they have endured in the process, and their rationales related to meaning-making and healing for doing so. The document then discusses these themes in light of relevant literature. This discussion includes the research areas of grieving patterns, continuing bonds, meaning-reconstruction, thanatosensitive design, and memorialization. The discussion of each research area includes brief speculations on the implications of the study for future related research. The document concludes with an explanation of the limitations of the study and a reflection on my experience conducting it.

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Chapter 1: Introduction

Profound learning can arise from profound tragedy.

—Robert Neimeyer (Tedeschi & Calhoun, 2004, p. ix)

For most, the human experience is replete with a multitude of relationships and situated within a persistent stream of life events. Central to humanity's experience of these relationships and events is the concept of change. Neither relationships nor any of the events one may witness can remain unchanged over time. Relationships evolve; events come and go. For many, this aspect of the human experience results in a sense of loss.

The word most used to describe this sense of loss is *grief*. When interpreted broadly, grief can be understood as the complex physical, emotional, and cognitive phenomena associated with loss. Grief can result from “the loss of a loved one, the loss of one's ability to do something, and/or the loss of time” (Fraher, 2010, p. 8). As explained by the American Psychological Association (n.d.), “Grief is the anguish experienced after significant loss, usually the death of a beloved person” (para. 1).

The experience of grieving a loved one is commonly referred to as *bereavement*. As life can involve a diverse array of relationships, one's bereavement experiences can also range widely. Some people's most significant experience with bereavement is the death of a parent or a spouse. The project described in this document focuses on the bereavement experiences of parents who have lost a child.

Parental bereavement has been described as “a devastating loss” (Tedeschi & Calhoun, 2004, p. 7) and “is widely recognized as one of the most intense and persistent types of bereavement” (Jaaniste et al., 2017, p. 1). This intensity and persistence may be related to the

confusion that can arise after the death of a child. In addition to the emotional pain and logistical challenges following most deaths, parental bereavement is often complicated by a sense of disorientation. This disorientation has been attributed to how grieving a child runs contrary to the “natural order of things” (Tedeschi & Calhoun, 2004, p. 5). Most commonly, children grieve their parents, rather than vice versa. Another source of the confusion that can complicate parental bereavement is the paradoxical sense of identity that can arise, that of having become a parent but not having a child.

Thus, as parental bereavement presents unique challenges to those experiencing it, so too does it involve unique challenges for those interested in better understanding these experiences through research (Stroebe et al., 2003; Akard et al., 2014). Central to these challenges are questions related to conducting ethical research (Hynson et al., 2006). While not considered to be a vulnerable research population (Gordon, 2020), the intensity of the experience of losing a child—along with the resulting stress—can leave parents in acutely sensitive states that may render them more susceptible to additional stressors. Therefore, the idea of risk minimization represents a key consideration for researchers intending to work with bereaved parents (Akard et al., 2014; Donovan et al., 2019). Further complicating research with this population are “low participation rates and small sample sizes” (Akard et al., 2014). Additionally, the highly individualized nature of grief responses amongst bereaved parents (Tedeschi & Calhoun, 2004) can present challenges to the transferability of a study’s findings.

Given the delicate state of bereaved parents and the challenges described above, one might ask why a researcher would endeavor to investigate issues concerning this population. While I cannot answer for others involved in research with bereaved parents, my motivation for

doing so is derived from my experience of losing my daughter, Julia Erin, and the resulting desire to help others in similar circumstances.

Julia was diagnosed at age two and a half with stage-four neuroblastoma on July 14, 2005. In the months that followed, Julia endured an aggressive treatment protocol. While Julia was declared cancer-free (no evidence of disease) in the spring of 2006, the aggressiveness of the treatment took a toll on her body from which she was not able to recover. Julia died on May 24, 2006.

Shortly following this experience, I enrolled in graduate school at the University of Minnesota to pursue a Master of Fine Arts (MFA) in Graphic Design with an emphasis in interactivity. I had been working as an interaction designer prior but decided to pursue an MFA in order to shift my career to higher education following Julia's death. This shift promised the opportunity to develop a research agenda with which I hoped to make a difference.

After completing the compulsory coursework for this degree, I directed the focus of my thesis project to entail the construction of a Web-based resource for “people whose lives have been affected by cancer” (Fraher, 2010, p. 1). This resource, HopeStrength.org, allowed people to combine images, text, and audio into an interactive gallery format and share these galleries with others. The intended purpose of these galleries was to provide a mechanism for individual expression and community involvement that would aid in processing traumatic experiences. This project represents the beginning of my efforts to use interactive design and digital media to support people in the process of grieving.

The project resulted in “a cross-disciplinary pilot study investigating the development of an interactive digital media-based therapeutic modality—or treatment protocol—to help people affected by trauma” (Fraher et al., 2013, p. 7). Following this, my wife, Laurel Dale, and I

collaborated on a self-published picture book, *See Me in the Wonder*, to provide a “sense of understanding and peace to the grieving process” (Fraher & Fraher, 2017, Inspiration section, para. 2). This led to the development of an Android and iOS app, *Seeing the Wonder*, that couples a digital version of the book with a picture journal that allows users “to gather photos, thoughts, memories” (Fraher & Fraher, 2020, About section, para. 6). The design and development of the picture journal involved integrating several theories and strategies for addressing grief and exists as “a practical example of interdisciplinary grief-related research” (Fraher, 2022, para. 1).

My previous work in this area—at the confluence of grief and technology design—has brought to my attention a deficiency in related research. Much of my previous inquiry at this junction can be described as *thanatechnology*. Thanatechnology is a term coined by Carla Sofka (1997) originally to describe emerging digital information technologies for “learning about thanatology topics” (p. 553). Thanatology can be understood as the holistic study of death and dying. As Massimi and Baecker (2010) explain, “very little is known about how technology intersects with the lives of the bereaved” (p. 1821). Massimi and Baecker (2011) further assert that “design considerations and guidelines for technologists working in this sensitive area are not well-established” (p. 1001).

The state of thanatechnological research may be due in part to Western cultures’ tendencies to avoid the discussion of death-related ideas. As Glaser and Strauss (1966) observed, “Americans generally seem to prefer to talk about particular deaths rather than about death in the abstract” (p. 3). This aversion may be due to the philosophical dilemma of being human. According to Becker (1973),

Man is literally split in two: he has an awareness of his own splendid uniqueness in that he sticks out of nature with a towering majesty, and yet he goes back into the ground a few feet in order to blindly and dumbly rot and disappear forever. It is a terrifying dilemma to be in and to have to live with (p. 22).

Becker's observation of humanity's dilemma presents a stark reality. Awareness of this reality has caused me to question how I will spend my time and energies as a towering majesty. My answer aligns with Massimi and Charise's (2009) work on establishing *thanatosensitive design* (TSD). Massimi (2010) describes this approach as "the multidisciplinary study, design, and evaluation of computing technologies which actively engage with issues of human mortality, dying, and death" (p. 2952). Central to Massimi and Charise's (2009) goals with TSD are, first, to persuade those working in human-computer interaction to see the importance of considering mortality, dying, and death in technology design, and second, to call for additional work in these areas.

In response to Massimi and Charise's call, the study described below seeks to further TSD, as well as other work related to understanding digital grieving practices (Beaunoyer et al., 2020; Kakar & Oberoi, 2016; Moncur & Kirk, 2014; Lingel, 2013; Walter et al., 2012; Odom et al., 2010). This study endeavors to discover and explore the user experiences of bereaved parents who have created digital media memorials for their deceased children. Digital media can be defined as digital images, video, audio, and/or text.

My decision to focus on digital media memorials is twofold. First, my background—and subspecialty within the field of thanatechnology—is at the intersection of grief and communication technology. Second, while thanatechnological research is progressing, as

Moncur and Kirk (2014) explain, “the design space for digital memorials has [...] been little explored” (p. 965). Beaunoyer et al. (2020) echo this idea in pointing out that “virtual memorials and forums represented a rather small proportion of the digital grief support landscape compared to practical and informational support” (p. 2522). Beaunoyer et al. exemplify “practical and informational support” as online grief support that offers advice on administrative tasks, funeral planning, etc.

Thus, the research questions of this study are:

1. How are bereaved parents using digital media to create memorials for their deceased children?
2. What are the experiences of bereaved parents when using digital media to create memorials for their deceased children?
3. Why are bereaved parents using digital media to create memorials for their deceased children?

The methods involved in this inquiry include the Grief Pattern Inventory (Appendix A)—a 14-question survey designed to identify patterns within people’s grieving experiences, in-person semi-structured interviews (Appendix B), and phenomenological data analysis and reflection.

The main goal of these methods is to produce the information required to answer the study’s research questions. A secondary goal of these methods is to identify a collection of emotionally powerful statements from bereaved parents regarding their experiences using digital media to create memorials for their deceased children. The purposes for collecting these statements are, first, to inspire a sense of empathy between the designers of digital media

technologies and this user group, and second, thereby grant designers in this field a deeper understanding of the importance of their work. A tertiary goal of these methods is to capture insights that represent opportunities for improving the technologies employed by bereaved parents to create memorials for their deceased children. Each of these outcomes is discussed below and represents an expansion of TSD practices as well as the related disciplinary dialogue.

The remainder of this document begins with a review of relevant academic literature to contextualize digital memorialization within existing research. This is followed by an explanation of the study's methods and methodology. This is followed by an analysis of the study's interview results. Finally, the document closes with a discussion of the key findings of this analysis and their implications for future research.

Chapter 2: Review of Literature

As previously described, the epistemological scope of thanatosensitive design (TSD) transcends any single discipline. In an article examining the Internet's influence on mourning practices, Walter et al. (2012) describe the breadth of perspectives considered by their research team, from “many disciplines and interdisciplinary fields, including death studies, journalism, media studies, cultural studies, memory studies, computer-mediated communication, human-computer interaction, sociology, psychology, medicine” (p. 276). In a general sense, the literature reviewed for this project addresses concepts and findings from many of these fields, but with special interest in bereavement studies and interaction design. More specifically, this review seeks to establish a foundation for understanding contemporary ideas and practices related to digital memorialization.

This review of literature is divided into two sections. The first focuses on ideas related to bereavement studies. The second focuses on understanding interaction design as a disciplinary context and considering the ways bereavement-related ideas are being incorporated into research projects within this discipline.

The first section of the review begins with an examination of concepts of death in Western societies. This is followed by a discussion of several sociological ideas related to death that are significant to this project. The review then pivots to address influential psychological perspectives on grief and bereavement. Following this, the review considers the role of material objects in the contexts of bereavement and memory. This section of the literature review closes with a brief chronology outlining use of media elements in memorialization practices.

The second section of the review begins with a discussion of the emergence of human-computer interaction as a field of study. This is followed by an explanation of interaction design

as a specialty area. This explanation leads to a discussion of the importance of empathy in design practice (and elsewhere). This is followed by an overview of significant TSD-related interaction design research projects—with a special interest in digital memorialization. This section of the literature review closes with an analysis of select TSD-related digital memorial designs.

2.1.1: Concepts of death

The bedrock of this literature review is the concept of death. Merriam-Webster (n.d.) defines death as “a permanent cessation of all vital functions” (para. 1). Death is an unavoidable aspect of living, literally in terms of the outcome of one’s own life, and practically as a member of any community. Simply put, we all die, and before we do, we will likely witness the death of others.

Humanity’s ideas on death range widely. According to Hallam and Hockey (2001), “death is conceptualized as either a continuity, rebirth, or as the absolute end of life” (p. 131). One’s perspective on death is often influenced by one’s cultural and/or religious affiliations.

Western societies have a reputation for death avoidance (Howarth, 2007). It is a topic considered by many to “retain a sense of taboo” (Massimi & Baecker, 2011, p. 1001; Walter, 2015; Feifel, 1963). As Glaser and Strauss (1966) explain, Western cultures “engage in very little abstract or philosophical discussion of death [and] are characteristically unwilling to talk openly about the process of dying” (p. 3). Becker (1973) argues that this reluctance stems from a fundamental human fear of death that “is natural and is present in everyone, that it is the basic fear that influences all others, a fear from which no one is immune, no matter how disguised it may be” (p. 15).

While Western societies may have a reputation for being reluctant to consider and discuss death, Howarth (2000) asserts that Western attitudes toward death are changing. She argues that

Western societies are opening to concepts and practices that are dissolving the historical divide between life and death. For example, many bereaved individuals are finding solace in conceptualizing a loved one’s death as a change in the relationship, rather than the end of it (discussed in greater detail in §2.1.3). Howarth (2000) explains that this is not an entirely new perspective on death, but the concepts have “been marginalised by the discourses and practices of modernity” (p. 127).

Walter (1996) presents a framework for understanding modernism’s waxing and then waning influence on Western societies’ evolving relationships with death (Table 1). The framework is comprised of three kinds of death: traditional, modern, and post-modern. Each is briefly explained below.

Table 1

Walter’s (1996) types of death

	Traditional death	Modern death	Post-modern death
Authority	Tradition	Professional expertise	Personal choice
Authority figure	Priest	Doctor	The self
Dominant discourse	Theology	Medicine	Psychology
Coping through	Prayer	Silence	Expressing feelings
The Traveller	Soul	Body	Personality

Bodily context	Living with death	Death-controlled	Living with dying
Social context	Community	Hospital	Family

Walter’s framework explains societies with a traditional approach to death as usually religious, having high infant mortality rates, and having a community orientation that is focused on honoring ancestors rather than the young. Massimi (2012) describes these traditional societies as “small, pre-industrial agrarian” (p. 9). Here, the threat of death is ever-present, and when it comes, it can come very quickly.

The framework characterizes societies with a modern approach to death as those that have pivoted from tradition and now embrace industrialized efficiency. Medical expertise is what is valued, as is the dominant sense of what is “good.” Walter (1996) explains that in modern societies, “Not only has dying been medicalised, but so too have disposal and grief” (p. 196).

The framework describes societies with a post-modern approach to death as highly individualized. These societies are supportive of people combining traditional, modern, or other ideas to suit their personal preferences. For example, Lofland’s (1978) *The Craft of Dying* explores late 20th century efforts to make death a personal experience.

In most Western societies, the transition from a traditional way of life to a modern approach began toward the end of the 19th century and beginning of the 20th century (Britannica, n.d.). The emergence of postmodern approaches to life began in the 1960s and 1970s (Stanford Encyclopedia of Philosophy, 2015). This chronology is evident in the historical developments discussed below.

2.1.2: Sociological ideas on death

Sociology can be defined as the “scientific study of society, including patterns of social relationships, social interaction, and culture” (American Sociological Association, 2008, para. 2).

The beginnings of sociology can be traced to Auguste Comte in the 1830s and early 1840s.

Comte was a French philosopher and mathematician whose ideas fueled Western societies’

transitions from traditional ways of life to a modern approach. Comte proposed a new

interdisciplinary science that drew upon all existing knowledge areas related to human activity.

This new field came to be known as positivism and is seen as the foundation for sociology

(Stanford Encyclopedia of Philosophy, 2022).

Central in sociology’s consideration of death is Émile Durkheim’s study of the social organization of traditional societies (Bell, 1997). Key for Durkheim (1915), a modern sociologist, was the dimension of religious life in these societies. Durkheim believed that religion can be instrumental in societal development due to allowing not just a shared identity, but also a working belief and symbol system.

Walter (2015) argues that Durkheim “provides a basis for a sociology of death” (p. 32) because “[...] many of the rites discussed by Durkheim were funeral rites” (p. 32). Durkheim observed how individuals’ deaths were processed by their community. He describes how a community member’s death can build solidarity and influence social order, “When someone dies, the group to which he belongs feels itself lessened and, to react against this loss, it assembles [...] Collective sentiments are renewed which then lead men to seek one another and to assemble together” (1915, p. 339, as cited by Walter, 2015, p. 32).

Walter (2015) points to the response of the American people to 9/11 as an example of Durkheim’s theory. Crosses and flags abounded, unmistakable evidence of a united America.

But here, the divide between religious identity and national identity was indistinguishable for many, as their belief and symbol systems were largely redundant.

Max Weber (1930) also considered the relationship between a particular group's religious beliefs and the societal implications of those beliefs. Weber, who initially trained in law before becoming active with sociology, was interested in the Protestant ethic of *predeterminism*. This ethic can be explained as the belief that who goes to heaven and who goes to hell is already decided by God, and no earthly deed (good or bad) will change this.

Weber argued that predeterminism “crucially contributed to the origin and development of modern capitalism as an economic spirit and system” (Zafirovski, 2018, p. 565). In light of predeterminism, one might ask, “Of what use are empathy and restraint when the end has already been written?” One might conclude, “Very little. Let the accumulation begin.” Thus, members of this group were enabled to conduct their personal and professional matters as they pleased, guilt-free. The legacy of this death-related religious doctrine is vividly evident in contemporary economic systems.

Each of the above examples examines the intersection of traditional religious beliefs and death. One addresses how death can influence the group dynamics of solidarity and social order. The other is concerned with a faith group's reactions to mortality and the resulting sense of social responsibility, or lack thereof. As Walter (2015) explains, “For both Durkheim and Weber, death may be the end of an individual, but its associated rites and beliefs can be at the heart of the formation or development of society” (p. 33).

Below, I consider two prominent sociological studies. Each of these studies focuses on the junction of institutionalized medical practices and the human needs and experiences of the dying and bereaved. Occurring historically at the dawn of postmodernism, both projects can be

seen as challenges to conventional power structures, as they each sought to democratize access to knowledge.

During a period when institutionalized death was becoming increasingly common, Glaser and Strauss (1966) investigated “the process of hospitalized dying” (p. ix). They were primarily interested in the social dynamics related to the “problem of awareness of dying” (p. 1). Their study included the medical practices of six hospitals in the San Francisco Bay area.

At the time, a patient’s terminal diagnosis was not universally shared with the patient and/or family members. This practice was due to the common conception that “the social and psychological problems involved with terminality are perhaps most acute when the dying person knows that he is dying” (Glaser & Strauss, 1966, p. 5). They discuss the technical and moral challenges of sharing terminal diagnoses between a broad range of stakeholders: physicians, support staff, patients, and families.

Glaser and Strauss (1966) also propose a spectrum for describing four types of patient awareness of their terminality. The first is *closed awareness*. The type describes situations in which the hospital personnel have the information, but the patient does not. The second is *suspicious awareness*. This type describes situations in which the patient does not know of their terminality, but suspects. The third is *mutual pretense*. This type describes situations in which both the hospital personnel and the patient are aware of the terminal diagnosis but pretend not to be aware. The fourth is *open awareness*. This type describes situations in which all parties are aware of the patient’s terminality and openly acknowledge it.

The results of the study argued for more transparent communication between all stakeholders. This work is seen as leading to more personalized approaches to hospitalized dying

on the part of medical personnel and institutions (Walter, 2015). Yet, this subject area remains complex terrain for hospital professionals to navigate.

Sudnow (1967) also studied hospital practices, but with an emphasis on identifying and understanding the influences of these practices on the process of dying. He contrasts the workings of two hospitals, one a low-income charity institution, the other a high-income private facility. Sudnow compares the perfunctory treatment of the poor and the venerated treatment of the rich. Key amongst the study's findings are observations related to the social role of the dying. Sudnow describes how the dignity of the dying can be usurped by hospital routine. Sudnow uses his observations to introduce the concept of *social death*, which is "marked by that point at which socially relevant attributes of [a person] begin permanently to cease to be operative conditions for treating him, and when he is, essentially regarded as already dead" (p. 66), discussed in greater detail below.

This work also considers the social interactions of the bereaved as they return home and share the news of the death with relevant social circles. Sudnow (1967) describes how the deceased' immediate family members occupy the center of these circles, with more distant family, and friends, etc. expanding outwardly. He also examines the accepted forms and timing of communicating the news of the death to the various levels. This examination included observations that those more distant from the deceased must also consider the timing of their condolences, so as not to be perceived as intruding.

Like Glaser and Strauss, Sudnow (1967) can be credited with increasing the visibility of death-related medical practices and legitimizing them as an important topic of professional consideration. But Sudnow goes further in considering how death is processed in the social structures of family and community. Emerging from this consideration are the ideas of solidarity

and social order, the same as those discussed previously in relation to Durkheim's study of the social organization of traditional societies (Bell, 1997).

The ideas of solidarity and social order represent long-considered topics of sociology. While not comprehensive means for encapsulating sociology's scope of interest, they are examples of two fundamental sociological concepts, social dynamics and social structure (American Sociological Association, n.d.). Below, I introduce two postmodern sociological topics and briefly examine them in terms of social dynamics and social structure.

The first of these topics is *social death*, as distinct from physical death. Depending on the circumstances surrounding a person's physical death, it may be preceded by, or may eventually be followed by their social death (Mulkey & Ernst, 1991). Walter et al. (2012) explain, "Social death refers to the withering and eventual extinction of social identity and social interaction" (p. 291).

In a situation where one has been compromised by longstanding illness, physical immobility, and/or cognitive decline, one's experience of social agency would also likely be affected. In such cases, a person may willfully withdraw from social structures or be left unable to participate well before physical death transpires. In other situations, where a person is socially active and death occurs, their social identity may persist for some time amongst friends, family, and other social structures. Walter (2015) explains, "Princess Diana, socially present in life largely through the mass media, was equally present in the media for another year after her untimely death" (p. 35).

Thus, the characteristics of one's social identity after physical death can be significantly influenced by the social structures one was party to while living (Özdemir et al., 2021; Lingel, 2013; Walter et al., 2012). For example, beyond one's family and friends, one might also be

remembered by coworkers or teammates, etc. The nature of these remembrances, how they are acknowledged, and how are they shared begets the discussion of social dynamics.

It is likely that people who share the same social structure(s) will possess related remembrances of a deceased individual, but it is not possible that any two are exactly the same. Similarly, people who do not share the same social structure(s) will likely have remembrances of an individual that diverge. Thus, the extent to which people's remembrances of the deceased concur, there is potential for solidarity and other social dynamics that have the potential to support grieving practices. To the contrary, when people's remembrances do not align, there is potential for conflict and other social dynamics that are less supportive of grieving practices. This may in turn lead to the simultaneous maintaining of distinctly different social identities by separate social structures, each of which may eventually experience its own social death.

Clearly, the circumstances leading to or staving off one's social death can be complex. Moreover, these complexities have been significantly elevated with the introduction of contemporary social media (Arnold et al., 2018; Özdemir et al., 2021; Lingel, 2013; Walter et al., 2012). Walter et al. (2012) assert, "now diverse grief reactions can be displayed online to a much wider social network of friends and acquaintances, so one would predict an increase in felt disturbance at how others deal with grief" (p. 291).

The second of the emergent sociological topics I introduce here is *death and digital media*. I believe it is difficult to overestimate the prominence of media material in Western societies. History's trove of traditional mass media—newspaper, radio, film, books—have long captivated the minds of Westerners. The introduction of digital media—practically infinite numbers of still images, videos, and audio recordings—enriched this captivation immensely.

And then came the Internet. And mobile devices. One might argue that our captivation is becoming our captivity.

The significance of digital media in the daily life of Western societies has long been acknowledged and discussed. This has included consideration of both the media content we consume, as well as the underlying sense of meaning we assimilate from this content. For example, Mitchell (1994) famously questioned the notion of visual truth in a post-analogue photography era. He passionately argues this point in a single sentence,

Protagonists of the institutions of journalism, with their interest in being trusted, of the legal system, with their need for provably reliable evidence, and of science, with their foundational faith in the recording instrument, may well fight hard to maintain the hegemony of the standard photographic image—but others will see the emergence of digital imaging as a welcome opportunity to expose the aporias in photography's construction of the visual world, to deconstruct the very ideas of photographic objectivity and closure, and to resist what has become an increasingly sclerotic pictorial tradition (p. 8).

Similarly, Johnson (1997) maintained that human-computer interface design represented an intensely important cultural development and should be acknowledged and practiced as such. He explains,

Where the Victorian novel shaped our understanding of the new towns wrapped around the steel mill and the cotton gin, and fifties television served as an imaginative guide to

the new suburban enclaves created by the automobile, the interface makes the teeming, invisible world of zeros and ones sensible to us. There are few creative acts in modern life more significant than this one, and few with such broad social consequences.

As influential as digital media has been in how Westerners interpret life, it has also come to influence how we interpret death. Walter (2015) and Staudt (2008) cite the prominence of death in news media as a key challenge to the Western denial of death. Staudt identifies it as central to Western societies' shift from death "concealment to recognition" (p. 3).

No longer is death sequestered out of view but is presented in "a drastic and naked exposure" (Walter, 2015, p. 36). Staudt (2008) elaborates, "The news media, with a long history of unrelenting fascination with murder and violence but also an acknowledged role in reporting on war, disaster, and current affairs, are offering death imagery in vivid techno-color in real time, around the clock" (p. 15). These media may represent not just the deceased, but also the dying and the bereaved.

At this scale, the social structures involved are—on one hand—massive. This includes both the multinational corporate news agencies as well as the political fiefdoms upon which they report. On the other hand, relevant social structures also include the intensely personal. These are the communities, the families, and the individual relationships of those involved.

Similarly, the social dynamics involved can be equally divergent. In the case of a single report of a single battle within a single war, the power of digital media can be understood by the spectrum of human interactions it may inspire. This includes the exuberance of winning, the hate of losing, and the despair of bereavement.

The role of digital media in Western societies' relationships with death is not confined to the objectives of news outlets. As Arnold et al. (2018) observe, "People are now discovering that these media also affect [...] in particular, how we are commemorated and remembered" (p. 1). As described in this study's research questions, the use of digital media in commemorating the dead is the central focus of the project. From a sociological perspective, the foundational social structure considered by the study is the nuclear family. Stemming from this structure, the study also sought insights related to the social dynamics that surround each participant's digital memorial—for example, to what extent parents share these memorials, and thus, they become social artifacts.

2.1.3: Psychological perspectives of grief and bereavement

Psychology can be defined as "the scientific study of the mind and behavior" (The Ohio State University, n.d., para. 1). The origins of psychology can be traced to the experimental methods and focus of Wilhelm Wundt in the 1870s and early 1880s. Working during the emergence of modernism, Wundt drew on his background as a physiologist to identify and examine the fundamental workings of consciousness. This early experimental psychology gave way to a wide array of other psychological methods and foci (Leahey, 1987), the most significant to this discussion are those associated with grief and bereavement.

The work of Sigmund Freud stands as not only one of the first but also one of the most enduring contributions to bereavement studies. Wundt and Freud, although practitioners of divergent methods of psychology, concurred that "psychology should not aim at the prediction and control of mental phenomena, but at the rigorous explanation of mental events" (Leahey, 1987, p. 26). Freud, who originally studied medicine, is recognized as the founder of

psychoanalysis, a theoretically-based therapeutic technique (Neimeyer, 2015; Stillion, 2015; Worden, 2015; Leahey, 1987).

Freud's psychoanalytic method involved a model of the psyche that he described as a topography of the mind. This topography consisted of the conscious, preconscious, and unconscious. According to this model, conscious information is that of which we are aware; preconscious information is that of which we are unaware but could become aware in reaction to certain stimuli. However, unconscious information remains "beyond the ability of the person to realize without expert probing or hypnosis" (Stillion, 2015, p. 18).

Central to Freud's clinical work, and subsequent writing, is the idea that one's behavior—including conscious thought—can be influenced by information that is beyond one's awareness. This idea is a key assumption in *Mourning and Melancholia* (1917/1957), his most significant work related to grief (Tedeschi & Calhoun, 2004). Freud's discussion of *mourning* pertains to his clients' grief-like symptoms, while his discussion of *melancholia* relates to his clients' depression-like symptoms. For Freud, mourning represented a nonpathological response to loss, whereas melancholia represented mourning that had gone "awry and become unhealthy" (Neimeyer, 2015, p. 308), and was thus pathological.

Central to Freud's opinion of what constituted pathological grieving was his model of cathexis/decathexis. For Freud, cathexis represented the psychic energy people invest in their relationships with others. The process of mourning "was accomplished gradually as the mourner's psychic energy [...] is systematically recalled, reexperienced, and then released, resulting in detachment," (Neimeyer, 2015, p. 308) or decathexis.

The idea that decathexis was the objective of the mourning process developed into the notion of *Trauerarbeit*, or grief work. As Tedeschi & Calhoun (2004) explain, the grief work

hypothesis is one of Freud's most influential ideas, and can be summed up as, "in order to successfully adapt to the loss, the grieving person's psychological systems need to engage in an active processing of the loss" (p. 18). While the grief work hypothesis was a major influence in bereavement practices for decades, contemporary critics argue against its universality. Key to the critique are more recent observations that nonpathological grieving does not require severing one's relationship with the deceased, discussed further later in this section.

The next major contribution to psychology's perspective on grief was made by Erich Lindemann, former head of the Psychiatry Department at the Massachusetts General Hospital. This hospital was then, as it remains today, one of the main teaching hospitals for the Harvard Medical School. This connection is important due to the circumstances that led to Lindemann's contribution.

On November 28, 1942, tragedy struck the Coconut Grove nightclub in Boston when a fire broke out. Approximately 500 people lost their lives. Many of these people were brought to Massachusetts General. This catalyzed Lindemann's interest in studying the survivors of the fire as well as the family members of the deceased. By working with other area hospitals who had also treated victims of the fire, Lindemann was able to establish a sample of 101 grieving patients (Worden, 2015). In 1944, Lindemann published his observations, which became "the clinical description of grief that had the greatest influence on clinicians in the United States in the 20th century" (Tedeschi & Calhoun, 2004, p. 19).

Lindemann (1944) described his observations of patients grieving processes in terms of *acute*, or normal grief, and *morbid*, or abnormal grief. Acute grief was used to describe patients that confronted their loss. The goal of the grieving process was for the mourner to adjust to life in a world without the loved one. Morbid grief was used to describe when the grief had become

pathological. This was due to the mourner repressing their feelings. Lindemann identified two types of morbid grief. The first was delayed grief, in which symptoms may not manifest for years. The second was distorted reactions, which—amongst other symptoms—included the presence of exaggerated acute grief behaviors and feelings (Worden, 2015; Tedeschi & Calhoun, 2004).

Lindemann's work is clearly influenced by the grief hypothesis. The treatment recommendation he developed based on his observations is summed up as, "Express your grief and you will return to normal" (Worden, 2015, p. 92). This characteristically modern homogenous edict is the focus of two contemporary criticisms. First, Lindemann's study did not consider the differences of individuals and how those differences may affect mourning processes. Second, Lindemann did not consider the possibility of a chronic grief. Yet, Lindemann's study continues to be credited for advancing psychology's reaction to mass tragedy (Worden, 2015).

John Bowlby's (1969) development of attachment theory represents the next longstanding contribution to psychology's understanding of grief. Bowlby was a psychoanalytic psychologist whose previous work had focused on separation anxiety. During the 1960s, he established an interdisciplinary framework that bridged psychology with biology. This framework sought to explain the psycho/social/physical dimensions of instinctual attachment between young children and their primary caregivers.

Key amongst Bowlby's observations is that the reactions of grieving individuals "are similar to those of young children separated from their primary caregivers" (Tedeschi & Calhoun, 2004, p. 20). Bowlby observed that both mourners and young children demonstrated a

series of predictable phases as they processed the separation. This observation is the foundation of Bowlby's eventual partnership with the next theorist discussed.

About this same time, Colin Murray Parkes, a psychiatrist interested in preventative approaches to problematic grief, was developing his ideas on psychosocial transitions (1970). Parkes' thinking was based on the idea of the *assumptive world*. For Parkes, one's assumptive world was comprised of everything one thought they knew about the world, including past, present, and future. Integrated into this assumptive world are one's sense of identity and belief structures.

Upon bereavement, Parkes (1970) argued, an individual experiences a psychosocial transition. This transition involves reassessment of one's assumptive world, as—with the loss of a loved one—many of one's previous assumptions may become invalid. Thus, as Tedeschi and Calhoun (2004) explain, “dealing with bereavement [...] involves the complicated rebuilding of the damaged assumptive world” (p. 22).

Bowlby and Parkes' related, yet distinct lines of thought converged in a partnership that saw the integration of many of their individual ideas. This partnership culminated in their defining four phases of grief. The first is *shock and numbness*, which they argued temporarily insulates a person against the immediate pain of loss. The second is *yearning and searching*, which is described as a verification process—making sure the loss is real. The third is *disorganization and despair*, which can be understood a process of accessing the new state of one's reality. The fourth is *reorganization*, which consists of the mourner identifying how to continue in their new reality (Bowlby & Parkes, 1970).

The idea of phases of grief quickly gained prominence amongst professionals in grief and bereavement related fields. Tedeschi and Calhoun (2004) propose that this may have been due to

Elisabeth Kübler-Ross's work at roughly the same time. Kübler-Ross was a psychiatrist who taught and practiced at the University of Chicago hospitals. Like Bowlby and Parkes, Kübler-Ross noticed patterns of experiences amongst the dying patients with whom she worked. These observations led to the publication of her seminal work, *On Death and Dying* (1969). In it, she describes five stages that people experience in the process of dying: denial, anger, bargaining, depression, and acceptance (Worden, 2015).

The introduction of Bowlby and Parkes' (1970) four phases of grief and Kübler-Ross' five stages of dying each represented readily accessible models. On the surface, the models were comprehensible to even the untrained professional. In light of this, the history of the rapid adoption and implementation of these models is not without its criticism. As Tedeschi and Calhoun (2004) explain, popular understanding of Bowlby and Parkes' four phases of grief represents "a somewhat more restrictive conceptualization than Bowlby [and Parkes] probably originally intended" (p. 21). The notion of these stages occurring sequentially continues to be a subject of debate (Wortman & Silver, 1989). Likewise, Worden (2015) explains that although many people "who were seeking a quick and easy way to understand bereavement began applying [Kübler-Ross' five stages of dying] to the bereavement process, [...] this was never [Kübler-Ross'] intent" (p. 93).

In contrast to these linear models, Simon Rubin's (1981) Two-Track Model for understanding the mourning process uses two axes. Rubin, both a clinical psychologist and professor, brought together two existing perspectives to form the model. The first is a personality-change model, which Rubin describes as sharing "the conceptual orientation of the stress and trauma literature" (p. 102). The second is Freud's (1917/1957) psychodynamic model.

The first of these tracks is used to assess the psychosocial functioning of the mourner. This includes consideration of any emotional symptoms (e.g., anxiety, depression, etc.), the quality and nature of interactions with family and friends, responsiveness to life tasks, as well as the mourner's self-esteem (Worden, 2015). As Rubin (1981) explains, "As a consequence of loss, [...] personality patterns are susceptible to structural change, growth, or damage" (p. 102).

The second of these tracks is used to assess the state of the mourner's ongoing attachment to the deceased. This includes monitoring the sense of closeness or distance the mourner experiences in their relationship to the deceased, their level of acceptance of the loss, as well as the mourner's self-perception (Worden, 2015). Rubin (1981) emphasizes, "The central process in the bereavement response is the loosening of the affective bond to the deceased" (p. 102).

Like many before him, Rubin's Two-Track Model (1981) is significantly influenced by Freud's grief work hypothesis. Early in his work with the model, Rubin elaborated on the dangers of not doing one's grief work, "According to this conceptual model, persisting manifestations of affective or behavioral effects of the loss typically indicate an irresolution of the affective detachment process from the deceased and reflect an incomplete adjustment to the loss" (p. 102). However, Rubin's more recent work with the model does not emphasize detachment in the same way. For example, in a study considering the life functioning of bereaved parents, Rubin and Shechory-Stahl (2012) found that "parents whose condition improved over the years describe a close and significant relationship with [their child]" (p. 365).

The next model discussed is also comprised of two main components but represents a fundamentally different way of considering grieving processes. Working in the Netherlands in the 1990s, Margaret Stroebe, a clinical psychologist, and Henk Schut, a psychology professor, collaborated to develop the Dual Process Model (1999) for understanding how people mourn.

This model combines, first, an axis that describes a person's coping activities and, second, a means for understanding the extent of change in one's coping activities. The ends of the coping axis are represented by the concepts of *loss-orientation* and *restoration-orientation*. The means for understanding a mourner's change in coping orientation is referred to as *oscillation*.

Coping activities considered to be loss-orientated are those that focus on processing the death. These include thinking about the deceased, reminiscing, trying to understand the circumstances that led to the death, and experiences of missing or longing for the deceased (Stroebe & Schut, 1999; Tedeschi & Calhoun, 2004). Stroebe and Schut (1999) explain, "The grief work concept of traditional¹ theories falls within this dimension" (p. 212).

Coping activities considered to be restoration-oriented are those concerning changed aspects of one's world. These include development of a new identity (e.g., widow rather than wife), new skills (e.g., home maintenance), and logistical strategies (e.g., financial literacy) (Stroebe & Schut, 1999; Tedeschi & Calhoun, 2004). This dimension addresses the activities undertaken by the mourner that are in preparation for "reengagement with a world transformed by their loss" (Worden, 2015, p. 96).

Stroebe and Schut (1999) describe the concept of oscillation as the "central component of the model that distinguishes it from classic stress-coping theory or bereavement models" (p. 215). This concept refers to the fluctuation in a mourner's loss and restoration activities. Key to

¹ Stroebe and Schut's use of the word "traditional" can be understood to mean "historical," rather than Walter's (1996) meaning of the word "traditional" in describing societies' views of death.

understanding the significance of this idea is how it allows for both confrontation and avoidance as nonpathological activities.

The introduction of the concept of oscillation marks the emergence of an understanding of grief as a personalized “complex regulatory process” (Worden, 2015, p. 96). This perspective on bereavement was the first to accommodate a dynamic grieving process and acknowledge the differences in how people mourn without being considered maladaptive (Stroebe & Schut, 1999). This shift toward a more individualized understanding of grief and bereavement is distinctly postmodern and continued in the next theory discussed.

In the mid-1980s, Phyllis Silverman and J. William Worden, both psychology researchers at Harvard, were conducting a study of school-age bereaved children. At the same time, Dennis Klass, both a clinical psychologist and professor, was reflecting on his clinical experiences with bereaved parents. The researchers’ findings amongst both groups aligned: instead of emotionally withdrawing, many of the bereaved sought to remain connected to the loved one they lost. This sense of connection was manifested through active remembering of the deceased, associating with the deceased through objects, and seeking ways to maintain their loved ones’ presence in their lives (Worden, 2015).

Together, Klass, Silverman, and Steven Nickman, a psychiatrist also at Harvard, used these findings as the basis for developing Continuing Bonds theory (1996). Central to this theory is the concept of a mourner’s inner representation of the deceased. As Klass, Silverman, and Nickman (1996) explain, “We can define inner representation, following Fairbairn (1952) and Kernberg (1976), as the part of the self [that is] actualized in the bond with the person, characterizations, and thematic memories of the person, and the emotional states connected with the characterizations and memories” (p. 200). Interaction with one’s inner representation of a

deceased individual can include feeling their presence, experiencing hallucinations, believing in the deceased influence in one's life, or integrating the deceased' ways of living into one's own life (Klass, 1993).

In light of the theories dominated by Freud's (1917/1957) psychodynamic model, the idea of a mourner perpetuating a relationship with a deceased individual would qualify as a pathological response to grief. Stroebe, Gergen, Gergen, and Strobe (1992) argue against the psychodynamic model's definitions of healthy and unhealthy as being extensions of modernism,

In psychology, modernism has given rise to the machine metaphor of human functionality. When applied to grief, this view suggests that people need to recover from their state of intense emotionality and return to normal functioning and effectiveness as quickly and efficiently as possible (p. 1206).

Klass (1993) elaborates on the key processes of parental bereavement as being, "adaptation, growth, and change, not recovery of the way they were before the death" (p. 363). This growth mindset is echoed by Tonkin (1996), a grief counsellor, in her description of the bereavement process as life growing around grief, rather than grief disappearing. She explains that this model

relieves [clients] of the expectation that their grief should largely go away. It explains the dark days, and also describes the richness and depth the experience of grief has given to their lives" (p. 10).

Klass (1993) explains that key to many bereaved parents' growth processes is the seeking of solace in their inner representations of their deceased children. He found that there are three categories of ways bereaved parents seek this solace and maintain these relationships: religious devotion, interaction with linking objects, and focused memory.

Klass's use of the word *religious* is not restricted to the ideas or practices of organized religion. Instead, the word is meant to convey bereaved parents' sense of being connected to—and embracing—something bigger. Examples of bereaved parents' religious experiences of inner representations of their deceased children include finding meaning in moments of unexplained synchronicity, senses of a mysterious presence, etc.

Linking objects are the things, places—even experiences—that can connect the bereaved to the deceased (Klass, 1993; Volkan, 1971; 1981). Examples of these include the deceased' favorite toys, clothes, activities, etc. The roles and significance of linking objects are discussed in greater detail in §2.1.4.

Klass (1993) acknowledges that, at the beginning of one's bereavement journey, memories can be “very painful, for they are reminders of the loss” (p. 358). But with time, focused memory time can become the foundation for personal ritual. Memorialization practices are discussed in greater detail in §2.1.4 and §2.1.5.

Another postmodern challenge to the universality of the grief work hypothesis was presented by Terry Martin and Kenneth Doka (2000), both psychology professors, in their work considering grieving patterns and gender stereotypes. Central to this framework are two patterns for grieving, *intuitive* and *instrumental*. These patterns contrast in terms of griever's experiences, expression, and strategies for adapting to loss (Martin & Doka, 2000; Doka & Martin, 2011).

Intuitive grieving is historically associated with femininity and would be considered healthy per the grief work hypothesis. Intuitive grievers are more open emotionally in their grief and often make greater use of social contacts in their grieving. Instrumental grieving is historically associated with masculinity and would be considered maladaptive per the grief work hypothesis. Instrumental grievers are less expressive emotionally—save for perhaps expressions of anger—and inclined to intellectually process their loss (Martin & Wang, 2006).

Stemming from this framework, Martin and Wen-Chi Wang (2006) created a tool, the Grief Pattern Inventory (GPI), for identifying these patterns in people's grieving processes. This tool was validated against the Grief Experience Inventory (Sanders, Mauger, & Strong, 1985). I used the GPI with participants in this study to better understand their experiences creating digital memorials for their deceased children. My method for doing so is described in greater detail in Chapter 3: Methods.

The final contribution to psychology's understanding of grief discussed here is Robert Neimeyer's Meaning Reconstruction Model (Neimeyer, 1998; Neimeyer, 2001; Gillies & Neimeyer, 2006). Neimeyer, a clinical psychologist and professor, proposes the model as a tool for both understanding the grieving process and guiding grief therapy. He describes this model as being rooted in constructivism. The Gale Encyclopedia of Psychology (2016) defines constructivism as "the ongoing lifelong process by which individuals organize their worlds by organizing themselves" (para. 5).

Constructivism is an educational theory that emerged from Jean Piaget's Theory of Cognitive Development (Gale Encyclopedia of Psychology, 2016). Constructivism, while considered by many to be a branch of cognitivism (Ertmer & Newby, 2013; Yilmaz, 2011), rejects the idea of an objective reality in favor of relativism, or the belief in multiple equally

valid perspectives on reality. Thus, constructivism is based on a belief that knowledge is unique to the learner. As Neimeyer (2001) explains, “I have found a constructivist emphasis on the individuality of meaning making, on the narrative construction of self, and on the (para)linguistic negotiation of changed meanings to provide a more responsive frame for holding the complexity of loss as a lived experience” (p. 289).

The model is based on several assertions (Neimeyer, 2001; Lister, Pushkar, & Connolly, 2008). The first is the concept of *narrative truth*. This concept is proposed to explain how truth is an individualized construction. The second is the notion of *discourse and rhetoric*. This notion is proposed to explain the importance of one’s narrative being recognized by one’s social context. The third is the idea of *tacitness*. This idea is proposed to explain that not all thoughts and feelings are verbally expressible. The fourth is the concept of *relational self*. This concept is proposed to explain one’s shifting sense of self in relation to various social contexts. The fifth is the notion of an *evolutionary epistemology*. This notion is proposed to explain how one’s self-narrative evolves over time and in different social contexts (Lister, Pushkar, & Connolly, 2008).

In developing this model, Neimeyer (and many collaborators) analyzed multiple theoretical perspectives in attempts to identify a consistent theme by which grieving processes could be better understood. As Gillies and Neimeyer (2006) describe, “We propose that the effort to find, create, or reconstruct meaning is the core element linking these theories” (p. 36). Further, they explain that the activities of grieving individuals attempting to reconstruct meaning can be organized into three categories: *sense making*, *benefit finding*, and *identity change*.

The idea of sense making in one’s grieving process can be seen as part of several of the theories already discussed. For example, Parkes’ (1970) assertion that bereavement involves rebuilding one’s assumptive world can be understood as being based on making sense of the

changes in one's life as brought by the death of a loved one. Likewise, Bowlby and Parkes' (1970) second phase of grief, yearning and searching, can be seen in light of one's attempt to discern what is "true." Further, Stroebe and Schut's (1999) Dual Process Model directly addresses sense making as related to loss-oriented coping activities.

The idea of benefit finding in one's grieving process is also evident in previously discussed theories. For example, Bowlby and Parkes' (1970) fourth phase of grief, reorganization, may involve the bereaved identifying insights into how the death brought about the conclusion of problematic circumstances, like chronic pain, and/or enabled new opportunities for personal growth, like increased self-sufficiency. This idea also aligns with the restoration-orientated coping activities described in Stroebe and Schut's (1999) Dual Process Model. Yet, Neimeyer and Anderson (2002) are clear that benefiting finding may take considerable time to emerge and that "the mining of life lessons from the vein of grief is by no means a certain outcome, and when it occurs, it is likely dependent on a host of maturational, personal and social resources" (p. 50).

The idea of identity change in one's grieving process is also a component in several of the theories discussed above. For example, like with sense making, rebuilding one's assumptive world can involve new ideas as to who one is or intends to become. Similarly, like with benefit finding, the process of reorganization may also include a new sense of self. Likewise, the restoration-orientated coping activities of Stroebe and Schut's (1999) Dual Process Model can also involve establishing a new identity.

This discussion of psychological perspectives of grief and bereavement, while not exhaustive, has included many prominent theories and models for understanding these practically inevitable human experiences. Early work in this area sought to create a universal solution for

the pain and struggle caused by bereavement. While noble in intent, more recent work understands grief and bereavement as deeply personal and involving a wide range of activities. From this discussion, I adopt Neimeyer's Meaning Reconstruction Model (Neimeyer, 1998; Neimeyer, 2001; Gillies & Neimeyer, 2006) as key to informing my understanding of the grieving process. As explained in Chapter 3: Methods, the importance that this model places on an individual's meaning-making process aligns well with the goals of this study.

2.1.4: Material objects, bereavement, and memory

This section of the literature review seeks to better understand the roles of material objects in memorialization. To accomplish this, I begin by discussing the collaboration between Mihalyi Csikszentmihalyi, a psychologist, and Eugene Rochberg-Halton (1981), a sociologist, at the University of Chicago considering the function of material objects in establishing personal identity. This discussion serves as a foundation for considering the observations of Vamik Volkan (1972; 1981), a professor of psychiatry at the University of Virginia, and the unique type of relationship some objects facilitate in bereavement. This leads to examining the ideas of anthropologists Elizabeth Hallam, University of Aberdeen, and Jenny Hockey, University of Sheffield, (2001) in their study of material objects in memorial practices.

Central to Csikszentmihalyi and Rochberg-Halton's (1981) consideration of material objects is Arendt's (1958) distinction between natural and synthetic contexts. On one hand, there is the natural environment of the planet. On the other, there is everything constructed through human effort. Thus, Csikszentmihalyi and Rochberg-Halton's (1981) conclude, "The material objects we use are not just tools we can pick up and discard at our convenience; they constitute the framework of experience that gives order to our otherwise shapeless selves" (p. 16). They

describe objects that contribute to the creation of order in one's consciousness as leading to cultivation of the self.

The notion of *cultivation* is key to understanding Csikszentmihalyi and Rochberg-Halton's (1981) explanation of objects as signs materialized by human psychic energy. They define cultivation as "the improvement, development, refinement, or resultant expression of some object or habit of life due to care, training, or inquiry" (p. 173). Thus, the meaning of these objects, or signs—and the extent to which they lead to cultivation of the self—is a function of the "activity of interaction and in the direction or purpose that this activity indicates physical and psychological growth" (p. 174). That is to say, the extent to which one's interaction with material objects is directed toward growth, the objects involved in that interaction take on meaning related to the self. For example, consider the significance of a basketball to one who has developed advanced skills with the object and become a professional player of the sport.

Csikszentmihalyi and Rochberg-Halton (1981) elaborate on the notion of the self in terms of the *personal* and the *social*. The personal self is a product of individualized internalization of one's social context. The social self describes individuals' presence within, and dependence upon that context. They argue that through growth-oriented activity, "an object is imbued with qualities of the self, it expresses the being of that person, [...] it becomes an objectified form of consciousness no less than words spoken into someone's ear, all forming part of the social self" (p. 190).

In this way, meaningful objects are understood as extensions of the social self in how they contribute portions of the personal self to one's social context. This delineation allows for perpetuation of one's social self, independent of one's personal self. Csikszentmihalyi and Rochberg-Halton's (1981) exemplify this in the context of one's physical death, "Although the

personal self has ceased to exist, the social self has a continued existence in those who will remember and through those artifacts that in whatever way give testimony to that person” (p. 191). This aligns with the previous discussion of one’s social identity after death. It is also in line with Volkan’s (1972; 1981) observations of certain material objects of the deceased becoming significant to mourners.

As explained by Lewis and Brown (2008), Volkan “was the first to identify the phenomenon wherein physical objects of the deceased become significant to mourners” (p. 135). Although occurring at point when postmodern ideas were starting to gain widespread acceptance, Volkan’s theories of about this phenomenon are thoroughly entrenched in Freud’s modernist grief work hypothesis. Volkan (1981) explains,

The established pathological mourner does not develop a disruptive identification with the representation of the dead, but maintains such a representation as an unassimilated introject.² He also invests certain inanimate objects of his own selection with magical qualities. Such “linking objects” furnish an external locus at which the self-representation can meet with the representation of the lost. The person in established pathological mourning can thus keep alive an illusion of continuing communication with the dead (p. 85).

² Volkan (1981) summarizes an introject as “the representation of the dead he keeps within his bosom” (p. 8)

While the significance Volkan's initial observations of this phenomenon continues to be acknowledged, more recent research suggests interpretation of linking objects as other than pathological.

Building on the work of Klass (1993) and Klass, Silverman, and Nickman (1996) in the development of Continuing Bonds theory, Inese Wheeler (1999), a psychologist and professor, conducted a study considering the roles of linking objects with bereaved parents. In a sample of forty-nine bereaved parents, seventy-eight percent reported identifying objects that linked them to their deceased children. Key amongst the study's findings are that these objects were meaningful and that these objects helped parents feel connected to their deceased children. Thus, Wheeler (1999) concludes,

The results of present study suggest that the use of linking objects by bereaved parents is not pathological and indicative of complicated bereavement. In fact, for some bereaved parents, linking objects play a positive role by providing a connection with the dead child. The tangible object may help bridge the gap between the past reality of the child's physical presence and the new and future reality of the child's physical absence. Instead of being seen as a hindrance to recovery, the linking object can be viewed as a resource for coping with the difficult challenge inherent in the death of a child (p. 295).

Wheeler's (1999) assertion that a linking object may help bridge the past, present, and future aligns with Hallam and Hockey's (2001) central argument "that material dimensions of memory making are significant not just in the marking of deaths, but also in the social and cultural processes through which lives are remembered and futures are imagined" (p. 20). Their work

examines the connections between spaces, actions, and objects in creating deeply personal and socially valid memories.

This work explores the spectrum of the sacred and the secular. They discuss the history of Western societies establishing spaces for acknowledging the deceased. These include sites of religious practice (e.g., churches and shrines), burial sites (e.g., graveyards and mausoleums), designated memorial locations, places of death, and the body itself (both the deceased and the mourner's). They describe the range of memorial actions performed at these sites. These include formal rituals (e.g., funeral rites and family prayer), informal rituals (e.g., candle lighting and moments of silence), as well as the domestic (e.g., cleaning and decorating). They also explain how these spaces and actions influence the objects that are employed in memorialization. This influence results in an almost incalculable diversity of artifacts spanning the sacred (e.g., statues and garments) and the secular (e.g., toys and drawings).

Amongst the diversity of artifacts used in memorialization, Hallam and Hockey (2001) highlight the emergence and evolution of Christian relics. In the Middle Ages, these artifacts were made up of the body parts and/or personal belongings of saints and martyrs. Relics “not only provided sites of collective remembering but were also approached for assistance with the earthly problems of living” (Hallam & Hockey, 2001, p. 134). However, during the Protestant Reformation relics lost their prominence as religious artifacts.

Yet, the preservation and use of human remains as memory objects continued outside religious practice. This is chiefly evident in the use of hair jewelry well into the 19th century. As Hallam and Hockey (2001) explain, “Human material that was regarded as ‘dead’ while the person was living, is thus transformed into a ‘living’ substance at death in the sense that it is reanimated as a possession capable of sustaining the deceased in close proximity to the

bereaved” (p. 136). However, the use of hair jewelry fell off quickly with the introduction of the photograph.

This development is notable in that, amidst their discussion of spaces, actions, and objects, Hallam and Hockey (2001) emphasize the significance of visual experience in memory making. They cite Stewart’s (1999) hierarchy of human senses that prioritizes sight and hearing over touch, taste, and smell. Hallam and Hockey (2001) point to images and texts as having “important material dimensions and/or bear[ing] connections with embodied persons which inflect their potential as memory ‘objects’” (p. 21).

Hallam and Hockey (2001) elaborate on the potency of photographs in memory making as “expressions of sentiment and in reducing the scale of the human body to its likeness in a miniature image or in salvaging a trace of the body, loved ones are sustained as treasured possessions” (p. 141). Similarly, they also highlight the influence of texts in memory making, specifically “narratives in the organization and communication of memories” (p. 155). They conclude, “Indeed, we can approach the written word as a memory vehicle, embedded within material cultures and possessing strong visual qualities” (p. 158).

The discussion above illustrates the potential significance of material objects in human experience and memory making. This significance ranges from establishing and communicating a sense of personal identity to maintaining a sense of connection to a deceased loved one. Central to this significance is the bridging of the past, present, and future. Key amongst the objects capable of becoming imbued with this significance are media elements: images and texts. The next section considers the evolution of the use of media elements in memorialization practices.

2.1.5: Media elements in memorialization practices

The earliest conventional use of a media element for memorialization in Western societies is the verse epitaph (Scodel, 1991). This late 16th century commemoration practice involved commissioning a poet to write text that would summarize some aspect of the deceased' life. This text would then be inscribed on the tombstone of the deceased. This commemoration practice was exclusive to the wealthy.

The exclusivity of this practice gave way in the early 17th century to a more accessible and descriptive form of text-based commemoration. As Barry (2008) explains, “the decline of the epitaph as a literary form at this time coincides with, or perhaps follows, the concomitant rise of the newspaper obituary” (p. 260). The emergence of the newspaper obituary allowed not only a more expansive summary of the deceased but also afforded broader dissemination of the information. The impact of this broader dissemination was that, as Arnold et al. (2018) elucidate, “newspaper and magazine obituaries made public a narrative that would otherwise be confined to family and community” (p. 18).

The next major shift in media-based memorialization was the 19th century development of the daguerreotype camera. This novel technological device gave rise to the practice of post-mortem photography. This practice involved situating the body of the deceased in a composed scene and sought to “memorialise persons at the final stage of life” (Arnold et al., 2018, p. 18). Hallam and Hockey (2001) elaborate,

Post-mortem photographs were visually compelling in their capacity to replicate ‘real’ scenes of death, replete with detail and texture. They could also appeal to sensual experience functioning as a record of touch, condensing the rich materiality of an interior

and capturing last moments of physical proximity between the deceased and the living (p. 144).

The enhanced fidelity of these images also came in a form that afforded reproduction and exchange, which in turn, further extended the public reach of the memorial artifact. The popularity of post-mortem photography declined in the late 19th century and by the mid-20th century had almost completely disappeared.

The time during which post-mortem photography was declining coincides with the emergence of the next significant shift in media-based commemoration, though the two are not linked causally. This next significant shift is the introduction of the phonograph, and eventually the gramophone during the latter part of the 19th century. Unlike the telephone and radio, which allowed a person's voice to be spatially separated from one's body in real-time, the phonograph allowed a person's voice to be recorded, and thus separated both spatially and temporally from one's body. According to Kittler (1999), Thomas Edison conceived of the phonograph as a commemorative device, and suggested that it be used to record "the last words of dying persons" (p. 12). Like the photograph, and the newspaper obituary before it, the development of the phonograph also increased both the fidelity and the reach of a memorialization.

Mechanisms for both image and audio capture continued to improve throughout the latter part of the 20th century. Yet, it is not until the widespread adoption of digital technology, and the concurrent emergence of the Internet, that we see a significant shift in media-based memorialization. With the introduction of new digital media elements—text, images, video, and audio—along with a revolutionary interactive communication system—the World Wide Web,

media-based memorialization became not only higher fidelity and more broadly reaching, but also increasingly common (Arnold et al., 2018).

The earliest Web-based memorials emerged in the 1990s and were “created and hosted by families and friends of the dead” (Arnold et al., 2018, p. 33). These sites were predominantly text-based, but often included simple graphical elements such as flowers or angels and/or a small image of the deceased. These sites were commonly dedicated to memorializing a single individual.

Amongst the first platforms to offer an online memorial as a service is The Virtual Memorial Garden, established in 1995 (The Virtual Memorial Garden, n.d.). Still live at the time of this writing, the site attests to the austerity of the early Web-based memorials (Figure 1). The site allows the bereaved to create simple text-based memorials that are supplemented by a modest flower graphic. The site is free to use.

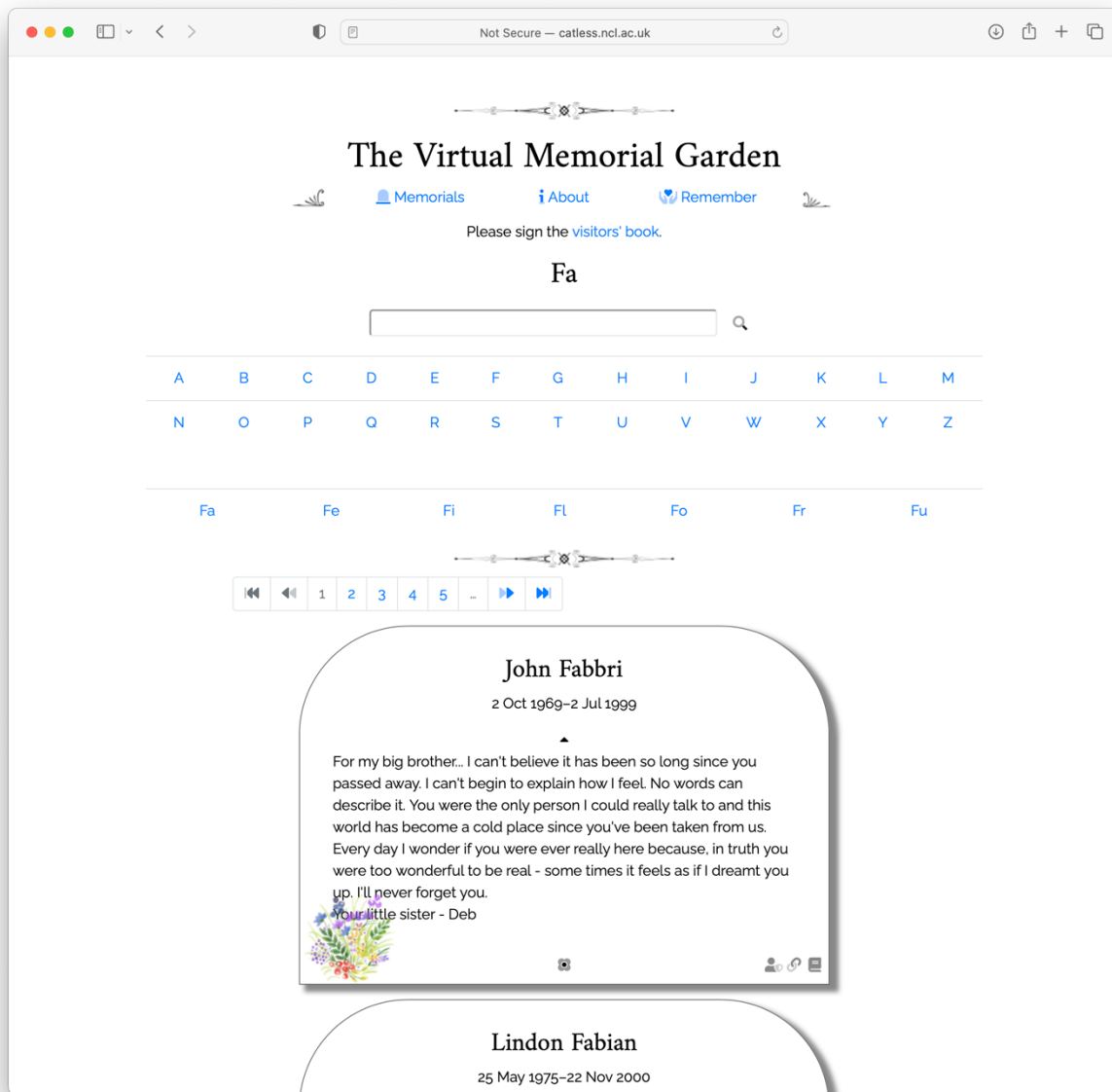


Figure 1. The Virtual Memorial Garden (The Virtual Memorial Garden, n.d.).

Since the appearance of these early memorial sites, the field of offerings has diversified considerably. Some remain free to use (e.g., MuchLoved.com, NeverGone.com); some involve advertising (e.g., Imorial.com); some are subscription-based (e.g., Tributes.com). Many memorial platforms now offer means for creating not only text-based obituaries, but also provide

condolence sections, private diaries, photo galleries, music and video integration, tribute environments, event calendars, and more (Figure 2). Amongst the more sophisticated sites are MuchLoved.com and Tributes.com. As Arnold et al. (2018) explain,

At their most extensive, web memorial sites may present thousands of words of biography, images, poetry, extended narratives and anecdotes, music, and video clips. Memorial sites buzz with sensory and emotional stimuli that provide multiple invocations of lives lived (p. 37).

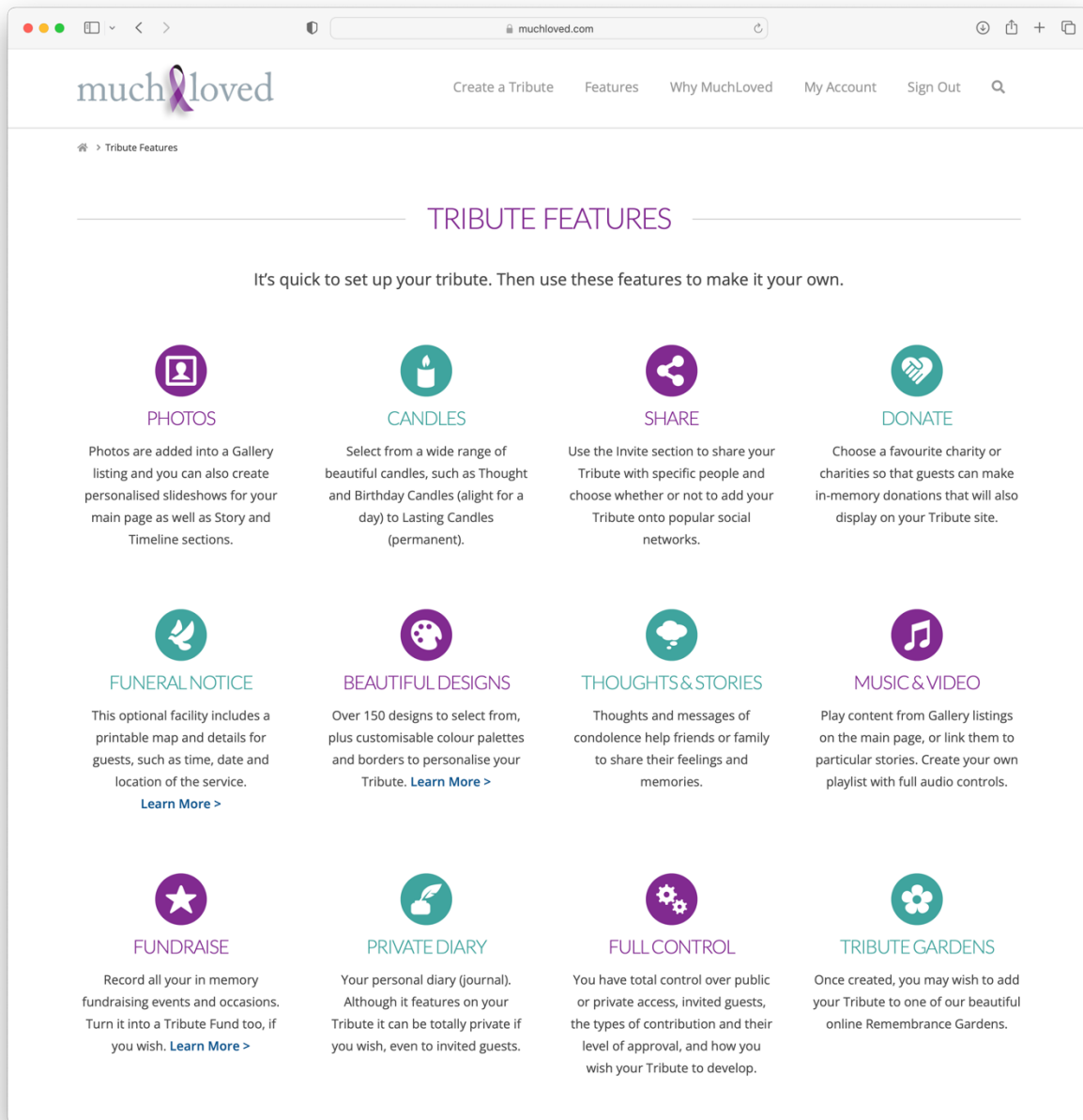


Figure 2. Example of diverse tribute features (MuchLoved, n.d.).

The next shift in media-based memorialization occurred in the mid-2000s with the arrival of social media platforms. The rapid adoption of social media platforms like Facebook and Twitter resulted in a shift away from dedicated memorial sites. Instead, the bereaved began

“appropriating the general-purpose resources” (Arnold et al., 2018, p. 53) of these platforms to memorialize the deceased.

While this shift in memorialization did not involve new media elements, it did introduce new digitally networked social structures. With these new social structures also came novel social dynamics. For example, until this point, the authorship of an online memorial was commonly under the custody of a single individual or small group of intimates. The repurposing of a deceased person’s Facebook account as a makeshift memorial brought with it the affordances of the platform, namely, the ability of friends—and in some cases, people unknown to the deceased—to post images and text to the deceased’ page. This sharing of authorship did not always involve compatible ideas of the deceased’ social identity.

Further, some argue the use of social media platforms for online memorials has eroded many people’s need for a dedicated, often private space for mourning. As Arnold et al. (2018) describe, “Social media memorialisation [...] celebrates a repositioning of the dead very much within the everyday flow of daily life” (p. 54). The shift toward a more public account of a deceased loved one’s life is consistent with the trends in media-based memorialization discussed above. It is also in-line with contemporary theories related to grieving, namely, acknowledging the solace that can be found by maintaining a relationship with the deceased.

The discussion thus far in this first section of the review of literature has addressed Western concepts of death, key sociological ideas related to death, as well as influential psychological perspectives on grief and bereavement. This was followed by an investigation of the role of material objects in bereavement and memory, and finally a brief chronology outlining use of media elements in memorialization practices. The purpose of this discussion has been to highlight key ideas related to bereavement studies. The next section of the review focuses on

understanding interaction design as a disciplinary context and considering the ways many of these ideas are being incorporated into research projects within this discipline.

2.2.1: Human-computer interaction as a field of study

According to the Association for Computing Machinery (n.d.), “the world's largest educational and scientific computing society” (para 1), human-computer interaction (HCI) is “a discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them” (Association for Computing Machinery, 1996, para. 2). HCI is a relatively new field of study, having evolved from more established disciplines.

Grudin (2006) identifies three key disciplines that shaped the development of HCI. Following World War II, the discipline of human factors and ergonomics (HFE), commonly associated with the field of industrial engineering, contributed to HCI's early body of knowledge. At the time, the focus of much HFE research was the “application of scientific management to the design of assembly lines and other work processes” (Grudin, 2006, p. 54). By the 1960s, computers became more common in the workplace, and the discipline of information systems (IS) developed. Grudin (2006) characterizes the nature of IS human-computer interaction at this time as “non-discretionary” (p. 54), with research focused on “efficiency and error reduction” (p. 54). The third discipline Grudin cites as providing direction to HCI is computer science (CS). Emerging at roughly the same time as IS, CS practitioners came to HCI “inspired by the early visionary writers and prototype builders and bringing decades of work on software engineering, artificial intelligence, and above all else, graphics” (Grudin, 2006, p. 55).

The subject of computer graphics is a key idea in understanding discretionary computer use. Grudin (2006) explains, “When discretion is involved, aesthetic design matters” (p. 55). By the mid-1980s, personal computers were becoming common in homes. This trend resulted in increasingly discretionary computer use. At this point, CS researchers who were interested in computer graphics influenced the HCI community to relax its dependence on science and engineering methods, and become more familiar with the qualitative approaches associated with design. HCI’s embracement of design practices gave rise to *interaction design* as a specialty area, which is discussed in greater detail in the next section.

2.2.2: Interaction design as specialty area

Interaction design is an interdisciplinary field of study that emerged from the coalescing of HCI (discussed above) and design. Design can be understood as a broad-ranging collection of creative fields that share the goal of “changing existing situations into preferred ones” (Simon, 1962, p. 111). Löwgren and Stolterman (2004) define interaction design as a “process that is arranged within existing resource constraints to create, shape, and decide all use-oriented qualities (structural, functional, ethical, and aesthetic) of a digital artifact for one or many clients” (p. 5). As Bagnara (2006) elaborates,

The complexity of interaction design's domain is evident in its parentage. On one side of its family is human-computer interaction (HCI), whose history (Baecker & Buxton, 1990) is the coming together of hardware and software engineering, and physiological and cognitive ergonomics; on the other, a range of design practices and discourses including

those of industrial design, graphic design, architecture, and film—each of which has a medium requiring a particular set of skills and mental attitudes (p. xxiii).

As an emerging discipline, interaction design researchers and practitioners borrowed heavily the theories and methods of these parent fields of study. This process of integration provided a foundation for the development of new approaches, models, frameworks, and principles. The discussion below begins with an overview of Saffer’s (2010) four approaches to interaction design. This overview is followed by an examination of Norman’s (1988) Seven Stages of Action and then Laurel’s (1993) *Computers as Theatre*. These contributions are amongst the most influential and enduring models and frameworks in contemporary interaction design. This examination is followed by an explanation of several principles key to interaction design as a specialty area.

Dan Saffer is a commercial interaction designer who has been a member of the discipline since its emergence. He (2010) explains, “Like other applied arts, such as architecture, interaction design involves many methods and methodologies in its tasks, and ways of working go in and out of vogue” (p. 4). Saffer presents four categories of approaches to interaction design (Table 2).

Table 2

Saffer’s (2010) four approaches to interaction design

Approach	Overview	Users	Designer
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User-centered design	Focus on the user needs and goals	The guides of design	Translator of user needs and goals
Activity-centered design	Focus on the tasks and activities that need to be accomplished	Performers of the activities	Creates tools for actions
Systems design	Focus on the components of a system	Set the goals of the system	Makes sure all the parts of the system are in place
Genius design	Skill and wisdom of designers used to make products	Sources of validation	The source of inspiration

User-centered design is an approach to interaction design that prioritizes the needs of a target user group. User-centered research investigates the sociodemographics, leisure activities, preferences, aspirations, etc. of a group of people as a means for informing how a design problem is solved. The role of the designer in user-centered design is to incorporate this knowledge of people into the characteristics of a design solution.

Activity-centered design is an approach to interaction design that prioritizes the tasks and activities that represent the design problem. Activity-centered research considers users inasmuch as they will ultimately perform the tasks and activities. However, the majority of the designer's

focus in activity-centered design is on creating compatible task flows for what are often complex activity sets.

Systems design is an approach to interaction design that prioritizes the relationships between the components of a system. Systems design research involves intensely analytic consideration of the functions and limitations of each component. In addition to this analysis, the focus of the designer is to establish the goals of the system and ensure the arrangement of the components accomplish the goals.

Genius design is an approach to interaction design that assumes a designer has skills and wisdom sufficiently advanced to justify pursuit. The role of users in genius design is as test subjects to either validate or invalidate the quality of the design. The role of the designer in genius design is to follow one's intuition and inspiration.

Practically speaking, many—if not most—design projects are a hybrid of Saffer's (2010) four approaches to interaction design. For example, the design process of a basic Web app would likely incorporate user-centered design for establishing the look and feel of the visual aesthetics, activity-centered design for creating a hierarchy for the app's core tasks, systems design in incorporating distinct components of the app (e.g., navigation, content display areas, databases, etc.), and perhaps even genius design in those moments of unexplained, yet profound designerly insight. Yet, identifying these approaches to design as distinct from one another allows focused consideration of the myriad ideas involved in interaction design. The focused consideration above was intended to provide a foundation for understanding the multitude of relationships between the ideas discussed below.

Donald Norman is considered by many to be a founding father of interaction design. With a background in electrical engineering and psychology, he has contributed to HCI and

interaction design's theoretical literature and applied practices for over six decades. His most acclaimed contribution, *The Design of Everyday Things* (1988), bridges each of these disciplines and ways of knowing.

A key model within this book is the Seven Stages of Action. This model breaks down goal-oriented action into seven stages. The first of the seven stages is the forming of one's goal. Picture, for example, being confronted with a soccer ball and a large glass window approximately 20 feet away. One might form the goal of putting the ball through the window. This initiates what Norman (1988) refers to as the "*The Action Cycle*" (p. 47) (Figure 3).

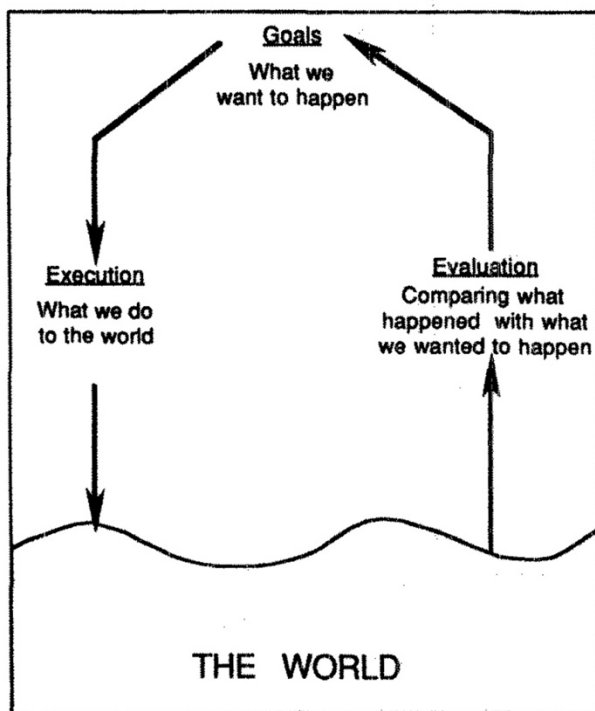


Figure 3. The Action Cycle (Norman, 1988).

The action cycle can be understood as the general structure of the model and is comprised of four elements: one's goal, what one does to the world, the world, and one's check of the world. Norman argues that every goal-oriented action "has two major aspects: doing something and checking" (p. 46). Norman refers to these aspects as *execution* and *evaluation*.

Norman describes stages two through four as the *Stages of Execution* (p. 47.) (Figure 4). This three-step sequence begins when one forms the intent to act. Continuing with the above example, this second stage can be understood as the moment when one might decide to pursue the goal of putting the ball through the window. This is followed by the third stage, structuring the sequence of actions required for the goal. This stage would include considering one's stepped route to the ball, the strength of the required kick, etc. Finally, one must physically execute their planned action sequence. This fourth stage would involve performing the planned stepping and kicking, etc.

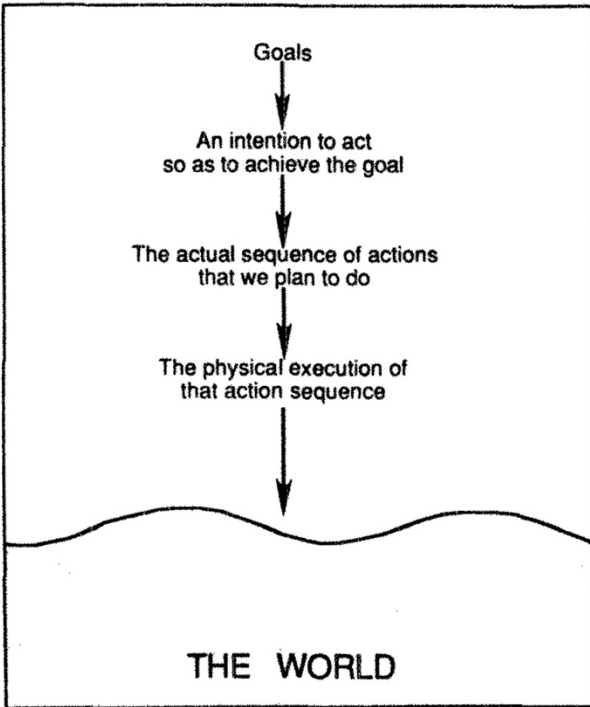


Figure 4. Stages of Execution (Norman, 1988).

Following this execution, one then evaluates what happened. Norman describes stages five through seven as the *Stages of Evaluation* (p. 47.) (Figure 5). This three-step sequence begins with one taking stock of the state of the world. This fifth stage would involve considering the location of the ball, the state of the window, etc. This is followed by interpreting one's perceptions relative to one's expectations. This sixth stage would include interpreting the ball's location as here or there and the window's state as intact or broken, etc. Finally, one must evaluate one's interpretations relative to one's expectations. This seventh stage would involve determining the outcome of kicking the ball at the window.

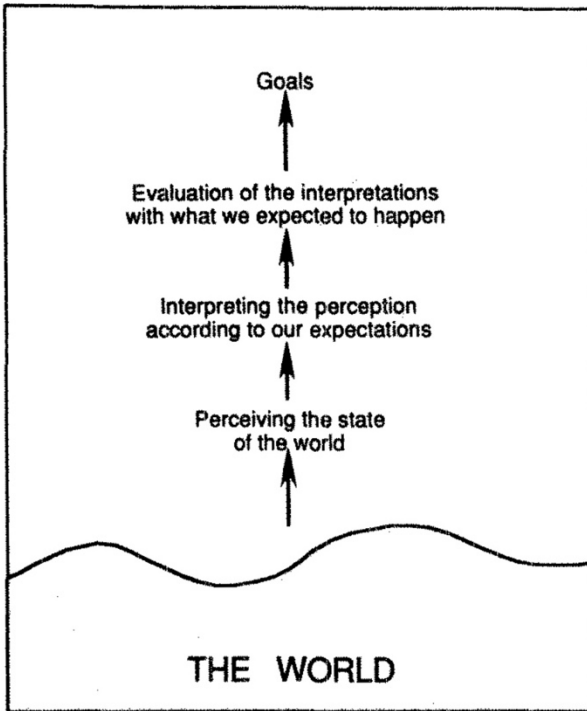


Figure 5. Stages of Evaluation (Norman, 1988).

Norman (1988) provides guidance on understanding and using the model,

The seven stages form an approximate model, not a complete psychological theory. In particular, the stages are almost certainly not discrete entities. Most behavior does not require going through all stages in sequence, and most activities will not be satisfied by single actions. There must be numerous sequences, and the whole activity may last hours or even days. There is a continual feedback loop, in which the results of one activity are used to direct further ones, in which goals lead to subgoals, intentions lead to subintentions (p. 48).

While the seven stages of action (Figure 6) may only be an approximate model, it has served many as a foundation for discussing how problems arise as well as how they might be avoided. Norman argues that the key to this problem solving is “deriving the relationships between the mental intentions and interpretations and the physical actions and states” (p. 50). He refers to mismatches between these stages of action as “gulfs” (p. 50).

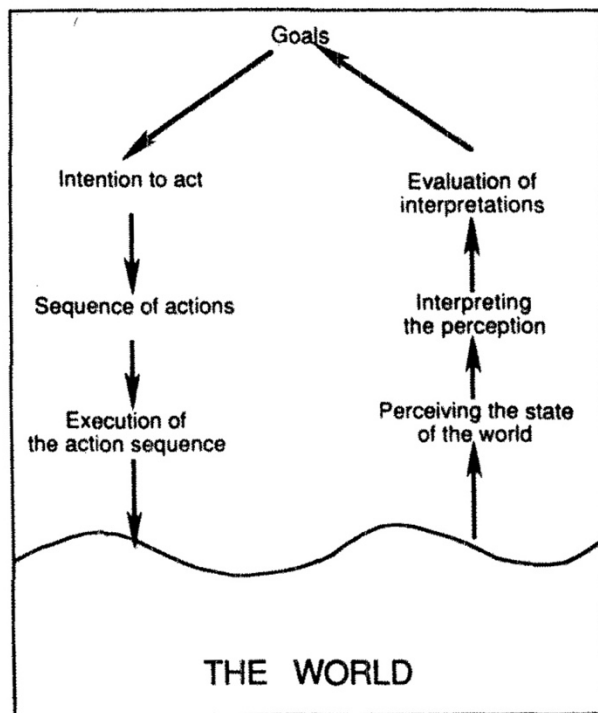


Figure 6. The Seven Stages of Action (Norman, 1988).

Norman (1988) sums up the possible gulfs in the execution stages as “the difference between [one’s] intentions and the allowable actions” (p. 51) of a system. Continuing with the soccer ball example, one would experience a gulf of execution if the soccer ball was

unknowingly constructed of an unconventional material. Consider, for example, how the outcome of the action might be different if the soccer ball was a latex balloon or cast bronze.

Norman (1988) describes the possible gulfs in the evaluation stages as relative to “the amount of effort [one] must exert to interpret the physical state of the system and to determine how well the expectations and intentions have been met” (p. 51). As with the soccer ball example, one would experience a gulf of evaluation if the soccer ball suddenly disappeared. Consider, for example, how one’s evaluation of the outcome of the action might be different if the soccer ball popped or one lost consciousness from the pain of a broken foot.

The influence of Donald Norman and the Seven Stages of Action can be found across the Internet as well as in many interactive products. Norman’s influence is also apparent in the work of Brenda Laurel, the next theorist discussed. Laurel, an interaction designer and researcher, credits Norman as being a mentor, especially through the beginning phases of her dissertation work (UX Pioneers, 2007). This dissertation (Laurel, 1986a) gave way to her classic book, *Computers as Theatre* (Laurel, 1993), the purpose of which she describes as “to suggest ways in which we can use a notion of theatre, not simply as a metaphor but as a way to conceptualize human-computer interaction itself” (p. 20).

Central to Laurel’s (1993) framework for designing interaction is an emphasis on computers’ “capacity to represent action in which humans can participate” (p. 1). The environments in which this action and participation occur are commonly referred to as human-computer interfaces. Laurel (1993) describes the human-computer interface as “not simply the means whereby a person and a computer represent themselves to one another; rather it is a shared context for action in which both are agents” (p. 4).

This notion of mutual agency is key in conceptualizing the rich interactive relationship that is possible between human and computer. Laurel (1993) argues that an interaction designer can enhance a user's sense of agency by crafting collaborative aspects into this relationship. Take for example, the case of task performance. Instead of the simpler and dispassionate request-and-response model for interaction, the activity of multiple agents can be represented as each working toward the same goal.

Collaboration between human and computer can be made apparent through how a user indicates their intent, how a computer acknowledges and interprets a user's intent, as well as how a computer responds in facilitating a user's intent. The media through which this collaboration can be made manifest are the multisensory design elements of an interface, such as the line, shape, color, sound, text, animation, and tactile components that are used to represent a user's intent and a computer's interpretation and response.

Laurel (1993) argues that the key to achieving a sense of collaboration between agents is the simultaneity of their interaction as each participates in these processes. Constant feedback not only provides a user a better understanding of the context in which one is operating, but also a more complete understanding of one's role within this context. She explains,

What [can be] represented in the interface is not only the task's environment and tools but also the process of interaction—the contributions made by both parties and evidence of the task's evolution. [...] Interface design should concern itself with representing whole actions with multiple agents. This is, by the way, precisely the definition of theatre (p. 7).

Laurel's (1993) argument for aligning theatre and human-computer interaction is not only based on the potential for collaboration in each environment, but also on the idea that both media excel in facilitating representations "that are like reality only different" (p. 10). These differences, which can be described as abstractions from reality, require a cognitive and emotional investment on the part of a viewer or user to understand what is being represented. But as Laurel (1993) explains, "The imprecision of dramatic representation is the price people pay—often quite enthusiastically—in order to gain [...] the possibility of surprise and delight" (p. 24). In this way, the notion of theatre serves as a powerful construct that can be used in human-computer interaction to elicit an emotional connection between humans and computers. Laurel (1993) stresses, the "human-computer experience [...] is about creating imaginary worlds that have a special relationship to reality—worlds in which we can extend, amplify, and enrich our own capacities to think, feel, and act" (p. 33).

One strategy available to interaction designers to enable the extension, amplification, and enrichment of a user's experience is the concept of *direct manipulation* (Laurel, 1993). This strategy uses the knowledge humans have about how objects act in reality to promote intuitive understanding of similar representations in the computing environment. Examples of direct manipulation objects are the many metaphors that populate the conventional Apple® and Microsoft® desktop environments, such as windows, scroll bars, and buttons. Laurel (1993) defines direct manipulation objects as computer representations that have three characteristics, "continuous representation, 'physical' action, and apparent instantaneity of response" (p. 9).

Related to direct manipulation is what can be understood as the emotional companion effect of *direct engagement*. Laurel (1993; 1986b) uses this term to encompass the cognitive and emotional aspects of a user's sense of involvement in human-computer interaction. Direct

engagement can be described as the feeling a user experiences when their actions within an interface are purposeful and rewarding. Laurel (1993) explains, “Engagement has cognitive components, but it is primarily understood as an emotion” (p. 113).

Empirically, the exact requirements for producing this emotional dimension of the interactive relationship are complex and illusive. But Laurel (1993, 1986a; 1986b) offers a model by which interaction designers can orchestrate interactivity in ways that promote direct engagement. This model is comprised of three concepts: frequency, range, and significance.

Within this model, the concept of frequency can be understood in terms of how often a user is presented with opportunities to act within an interface. Is a user’s activity limited to initiating a display of information that they are then to perceive passively; or, does the interface require a user’s sustained involvement to complete the communication process? Similarly, the concept of range can be understood in terms of how diverse a user’s choices are within an interface. Is a user simply starting and stopping a predetermined course of action; or, is a user given the ability to collaborate with an interface in crafting a unique series of events? Finally, the concept of significance can be understood in terms of how noticeable the consequences of a user’s choices are within an interface. Is a user’s impact on the action being represented relegated to superficial changes; or, is a user’s activity within an interface the primary influence of what and how action is represented?

The final aspect I discuss of Laurel’s (1993) framework for conceptualizing human-computer interaction is *multisensory stimulation*. This approach to interaction design is another strategy for enhancing a user’s sense of direct engagement. The unique potential offered by multisensory stimulation is found in how it allows users to discern and develop connections

across sensory modalities between the phenomena presented by the interface (e.g., sights, sounds, smells, tastes, and touches).

For example, while a person can appreciate the individual sensory characteristics of a stimulus, such as an apple, and come to some understanding of the object, that person's understanding is significantly expanded if they are allowed to appreciate two or more of the sensory characteristics together. For interaction designers, the use of multisensory stimulation to create a feeling of direct engagement can greatly enhance a user's sense of agency, or first-personness within an interface. As Laurel (1993) explains, "Quite simply, the experience of first-person participation tends to be related to the number, variety, and integration of sensory modalities involved in the representation" (p. 117).

Yet, Laurel (1993) cautions, "we mustn't fall prey to the notion that more is always better, or that our task is the seemingly impossible one of emulating the sensory and experiential bandwidth of the real world" (p. 118). Instead, it is the designer's responsibility to be selective in which sensory modalities are employed as well as which stimuli therein. Thus, in addition to the principles of agency, collaboration, frequency, range, and significance, the concept of selective multisensory stimulation can be used by interaction designers to craft an emotional dimension of the relationship between human and computer, and in turn promote users having engaging computing experiences. Below, I discuss several additional principles that are key to understanding interaction design as a specialty area.

Visibility. The principle of visibility argues for making the actions that a system allows apparent to the user of the system. This includes the consequences of those actions (once initiated) as well as the status of the system (if changed or waiting). As Rogers et al. (2007) explain, "The more visible functions are, the more likely users will be able to know what to do

next” (p. 29). Lidwell et al. (2003) elaborate, “When it comes to the design of complex systems, the principle of visibility is perhaps the most important and most violated principle of design” (p. 202).

Mapping. The principle of mapping argues for a corresponding relationship between a control’s characteristics (e.g., placement, movement, etc.) and the effect it produces. As Lidwell et al. (2003) explain, “Good mapping is primarily a function of similarity of layout, behavior, or meaning” (p. 128). For example, consider a car’s power window control that is placed on the car door and is toggled up and down to move the window up and down.

Feedback. The principle of feedback argues for providing back to the user of a system information about what action has been undertaken by the system. The purpose of this information is for the user to understand the state of the system. As Rogers et al. (2007) explain, “Various kinds of feedback are available for interaction design—audio, tactile, verbal, visual, and combinations of these” (p. 31). Norman (1988) elaborates, feedback “is a well-known concept in the science of control and information theory” (p. 27).

Constraints. The principle of constraints argues for limiting the actions that a system allows for the sake of making the system easier to use (correctly). Norman (1988) classifies constraints into four categories: physical, semantic, cultural, and logical. An example of a physical constraint is an electrical plug that cannot be plugged into an outlet incorrectly; an example of a semantic constraint is the use of a skull and crossbones symbol to denote poisonous contents; an example of a cultural constraint is use of the color green to connote “go;” an example of a logical constraint is a volume control with up and down buttons (Lidwell et al., 2003).

Consistency. The principle of consistency argues for designing the components of a system that have similar purposes to look and/or operate in similar ways. As Lidwell et al. (2003) explain, “consistency improves usability and learnability by enabling people to leverage existing knowledge about how the design functions” (p. 46). An example of consistency in interaction design is the consistent user action of clicking to trigger the control of audio playback components. Use of the system would be significantly more complicated if each control required a different user action (e.g., hovering, clicking and dragging, double-clicking, etc.).

Affordance. The principle of affordance argues for designing the physical characteristics of an object to correspond to its function. For example, a button affords pushing; very few people would approach a conventional button and try to slide it up or down. Norman (1988) explains, “When affordances are taken advantage of, the user knows what to do just by looking: no picture, label, or instruction is required” (p. 9).

The discussion above has addressed different approaches to design, time-honored ways of thinking about human action and human-computer interaction, as well as several design principles. All of this was provided to establish interaction design as a specialty area within the overlapping purviews of HCI and design. The next section of this review addresses another fundamental aspect of interaction design, but this one unites it with many of the disciplines discussed thus far.

2.2.3: Importance of empathy in design practice (and elsewhere)

If the concept of death is the bedrock of this literature review, then the concept of empathy is its pervading atmosphere. Introduced to the English language in 1908, *empathy* was translated from the German *Einfühlung* (*ein* "in" + *Fühlung* "feeling"), which had been previously translated

from the Greek *empathia* (*en* "in" + *pathos* "feeling") in 1858 (Online Etymology Dictionary, n.d.). Merriam-Webster (n.d.) defines empathy as “the action of understanding, being aware of, being sensitive to, and vicariously experiencing the feelings, thoughts, and experience of another” (para. 1).

Empathy has been a topic of significant debate amidst philosophers interested in phenomenology (explained in Chapter 3: Methods). The concept of empathy played a “crucial role in [Husserl’s] transcendental phenomenology” (Luo, 2017, p. 45). Heidegger (1920) also admits, “Every word, every act is only understood in that the person expressing them shares a common ground (*Gemeinsamkeit*) with the one who understands (what we now call ‘empathy’)” (para. 17, as cited by Ferencz-Flatz, 2015, p. 490).

Likewise, empathy has long been considered an integral component of the therapist-client relationship. Carl Rogers (1974/1980), distinguished psychologist, elucidates, “I and my colleagues realized that this empathic listening provided one of the least clouded windows into the workings of the human psyche, in all its complex mystery” (p. 50). The role of empathy in the therapeutic context continues to be explored and elaborated in contemporary counseling practices. Finset and Ørnes (2017) add to the discipline’s ongoing discussion of an expanded definition of empathy as a “sequence, starting with the patient’s expression of emotion, followed by the perception, vicarious experience, and empathic response by the clinician” (p. 65).

Empathy has also emerged as a transdisciplinary element of design practice. Stanford University (n.d.) positions empathy as the first in its five-stage designing thinking process, describing it as “the centerpiece of a human-centered design process” (p. 2). The complete five stages of this process are (in brief): *empathize* (research users' needs), *define* (state users' needs

and problems), *ideate* (challenge assumptions and generate ideas), *prototype* (choose and create a solution), and *test* (try the solution against the problem) (Dam & Siang, 2021).

As Wright and McCarthy (2008) elaborate, “empathy has been used as a defining characteristic of designer-user relationships when design is concerned with user experience” (p. 637). Yet, they go further than Stanford University and present a perspective on empathy and users’ experiences that is not confined to a particular phase of the design process. Their perspective considers user experience holistically and treats as inseparable “people’s intellectual, sensual, and emotional responses, and [...] conceptualizes self, artefacts, and settings as multiple centres of value interacting with each other” (p. 638). They argue that

an empathic methodology does not stop after fieldwork and direct engagement with the participants/users. It also carries through into the genre used to give expression to member’s experience in the analysis (p. 640).

Here, we arrive at an appreciation for empathy that resonates more profoundly with my own. For me, empathy is not a sequential module within a problem-solving process. It is a mindset I attempt to maintain moment-to-moment, not just throughout the entirety of my interaction design practice—but throughout all my interactions, broadly speaking. It is this mindset I have sought to bring to the totality of this project.

The focus and scope of this project were defined based on the unique perspective I believe I bring to the stated problem context. I have over twenty years’ experience as an interaction designer. Since 2009, I have been actively engaged in supporting those affected by trauma and bereavement. I am also a bereaved parent. This is not a qualification I would wish

upon anyone, yet it uniquely credentials me for investigating the experiences of the target user group. As Tedeschi and Calhoun (2004) explain, “because parental bereavement deals with the loss of the most precious person, empathy born of direct experience is usually more of an issue” (p. 19) for parents.

GoodGoodGood (2023) attributes the following quote to Max Carver, an actor and activist (original source unknown)

Empathy is the starting point for creating a community and taking action. It’s the impetus for creating change (On Leadership section, para. 9).

As an interaction designer, I believe in the power of focused change. Below, I discuss the work of others who have also engaged in focused change to address the “issues of human mortality, dying, and death” (Massimi, 2010, p. 2952) in the context of technology design.

2.2.4: Significant TSD-related interaction design research projects

Michael Massimi and Andrea Charise, both graduate students at the University of Toronto, introduced the concept of thanatosensitivity to the HCI community at the 2009 Conference on Human Factors in Computing Systems (CHI 2009³). Their paper, entitled *Dying, Death, and*

³ The inconsistencies in the acronyms (e.g. HCI vs. CHI) as well as the discrepancies in their meaning (e.g., CHI being used to describe the Conference on Human Factors in Computing Systems) has long been a source of confusion for those new to the HCI community. An

Mortality: Towards Thanatosensitivity in HCI, begins by describing their goals for TSD (discussed previously) and then outlines a rationale for using a humanistic approach for establishing this perspective on technology design.

Their argument proceeds first by describing a humanities-based methodology as less invasive. Comparing this humanistic approach to conventional computer science methods, they assert, “studies of death and mortality are rarely amenable to laboratory study [...] To ask participants to test a new prototype or answer interview questions while they are grieving can be ethically, logistically, and technologically difficult” (2009, p. 2461).

The second aspect of their argument is based on mortality being universal in the human experience, and thus, the humanities’ multi-millennia consideration of this experience represents a wealth of knowledge. They explain, “Employing the critical humanist tradition as a preliminary theoretical approach places current issues in HCI research within a much-needed historical perspective” (Massimi & Charise, 2009, p. 2462).

Their paper also identifies several areas of HCI research that they believe have potential to incorporate TSD. These areas consist of: user-centered design, user modeling, intelligent agents, research methodology, and privacy. The TSD-related projects described below touch on each of these categories but prioritize user-centered design and research methodology.

A year later, at CHI 2010, Massimi, along with his doctoral thesis supervisor, Ronald Baecker, presented a survey and interview study which they describe as “one of the first

explanation of the source of the inconsistency can be found here:

<https://sigchi.org/conferences/conference-history/chi/>

characterizations of technology use by the bereaved” (Massimi & Baecker, 2010, p. 1821). Their investigation examines three areas: inheriting technology, using technology to remember, and changes in behaviors and attitudes. I briefly describe their rationale for each area below.

Massimi and Baecker’s (2010) interest in technology inheritance stems from the dual digital/physical nature of computing devices. For example, an inherited computer may offer a library of digital photos, or itself may be considered a linking object (Wheeler, 1999; Klass, 1993; Volkan, 1971; 1981). One goal with this area of investigation is to consider “what new kinds of practical problems occur as a result of inheriting data” and devices (p. 1821).

Massimi and Baecker’s (2010) interest in the use of technology to remember is based on the ubiquity of honoring the deceased in most cultures. They list symbolic artifacts including gravestones, photos, jewelry and clothing as examples of material objects historically used in remembrance. This area of investigation seeks to identify how “digital artifacts [can] support or replace more material ways of remembering” (p. 1822).

Massimi and Baecker’s (2010) interest in potential changes in bereaved people’s technological behaviors and attitudes towards technology extends from other ways the death of a loved one can cause new responsibilities and ways of thinking. For example, the death of a spouse may result in the development of new skills (e.g., home maintenance). Thus, they investigated the extent to which the “bereaved become more aware of their digital estate after the death of a loved one” (p. 1822).

From these areas of investigation Massimi and Baecker’s (2010) identify a list of ten opportunities for TSD. These opportunities are summarized as follows:

1. *The Generational Problem*: This problem assumes that, with each passing generation, an increasing number of meaningful artifacts will be digital, and to date, “well-considered ways to inherit them still do not exist” (p. 1829).
2. *The Claiming Problem*: This problem extends from a lack of deliberately designed affordances for claiming or bequeathing an item.
3. *The Will-Drafting Problem*: This problem emerges from the susceptibility of digital assets being omitted from the will-making process.
4. *The Domestic Data Problem*: This problem stems from the shared ownership that can govern technology use patterns within a household and the social dynamic challenges that can result from a changed social structure.
5. *The Desirable-to-Inherit Problem*: This problem considers situations in which a dying individual wants to bequeath an object and the importance of aesthetics and sustained functionality.
6. *The Role Inheritance Problem*: This problem addresses the “social and practical role commitments” (p. 1829) one takes on when inheriting data.
7. *The Support Problem*: This problem acknowledges the dearth of social support technologies available to the bereaved.
8. *The Reconciliation Problem*: This problem stems from the challenges of digital legacy management and reconciling one’s impressions of the deceased in life and in their digital assets.
9. *The Afterlifelog Problem*: This problem reimagines lifelogging technology as means for communicating after death.

10. *The Attitude Spectrum Problem*: This problem emerges from the general naïveté that many people have as to the potential problems associated with one’s digital assets after death and advocates for supporting “informed decision-making surrounding this issue, and provid[ing] options for a range of data distribution policies after death” (p. 1830).

Also at CHI 2010, Odom et al., a research team that bridged Carnegie Mellon University's Human-Computer Interaction Institute, Microsoft Research at Cambridge, and University of Nottingham's Mixed Reality Lab, presented another interview study that built upon Massimi and Charise’s (2009) introduction of TSD. In this study, Odom et al. (2010) discuss relevant social science literature as a means for establishing a theoretical lens through which they examine technological issues related to bereavement. They describe their goal in doing so as, to “sensitize the design space in ways that might better support the social processes that unfold when bereavement occurs” (p. 1831).

Odom et al. (2010) use their theoretical lens to discuss the findings of 11 in-depth interviews. From this discussion, they distill two areas of priority. The first is the *moral endurance of an archive*, or the development of “more nuanced practices of owning, storing and managing materials, in ways that enable appropriate relinquishment beyond the life of the owner” (p. 1838). The second is *richer forms of contextualization*, or the ability to “implicitly or explicitly ascribe explanation or descriptive contextual attributes to convey why an object is significant to the owner and why it may be of significance to the receiver(s)” (p. 1839).

Odom et al. (2010) then explore these priorities to suggest several areas for future research. These areas are summarized as follows:

1. *Designing for deep storage, sedimentation & graceful decay*: This research area might include developing dynamic storage hierarchies (e.g., layered storage mechanisms based on permissions, means for detecting more and less significant content over time, etc.).
2. *Clarifying exchanges through contextualizing content*: This research area might explore the use of metadata to distinguish meaningful digital artifacts from the trivial (e.g., incorporating narratives into digital objects, enabling collaborative interactions, etc.).
3. *Emphasizing reciprocity & engagement*: This research area might include developing means for reducing unmanageable amounts of digital data to identify and prioritize the most significant (e.g., mechanisms for determining smaller collections, incorporating richer interaction, etc.).
4. *Marking shifting status and state*: This research area might explore deeper integration of life states (e.g., married, new parent, deceased, etc.) into communication system design.

From the two papers discussed above, we see that—in the span of a single year—the HCI community expounded on the concept of TSD sufficient to establish a diverse set of problem contexts and areas for future research. Based on this literature review’s previous discussion of sociological ideas related to death and influential psychological perspectives on grief, two of these opportunities—Massimi and Baecker’s (2010) *The Support Problem* and Odom et al.’s (2010) *Emphasizing reciprocity & engagement*—appear to have special potential for addressing

digital memorialization. The next two papers discussed were presented the following year at CHI 2011; each is concerned with one of these opportunities.

Building on their previous work determining opportunities for designing for the bereaved, Massimi and Baecker (2011) report on a follow up study that presents three categories of considerations for those designing systems to support bereaved parents. The development of these categories is based on an analysis of findings from three focus groups, diverse observational field work, and discussions with bereavement professionals. These categories are *interpersonal communication*, *new ways of being in the world*, and *materiality*, each briefly discussed below.

Massimi and Baecker (2011) address the challenges of both private and public communication following the death of a loved one. They draw upon Martin and Doka's (2001) grief pattern framework for discussing the tensions that can arise between family members who may have different grieving styles (e.g., *intuitive* or *instrumental*). They also discuss the complex social dynamics that can arise between members of disparate social structures.

Thus, Massimi and Baecker (2011) arrive at two considerations related to interpersonal communication. They describe the first as *managing communication availability*. Borrowing from Sudnow (1967), they use the metaphor of concentric circles to map out levels of intimacy for various social structures. They highlight the potential value of a system that allows bereaved parents to manage to whom and when they are reachable.

They describe the second interpersonal communication consideration as *storytelling*, *narratives*, and *the importance of time*. Their justification for this consideration aligns with the first two tenets of Neimeyer's Meaning Reconstruction Model (Neimeyer, 1998; Neimeyer, 2001; Gillies & Neimeyer, 2006), *narrative truth* and *discourse and rhetoric*. Massimi and

Baecker (2011) explain the importance of storytelling during bereavement as it relates to meaning making as well as describe the importance of sharing stories with others in creating opportunity for affirmation.

Massimi and Baecker (2011) also address the struggles that bereaved parents experience related understanding their place in the world. They call out Parkes's (1970) concept of one's damaged *assumptive world* as a means for explaining the disorientation bereaved parents can feel. They also emphasize the profundity of parental bereavement in explaining the longevity of many parents' grief processes.

From this, Massimi and Baecker (2011) arrive at two considerations related to new ways of being in the world. They describe the first as *permanence and continuity*. They explain how many parents do not conceive of parental bereavement as something one recovers from, and instead as a new permanent state. Their explanation aligns with Klass's (1993) description of parental bereavement as involving adapting and growing, not recovering to a previous state of being. Massimi and Baecker argue that thanatosensitively designed systems for bereaved parents would consider this permanent change in parents' senses of self.

Massimi and Baecker (2011) describe the second consideration as *expression and emotion—finding something to do*. They argue that “if the bereaved are in a state where they are permanently changed in thought and emotion, there must be manifestations of this change to be found in their behaviour” (p. 1006). Thus, they outline three categories of bereavement activities (e.g., group/prescriptive, group/creative, individual/creative) that might become mediated by technology. They justify the potential value of these activities as new ways for parents to do their grief work.

Massimi and Baecker (2011) also address the materiality of the grief process. They describe how material objects can be involved in grieving activities. Thus, they propose two considerations related to the materiality of grieving.

The first is *heterogeneity, sediment, and upkeep*. Massimi and Baecker (2011) acknowledge the potential for special possessions to take on the significance of linking objects (Wheeler, 1999; Klass, 1993; Volkan, 1971; 1981). They also highlight the wide range of objects that may do so. Thus, they argue for system design that facilitates a heterogeneous mix of content types. They also discuss the potential value of allowing memory items to accumulate in a system over time. They explain how this development of sediment can be helpful for understanding one's changing thoughts and emotions throughout the grieving process. They also discuss how sediment might facilitate ongoing maintenance of a system, which "can be a treasured activity and not necessarily an unwanted burden worth automating" (p. 1008).

Finally, Massimi and Baecker (2011) describe the second consideration as *display and control of mourning symbols*. Like with *managing communication availability* above, the thinking behind this consideration reflects Massimi and Baecker's (2011) understanding of grieving as a dynamic process and the individuality of different people's responses to bereavement. They advocate for systems "that enable the bereaved to control how much they wish to share, and how much they wish to hide" (p. 1008) at different moments in time.

The second paper presented at CHI 2011 that I discuss reports on a small study involving emerging grieving practices on Facebook. Getty et al. (2011), a research team from Cornell University, analyzed messages from the friends and family of 11 deceased Facebook users to better understand this new frontier of mourning. Key amongst the study's findings is that

“mourners use profiles as a way to maintain a continuing bond with the deceased, as well as a way to accomplish specific front stage bereavement communication” (p. 997).

Getty et al. use Turner and Edgley’s (1976) *death as theater* metaphor to delineate *front stage* activities, such as public expression of grief, from *back stage* activities, such as private grieving practices. They explain that, historically, front stage grieving activities have been part of death-related ceremonies, and thus restricted to a particular time and place. They argue that “in our increasingly mobile society, social networking sites should provide [a front stage] space that is not bounded by space or time for grieving individuals to come together” (p. 998).

Getty et al. (2011) present several additional suggestions for redesigning Facebook’s memorialized user pages. These suggestions include establishing separate spaces for community interaction, messaging the deceased directly, image sharing, condolences, etc. More germane to this discussion than the merit of Getty et al.’s suggestions is that their argument for using Facebook as a public mourning context aligns with Odom et al.’s (2010) thoughts related to emphasizing reciprocity and engagement as a future area for research. Specifically, the curation that users exercise when selecting content to upload to Facebook may prove to be a valuable mechanism for “enabling people to carefully craft and deliver smaller selections of digital materials” (p. 1839) and thus facilitate less problematic inheritance of a person’s digital data.

The next two interaction design research projects demonstrate TSD’s continued maturation as a research emphasis and report on researchers’ ongoing work related to Massimi and Baecker’s (2010) *The Support Problem* and Odom et al.’s (2010) *Emphasizing reciprocity & engagement*. The first is a project presented by Massimi at the 2013 Conference on Computer-Supported Cooperative Work & Social Computing. The second is a framework developed for both analyzing and guiding the design of digital memorials.

Massimi's (2013) presentation focused on "Besupp, a website where bereaved individuals can participate in online support groups" (p. 1169). Besupp, a contraction of *bereavement support*, is the name Massimi (2012) gave the system, which he created in partial fulfillment of his doctoral thesis in computer science.

The Besupp system was comprised of two main components. The first was *The Circle*, which allowed "users to create profiles, share background stories, and converse with peers in an effort to create a social support environment" (Massimi, 2013, p. 1169). The second was a *Memory Box*, which supported "remembrance about the deceased by offering a place to host and share digital mementos" (Massimi, 2013, p. 1169). Massimi uses the phrase "digital mementos" to describe the five content types that users could include in their Memory Box: "photos, videos, stories, links, and journal entries" (p. 1172).

Massimi (2013) reported on a study that involved monitoring three support groups' use of Besupp over ten weeks. The support groups were established based on demographic characteristics (e.g., young adult, bereaved parents, and spousal and partner loss). In addition to observing use patterns, Massimi also conducted semi-structured interviews with each participant at the beginning, middle, and end of the study.

Based on the observational findings and interview data, Massimi (2013) describes "a series of implications for the design of systems for social support, remembrance, and bereavement more generally" (p. 1178). These implications are summarized as follows:

1. *The value of digital mementos changes over time*: Participants used these digital assets more toward the beginning of the study for getting to know one another but were "less useful resources in a support setting" (p. 1178).

2. *Consider distinctions between loss and grief*: Digital mementos were helpful in sharing loss but gave rise to emotions that complicated grief support.
3. *People who have learned to cope can find value in offering support to those with fresher losses*: Support system design can acknowledge those further along in their grief journeys.
4. *Systems should be designed for intermittent use*: Use patterns indicate that participants adopted the system as a “a place to unload thoughts and feelings, log out, recharge for a few days, and then revisit later” (p. 1178).
5. *Consider ways to mitigate burnout*: Support group communication can be exhausting; designing constraints into the system to reduce availability may prove helpful.
6. *Technology operates among a rich set of supports*: Online communication should not be seen as a way to replace in-person interaction.

The next TSD-related interaction design research project represents a narrowing in the focus of this discussion. At the 2014 Conference on Designing Interactive Systems, Wendy Moncur, University of Dundee, and David Kirk, Newcastle University, presented a framework for better understanding and creating digital memorials. Building on earlier TSD-related work, Moncur and Kirk (2014) describe this framework as “grounded in examples of current memorialization practice, and situated within a contextual understanding of memorials as an emergent digital phenomenon within a networked society” (p. 965). They explain the framework as divided into four components: *actors*, *inputs*, *form*, and *message*, each of which is briefly discussed below.

The first component of Moncur and Kirk’s (2014) framework is *actors*. They split the actors involved in digital memorials into two groups: authors and audience. They describe

authors as those responsible for bringing a memorial into being. They explain that “a memorial may be authored by an institution, multiple authors, an individual, or even by the deceased in a process of self-memorialization in advance of their death” (p. 966). Moncur and Kirk define the purview of the author(s) as accountable for the scope and maintenance of a memorial’s content as well as a memorial’s narrative voice. They explain how the make-up of the authorship affects the narrative characteristics of a memorial, with multiple voices resulting in heteroglossia, or “a diversity of voices, styles of discourse, or points of view in a literary work” (Merriam-Webster, n.d., para. 1).

Moncur and Kirk (2014) describe memorial audiences as those who will witness the memorial. They explain the perspective of audiences as “situated on a spectrum from public to private, and may change over time” (p. 967). They discuss how an audience’s point on this spectrum can result in both public and private experiences with a memorial. To substantiate this point, Moncur and Kirk describe large national memorials that are positioned in public spaces but allow for private interactions, such as audio content that is accessible via mobile phone. They also discuss informal memorials, such as roadside shrines, and in-home memorials, such as spiritual alters, as providing different mixes of public and private experiences.

The second component of Moncur and Kirk’s (2014) framework is *inputs*, which they divide into three types: *subject*, *circumstance* and *content*. Amongst these types, they delineate between subject and circumstance as being determined by past events, and content which is determined by a memorial’s author(s). They discuss a memorial’s subject matter as usually concerned with people, events, or places. They qualify the circumstances leading to a memorial in terms of being expected/unforeseen, timely/premature, and tragic/traumatic. They also outline

the content types commonly included in a memorial as material possessions of the memorial's subject, memories/testimonies provided by the living, and/or material elements of the subject.

Regarding material possessions of the memorial's subject, Moncur and Kirk (2014) emphasize the potential of these artifacts to "take on sacred qualities, as they are imbued with emotional and symbolic meaning through their power to invoke memories of the dead" (p. 968). This assertion aligns with previous discussion on the subject of linking objects (Wheeler, 1999; Klass, 1993; Volkan, 1971; 1981).

The third component of Moncur and Kirk's (2014) framework is *form*. They discuss three axes by which the form of a digital memorial can be understood. The first of these axes describes the extent to which the memorial is digital. Memorials can be wholly digital, a hybrid of digital and physical elements, or almost completely physical.

The second of these axes addresses the experiential dynamics of a memorial. Moncur and Kirk describe the simple end of this axis as concrete, and use the example of a virtual gravestone. Conversely, they describe the complex end of this axis as performative, and use the examples of audience members' physical behaviors and/or speech executed as part of rituals.

The third of these axes explains how the form of a memorial may change over time. On one end of this axis is the notion of a memorial being static, or functioning to preserve a record of its subject. On the other end of this axis is the concept of evolution.

To discuss a memorial's evolution over time, Moncur and Kirk introduce the ideas of active and passive evolution. The former is used to describe situations in which a memorial changes as a result of deliberate human action, for example, contributions to a memorial's content. The latter is used to describe how a digital memorial can change as the result of neglect,

for example, older digital components ceasing to function due to incompatibility with newer components.

The fourth component of Moncur and Kirk's (2014) framework is *message*. They discuss the concept of message in terms of the intentions of a memorial's author(s). They present two axes by which authors' intentionality—and thus, a memorial's message—may be understood. The first of these axes ranges from personal to cultural. Moncur and Kirk describe how some authors' intent may only be to make sense of a loss. Conversely, some authors may intend to communicate a broader societal message.

The second of these axes ranges from sacred to secular. Moncur and Kirk discuss how the essence of some memorials is dependent on connections to larger spiritual or religious worldviews. Alternatively, some memorials are not, and instead convey their significance through more earthly connections.

The discussion in this section of the literature review has involved several significant TSD-related interaction design research projects. This has included the introduction TSD to the HCI community as well as early work considering problem contexts and areas for future research. The discussion also addressed work related to Massimi and Baecker's (2010) *The Support Problem* and Odom et al.'s (2010) *Emphasizing reciprocity & engagement* and highlighted ideas connected to digital memorialization. This included implications for the design of systems for social support as well as a framework for analyzing and guiding the design of digital memorials. As such, this discussion has traced the development of TSD as a research emphasis—with a special interest in digital memorialization. The next section of this review considers two more interaction design research projects that can be understood as exploring the convergence of ideas related to bereavement support and engagement.

2.2.5: Select TSD-related digital memorial designs

This final section of this literature review addresses two distinct, yet related interaction design research projects. Each project represents a novel approach to digital memorial design. I selected these projects based on the ideas and forms they explore as well as their connections to TSD. I provide an overview of each project below.

The first of these projects is Moncur et al.'s (2015) *Story Shell*. In a paper presented at the 2015 Participatory Innovation Conference, Moncur et al. describe drawing upon Moncur and Kirk's (2014) framework for memorial design (previously discussed) and explain their use of a participatory design⁴ process to partner with a bereaved mother to create a bespoke memorial for her deceased teenage son. Moncur et al. (2015) describe their research methodology as "research through design, whereby research uses design action as a tool or a method of inquiry" (p. 471).

In defining the context of the project, Moncur et al. (2015) cite Massimi and Baecker's (2011) work in which they present three categories of considerations for designing systems to support bereaved parents (*interpersonal communication, new ways of being in the world, and materiality*), previously discussed above. Moncur et al. (2015) also state their belief that "with thoughtful design, technology may support an ongoing (if asymmetric) relationship whereby the

⁴ Participatory design can be understood as "a collaborative design approach that involves end-users in the design process. Its aim is to create products and services that better meet the needs and expectations of users by applying their knowledge and experiences" (Interaction Design Foundation, n.d., para. 1).

bereaved continues their relationship with a deceased loved one” (p. 471). Thus, the project can be understood as philosophically aligned with the thoughts underlying Continuing Bonds theory (Klass et al., 1996; Klass, 1993). The project proceeded through five phases: planning and participant recruitment, requirement gathering, idea generation, creating, and deployment.

The final product of the process (Figure 7) is a 14-centimeter spherical hand-held audio playback device. The shell of the device is a 3D-printed plastic sphere with an open top. Inside the sphere are an Arduino microcontroller, spatial positioning sensors, a speaker, LED lights, and decorative laser-cut paper to hide the digital technology.



Figure 7. *Story Shell* (Moncur et al., 2015).

In their paper, Moncur et al. (2015) use Moncur and Kirk’s (2014) framework for memorial design to analyze the final product of the project. However, their doing so does not account for all the framework’s components. To better understand both the *Story Shell* memorial and the framework, I repeat this analysis below in greater detail.

The first component of Moncur and Kirk's (2014) framework is *actors*. The first subcomponent of actors is authors, who define the scope of a memorial and are responsible for its maintenance. Thus, both the bereaved mother and Moncur et al. (2015) are authors of the memorial. The second subcomponent of actors is audience, the nature of which is explained as situated on a spectrum from public to private. The audience for *Shell Story* a very private. Moncur et al. (2015) describe the memorial is "intended for only one person at a time" (p. 474).

The second component of Moncur and Kirk's (2014) framework is *inputs*. The first subcomponent of inputs is subject, which is usually people, events, or places. The subject of *Shell Story* is the deceased teenage son. The second subcomponent of inputs is circumstance, understood in terms of being expected/unforeseen, timely/premature, and tragic/traumatic. Moncur et al. (2015) describe the death as unexpected; moreover, it would be difficult to understand a teenaged death as other than premature, tragic, and traumatic. The third subcomponent of inputs is content. The primary content of *Shell Story* are audio recordings of the bereaved mother telling stories about the teenage son. Secondary content of the memorial includes the LED lights and decorative laser-cut paper.

The third component of Moncur and Kirk's (2014) framework is *form*. The first subcomponent of form is an axis describing the extent to which a memorial is digital. *Shell Story* is a complex hybrid of digital and physical elements. The second subcomponent of form is an axis addressing the experiential dynamics of a memorial, from concrete to performative. *Shell Story* is a mix of these characteristics as it exists as a tangible object and involves rotational gestures to navigate the audio playback. The third subcomponent of form is an axis explaining how a memorial may change over time, from static to evolving. Other than the deterioration

inherent to physical material, *Shell Story* can be understood as static. Moncur et al. (2015) do not mention any intent to record additional stories.

The fourth component of Moncur and Kirk's (2014) framework is *message*. The first subcomponent of message is an axis addressing the intended breadth of the message, from personal to cultural. *Shell Story* has a very personal message. Moncur et al. (2015) explain, "without thinking about it [the mother] naturally addressed [the teenage son] directly in her stories, for example by saying 'Do you remember when you were little...'" (p. 476). The second subcomponent of message is an axis ranging from sacred to secular. The message of *Story Shell* is predominantly secular. Moncur et al.'s only mention otherwise is in reference to the experience provided by the memorial, which they describe as "containing qualities akin to the quiet reflection afforded by prayer and meditation" (p. 474).

The second approach to digital memorial design is Wallace et al.'s (2020) *ReFind*. In a paper presented at CHI 2020, Wallace et al. explain the project's broader context, the design and construction of the memorial, and findings from an "emergent" (p. 1) experiential methodology. They describe this methodology as "autobiographical design [which] can yield [...] deep experiential understanding, often leading to reflection on ethical implications of a design, but not generalizable knowledge" (p. 3).

Wallace et al. (2020) explain their application of autobiographical design as involving the first author's use of the memorial over 10 weeks. They describe this use context as "lived experience" (p. 1). They explain this approach as being

not about generalizability of the specifics of the design itself. The approach gave us the ability to critique our design from a new, personally invested vantage point. It also enabled a number of deep insights and understandings (p. 8).

Wallace et al. (2020) further define their approach by distinguishing it from previous work focused on bespoke memorials,

It is significant to mention that although we were clear that the first author was going to use the final design, we were not conceiving something bespoke for them. We wanted to make something that other people could also use and tailor to themselves within the life of the wider project. Our design process took an open, product design route, rather than a bespoke tailored one because of this (p. 4).

In describing the basis of their investigation, Wallace et al. (2020) cite Massimi and Baecker (2010), Odom et al. (2010), as well as Moncur et al. (2015). Thus, their work can be understood as grounded in TSD. Wallace et al. (2020) also call out Klass (1993) and Klass et al. (1996) in explaining the goals of their investigation. Wallace et al. (2020) elaborate,

We take as our starting point the notion of ongoingness in continuing bonds [...] our work envisions dynamic and future-focused forms of continuing bonds and seeks to further develop ongoingness as a theoretical construct and pragmatic resource for design [...] Ongoingness practices have characteristics of an active and dynamic continuation of a

relationship [...] We are keen to investigate if and how it is possible to go beyond feeling a connection to the deceased to experiencing a form of ‘dialogue’ with them (p. 2).

To pursue these goals, the first author curated an archive of 63 images of her deceased mother. Wallace et al. (2020) cataloged these images in an online database and tagged the images’ entries with keywords corresponding to the images’ content. They also created a web app that allowed the first author to send a new image to the database’s Web server. This process involved using a Web browser to upload the image and tag it with keywords that corresponded to its content. Upon receiving this new image and data, the Web app would evaluate the new image’s keywords, select the five most similar images of the first author’s deceased mother, and then send this set of five images and the most recently uploaded image to a hand-held image viewer (Figure 8).



Figure 8. *ReFind* (Wallace et al., 2020).

The final design of this hand-held image viewer is an 8.5-centimeter by 1.4 centimeter disc. The main structure of this disc-shaped image viewer is made from Corian, a synthetic solid surface material. This structure holds a “a deconstructed Fossil Q DW5A smartwatch running Android Wear 2.0 OS” (Wallace et al., 2020, p. 6). The smartwatch screen is kept in place by crystal glass, a brass housing, and steel screws. To better understand the *ReFind* memorial, I briefly analyze it below using Moncur and Kirk’s (2014) framework.

The authors of *ReFind* are the first author and the rest of the research team. The audience for the memorial is very private. The subjects of the memorial are the first author’s deceased mother and the first author’s current life situation. The circumstance leading to the memorial is undisclosed. The content of the memorial is the archive of 63 images of the first author’s deceased mother and the images uploaded by the first author. The form of the memorial is a complex hybrid of digital and physical elements. The experiential dynamics of the memorial is a mix of concrete and performative characteristics as it exists as a tangible object and involves rotational gestures to navigate the images. The extent of change the memorial will undergo over time will be dictated by the durability of the materials and the number of images sent to it. The message of the memorial is very personal and secular in nature.

The discussion contained in this section of the literature review has addressed two novel approaches to digital memorial design. Both approaches draw upon TSD as a basis for their investigation. Similarly, both approaches involve explicit integration of Continuing Bonds theory. While the forms explored in these approaches vary, each uses curated selections of digital media in a compelling manner to support bereaved individuals. I present this discussion—along with the broader discussion contained in this review—as a theoretically and practically grounded means for understanding contemporary ideas and practices related to digital memorialization. I

see this understanding as foundational to understanding the project's research questions and key findings. In the following chapter, I describe the methods I employed to ask these questions and identify their answers.

Chapter 3: Methods

The primary method of investigation in this study is phenomenology. *Phenomenology* is a term used to describe the study of phenomena. The term can refer to a range of philosophical perspectives as well as a group of qualitative research methodologies (Gill, 2014).

Phenomenology began as a philosophical movement founded by German philosopher, Edmund Husserl. As Wojnar and Swanson (2007) explain, Husserl's key realization was that "consciousness was the condition of all human experience" (p. 173). Husserl attempted to apply this realization to first identify, and then suspend his prior conceptions about a phenomenon to achieve a direct perception of the events or objects of interest. In Husserl's opinion, it is this transcending of one's previous ideas that allows for pure description of a phenomenon (Gill, 2014). Husserl's goal in arriving at a pure description was to develop "a new fundamental science [that was] inferior in methodological rigor to none of the modern sciences" (Husserl, 1981, p. 10, as cited by Lichtman, 2013, p. 84).

Husserl's belief in the possibility of objective experience was challenged by many, most notably, Husserl's student, Martin Heidegger. Heidegger diverged from Husserl's attempts at a purely descriptive phenomenology. Instead, he developed a related but distinct hermeneutic—or *interpretive*—phenomenology.

Heidegger's concept of experience did not seek to separate the observer and the world. Instead, he conceived of the observer and the world as existing together, a concept he referred to as "Dasein" (Gill, p. 120). Thus, to allow for a clearer interpretation of a phenomenon, those interested in applying descriptive phenomenology would first reflect on, and then explicate related prior experiences, preconceptions, and biases (Wojnar and Swanson, 2007).

In the process of conducting interpretive phenomenology, understanding is achieved through a persistent back and forth between the parts of a situation (e.g., the observer, prior conceptions, the perceived phenomenon, etc.) and the whole (i.e., the context[s] comprising the parts). This process is understood as the hermeneutic circle (Smith, 2007). The work of phenomenological theorist, Friedrich Schleiermacher, provides insight into the process of interpretation. “For Schleiermacher, interpretation is not a matter of following mechanical rules. Rather it is a craft or art involving the combination of a range of skills, including intuition” (Smith, 2007, p.4). In analyzing interviews, Schleiermacher’s interpretive process proceeded on two levels, the grammatical and the psychological (Schleiermacher, 1998). In this way, he was concerned with both what was said and the person who said it. For example, to understand an individual’s assertion that “life is long” or “life is short,” one’s insight would likely be aided by considering that individual’s circumstances of existence (e.g., age, physical health, financial status, living situation, etc.).

Smith and Osborn (2004) echo this notion as they describe the process of interpretive investigation, “there is a wish to try to enter, as far as is possible, the psychological and social world of the respondent” (p. 233). Schleiermacher uses the word “intersubjectivity” to explain the possibility of one person making sense of another. Key to the notion of intersubjectivity producing understanding is how the parts share the context of the whole (Smith, 2007). Smith (2007) elaborates, “there is the possibility of bridging the divide between selves because we are all at the same time part of a larger whole, a collectivity that allows the possibility of mutual understanding” (p. 5).

Since its emergence, interpretive phenomenology has been applied as a qualitative research methodology to generate deep contextual understanding of situations and problems in

many fields of study. Qualitative research is based on a philosophical perspective known as ontological pluralism. Ontological pluralism, like constructivism discussed previously, rejects the idea of an objective reality in favor of relativism, or the belief in multiple equally valid perspectives on reality. As Johnson (2017) explains, this perspective on the nature of reality accepts that multiple, seemingly contradictory statements about reality can be understood as true or appropriate.

Creswell and Creswell (2018) describe qualitative research as “an approach for exploring and understanding the meaning individuals or groups ascribe to a social or human problem. [...] Those who engage in this form of inquiry support a way of looking at research that honors an inductive style, a focus on individual meaning, and the importance of reporting the complexity of a situation” (p. 4). To succinctly elucidate these ideas, Lichtman (2013, p. 18) cites Rubin and Rubin (2005) explaining that through qualitative research “you can understand experiences in which you did not participate” (p. 3).

Divergent approaches to using phenomenology as a research methodology have developed within the humanities and social sciences, “including nursing, pedagogy, and psychology” (Gill, 2014, p. 119). The differences between these approaches can include underlying philosophies, assumptions, goals, and processes. According to Heidegger (1982), “there is no such thing as the one phenomenology” (p. 328). To apply phenomenology as a research methodology, researchers must first contemplate the nature of the information they are trying to elucidate and then “consider the assumptions and implications of different types” (Gill, 2014, p. 127).

For this study, I selected Smith’s Interpretive Phenomenological Analysis (IPA) (Smith & Osborn, 2004; Smith, 2004; Smith, 2007). This selection was based on IPA’s philosophical

perspective and methodological goals. The defining features of this approach to phenomenology are that it is idiographic (focusing on the value of uniqueness), inductive (developing understanding from the particular toward the general), and interrogative (oriented toward answering a question). This study applies IPA to understand the experiences of bereaved parents when using digital media to create memorials for their deceased children.

I believe IPA holds special potential for addressing grief-related experiences due to how it “attempts to explore/understand/make sense of the subjective meanings of events/experiences/states of the individual participants themselves” (Smith & Osborn, 2004, p. 229). This emphasis on individual meaning-making aligns well with Neimeyer’s (1998; Neimeyer, 2001; Gillies & Neimeyer, 2006) Meaning Reconstruction Model for understanding bereavement. As discussed previously, the Meaning Reconstruction Model has emerged as one of the most influential theories for understanding the process of grieving. In short, meaning reconstruction—or the process of assimilating one’s grief experiences and evolving sense of personal identity—appears to be the central process of grieving (Neimeyer, 2001).

Smith (2004) elaborates on the emphasis on meaning-making within the IPA methodology, describing it as “double hermeneutic. The participant is trying to make sense of their personal and social world; the researcher is trying to make sense of the participant trying to make sense of their personal and social world” (p. 40). As Smith and Osborn elaborate, “[IPA] is particularly suitable where the topic under investigation is novel or under-researched, where the issues are complex or ambiguous and where one is concerned to understand something about process and change” (p. 231).

3.1: Forestructure Reflection

Due to the interpretive nature of qualitative inquiry, researchers interested in this form of investigation must acknowledge the forestructures of understanding that they bring to the research process. As Creswell and Creswell (2018) explain,

[A qualitative] inquirer is typically involved in a sustained and intensive experience with participants. This introduces a range of strategic, ethical, and personal issues into the qualitative research process. With these concerns in mind, inquirers explicitly identify reflexively their biases, values, and personal backgrounds [...] that shape their interpretations.

A key forestructure I bring to this project is my theory of knowledge. My theory of knowledge is based on a relativistic view of reality. This perspective allows for different people to have equally valid differing views of reality. My theory of knowledge posits that differing views of reality enhance knowledge. Thus, I understand knowledge as a social construct. I bring to this project a belief that data alone (quantitative or qualitative) are practically meaningless. Other than their content, data have no intrinsic value. Data only becomes meaningful when considered in terms of one or more person's values.

Another key forestructure I bring to this project is my identity as a bereaved parent. My experience losing a child has undoubtedly been influential in my life. I bring to this project a belief that one's present moment should be appreciated as much as possible. I also bring to this project a personal value that children are amazing and should be appreciated as much as possible.

Another key forestructure I bring to this project is my experience as an interaction designer. Not only have I used digital media to memorialize my own daughter, but I have also

created software-based tools to support others in similar processes, as described above. I bring to this project a belief that using digital media to memorialize my daughter has been helpful to my grieving process. I also bring to this project a belief that through creating software-based tools to support others in similar processes, I provided some sort of benefit to humanity.

3.2: Sample

To begin with IPA, Smith and Osborn (2004) argue for acquiring a homogenous sample. They explain, “having determined which group would be suitable for one’s research question, one attempts to make the group similar on obvious socio-economic variables: gender, age and so on” (p. 232). Their argument is based on the goal of the methodology being a deep understanding of a particular circumstance amongst a particular group. In addition to the potential for more cohesive insights, the homogeneity of one’s sample also helps “draws a boundary around the claims to generalizability” (p. 232).

In light of Smith and Osborn (2004) urging a homogenous sample, the primary inclusion criteria for this study are adult parenthood (aged 18+), experiencing the death of one’s child (aged zero–17), and the use of digital media to create a memorial. My rationale for limiting the inclusion to parents whose children were minors assumes that these parents would be at more similar stages in life than if I opened the study to bereaved parents who lost adult children.

As Smith (2004) explains, “It is only possible to do the detailed, nuanced analysis associated with IPA on a small sample” (p. 42). In this publication, he identifies a range of five to 10 participants as appropriate to the methodology. Later, Smith and Osborn (2004) state that IPA study sizes are usually between six and 15 participants. Gill (2014) asserts that IPA can be used in studies as small as “[one] or more” (p. 122). Considering this information and the goals

of the study, my initial target for the study's sample was five to 15 participants. However, I recognized that the exact number of participants would be determined when a point of saturation—or the time at which no significant new information is being discovered—had been reached in the data analysis.

Initially, I sensed saturation emerging after interviewing the study's fifth participant. I understood the participants describing many of the same experiences and explaining many of the same ideas. However, amongst these main themes there existed additional information that was not shared between participants. At the time, I was unclear if this additional information represented new main theme material—the significance of which I could expect to become clearer through additional participant interviews—or if it should be attributed to the individualized nature of grief processes. In consultation with the other members of the study's research team, Dr. Brad Hokanson and Dr. Laura Lewis, it was decided that an additional two or three participants should be interviewed, as doing so promised to support the study's findings either way.

In the end, the study's sample consists of eight participants, all of whom are bereaved mothers. Their ages range from early 30s to mid-60s years, with the mean age of the sample being 41.6 years. Seven of the participants identified as Caucasian Americans; one identified as Black and Puerto Rican American. Six of the participants identified as religious, four of which indicated a form of Christianity as their religion. The other religions mentioned are Unitarian Universalist and a personal Buddhism/Christian hybrid.

Seven of the participants are married or are in a live-in relationship; one participant is single. All eight participants achieved some type of post-secondary education. Six participants

have bachelor's degrees; one has an associate's degree; one has a Juris Doctorate. On average, participants rated their computer skills 7.1 out of 10.⁵

Participants skew toward intuitive grieving. Participants scored an average of 3.8 out of five on the GPI's intuitive questions. Participants scored an average of 2.1 out of five on the instrumental questions.

Participants' time since bereavement ranges between seven months and 11.5 years, with the mean time being 62.6 months, or 5.2 years. Seven of the participants lost a single child; one participant lost three children. The ages of the children lost by the participants ranges from approximately 20 days to 16 years, with the mean age of the children being 2,226 days, or approximately 6.1 years. Four of the participants cited removal from life support as the cause of their children's deaths; other causes cited include brain injury, homicide, suicide, and auto accident. Three of the participants described the loss of their children as unexpected.

3.3: Data Collection

To recruit participants for the study, I created a digital flyer (Appendix C) with the study's details and sent it to an array of organizations. These organizations include local grief groups, independent online grief support communities, social media-based grief groups, and grief blog authors. The flyer instructed interested persons to contact me to discuss the study and their eligibility for inclusion. Individuals who are not the adult parents of a deceased child, or who

⁵ Based on my conversations with participants and my experience with computers, I rated participants' skills an average of 5.1 out of 10.

have not used digital media to create a memorial, or who are members of a vulnerable population are ineligible for the study. Vulnerable populations for research include “children, prisoners, pregnant women, fetuses, mentally disabled persons, and economically and educationally disadvantaged persons” (Gordon, 2020, p. 35).

Eligible individuals who chose to participate were then scheduled for an interview. The first six participants were interviewed in-person at the location of their choosing. The last two participants were virtually interviewed via Microsoft Teams.

These meetings began by discussing informed consent (Appendix D). After consent was granted, the meetings proceeded by participants completing the Grief Pattern Inventory (GPI) (Appendix A) (Martin & Wang, 2006). The GPI is a validated tool for assessing Martin and Doka’s (2000) grieving patterns, as discussed previously in the literature review. The data from this tool will be used to inform the discussion of the study’s findings relative to existing bereavement literature.

Next, I conducted a semi-structured interview with each participant. The audio of these interviews was digitally recorded. The focus and sequence of the interviews were guided by a list of prepared questions (Appendix B). The flow of these interviews began with my attempting to learn about the participants’ lived worlds and their deceased children. This general focus at the beginning was intended to build trust with the participants. When I determined an adequate amount of trust had been built, the discussion shifted to the circumstances around their children’s passing. Following this, I sought to learn about how they have been dealing with their children’s passing.

This foundational information lead to discussing how they have used digital media to create memorials for their deceased children and the experiences they had doing so. These

discussions included why they chose which tool(s), what they made, and how their experiences were. I also asked them about how they *wished* they could use digital media to memorialize their children. This portion of the interviews often involved me experiencing what they made and/or witnessing how they use their tool(s).

Finally, I asked participants why they chose to create digital memorials for their deceased children. With this final area, I attempted to achieve as deep of an understanding as possible. This discussion included participants explaining how their memorialization serves them in their grieving and what the memorials mean to them.

The recordings of these interviews were then transcribed and analyzed to identify themes that align with the purposes of the study. I applied the IPA methodology to guide the nature of the analysis. I partnered with Dr. Laura Lewis in the early analysis of the interview data. The purpose of doing so was to calibrate the analysis process, as Dr. Lewis has significant experience with phenomenological analysis.

As Smith & Osborn (2004) describe, the IPA methodology proceeds first with an analysis of a single interview transcript, with the researcher(s) reading it closely for emerging themes. These themes are noted and organized hierarchically based on emphasis. Then, the researcher(s) move(s) to the second transcript and conduct(s) another close reading for themes. The researcher(s) then compare(s) the themes of the two transcripts to work toward developing a master list of themes. This process is carried out iteratively across all participants' transcripts. Once the master list of emerging themes is complete, the researcher(s) translate(s) it into a narrative with specific examples for support.

In the next chapter, I present the results of our analysis as a narrative of my experience. My primary goal for this narrative—and my inclusion of the specific examples contained

within—is to provide the descriptions required to answer the study's research questions. My secondary goal for the narrative is to establish a set of emotionally powerful statements that have the potential to inspire a sense of empathy within designers of digital media technologies, and thereby grant them a deeper understanding of their work. A tertiary goal for the narrative is to capture insights that represent opportunities for improving the technologies employed by bereaved parents. Each of these outcomes represents an expansion of TSD practices.

Chapter 4: Results

The purpose of this chapter is to report on the results of the analysis process explained above. As Smith and Osborn (2004) explain, the findings produced through IPA analysis “will form the results section of a project write-up, dissertation, book chapter or paper for publication” (p. 234). Thus, the discussion that follows presents the master themes that were identified through our analysis of the study’s interviews.

The structure of this chapter is based on a key philosophical tenet of IPA. As Smith (2004) describes,

The skill in writing IPA is in allowing the reader to parse the narrative in two different ways: a) for the themes which have emerged and which the participants share (but illustrate in particular ways); b) for the individual’s own account. By linking material presented on that person through the write up, one should be able to learn something about both the important generic themes in the analysis, but also about the life world of the particular participants who have told their stories (p. 42).

Therefore, to support this bi-modal reading of the chapter’s narrative, I begin by briefly introducing each participant. My goals in doing so are to provide insight into their life worlds and begin to demonstrate the main themes that emerged during the analysis process. Following this introduction, I expound on these master themes. My explanation of these themes is guided by the study’s research questions. The chapter finishes with an overview of additional insights that were identified during the analysis process. These additional insights include special cases

and themes that are aligned with the purpose of the study, but that do not directly relate to the project's research questions.

4.1: Participant 1

Participant 1 is in her early 30s, a wife, and a mother of one. She lost her son due to a brain injury when he was approximately 20 days old. Participant 1's Grief Pattern Inventory (GPI) results indicate she is primarily an intuitive griever. She scored 4.16 out of five on the intuitive questions and 1.66 out of five on the instrumental questions.

Participant 1 is a year and a half into her bereavement. She says of her journey, "It's getting better. It's getting better, yeah." My impression of Participant 1 is that of an optimistic, hard-working individual. She describes her family's time in the neonatal intensive care unit,

I was down there from probably 6:00 AM every day until like midnight. Doing my schoolwork. [...] The only thing that I could like do for him was pump. So, I just pumped every two to three hours like clockwork all through the night.

She describes her philosophy on life, "You have no idea what's going on in someone's life. Like, just be nice to them."

As with the other participants, Participant 1 created a slideshow to memorialize her son. She used it as part of a grief talk she did for a local grief group. However, this slideshow makes up only a small part of her memorialization efforts with digital media. Participant 1 is an avid user of social media, particularly TikTok. She posts about her bereavement journey regularly. She has thousands of followers.

She describes her thinking behind her sharing, “Even though, like you go through this extremely terrible, terrible situation. We have learned so much from it, and it would be doing him a disservice to not share his story.” She explains what doing so means to her,

It makes me feel like his life mattered and like he won't be forgotten [...] It makes me feel like the world got to know him, even though he was only here for [approximately 20 days] [...] even though his life was cut short his mark on the world was not.

Also like the other participants, Participant 1 described her experience sharing her son's story as *healing*. She explains, “It was very healing for me to share our journey. And it was healing for me to at least have some good come out of it.” Later in the interview she revisits the topic of healing and adds, “I feel like it has been my own type of therapy to talk through things on my own.”

As with the other participants, Participant 1 cited helping others as central to her sense of purpose in sharing her story. She describes,

Sharing his story has helped others grow in their faith as well, and has helped a lot of people through some very hard situations [...] I get messages every day saying like, ‘Thank you so much for sharing your story. Because, like, we couldn't find anything like [it].’

Also like the other participants, Participant 1 identified her son's legacy as a key motivator for her sharing, "It helps keep his memory alive." She elaborates on what her son's legacy means to her,

Try to live every day to its fullest. And we know how quickly life can change. And so, we now feel like, we love so much deeper. We have so much more fun [...] I feel like I personally enjoy certain things more. I don't take things for granted like a normal person would.

4.2: Participant 2

Participant 2 is in her mid-40s, a wife, and a mother of two. She lost her three daughters due to homicide when they were adolescents. Participant 2's GPI results indicate she is a *blended* griever (Martin & Doka, 2000; Doka & Martin, 2011; Martin & Wen-Chi Wang, 2006), or someone who makes use of a mix of intuitive and instrumental grieving strategies. She scored 3.66 out of five on the intuitive questions and two out of five on the instrumental questions.

Participant 2 is 11 years into her bereavement. Participant 2 describes her life-perspective, "It's [...] my kind of philosophy of how I'm surviving, that you need to hold the good and the bad and you can't have one without the other." My impression of Participant 2 is that of a warm and generous human being. She describes her spiritual perspective,

I believe that there is value in truth and most religious belief systems and many paths to the same summit. So, I give every kind of belief system its own, that there are values to that and truth in all of them and try to tie that together.

Participant 2 has extensive experience memorializing her daughters through digital media slideshows. She's created several. She uses these slideshows at the grief-oriented speaking events she does. She explains, "Slideshows and things like that make it really easy to share the girls." Participant 2 also has experience using streaming video, personal websites, and social media to share her girls.

Participant 2 explains her sense of purpose in sharing her girls' story, "My goal is more to remember how they lived, not how they died [...] try to bring about some good if possible." Participant 2 realized that "it wasn't just my loss, it was everyone's loss." She describes learning to share her grief with her community,

Your grief is the last thing you have to hold, and to be able to share that and let other people carry it for you, that's hard. But I knew it was important and it was the only way I was going to survive.

As a result, she describes her grief perspective as grieving based on gratitude. She explains her grief journey and evolving sense of identity as

trying to understand myself and who I am now because it's it is changing on an almost molecular level. Just like becoming a mother changed me down to my marrow, losing them changed me yet again, and now this person who is, you know, grieving with gratitude is also a new person.

Participant 2 describes how reflecting on her experience has been helpful to her healing process,

The process of making memorials, whether you know digital or writing or anything [...] for me, it was incredibly healing. It really helped me connect with what was left of my girls in a way that filled the gap and got me through the next day.

Participant 2 explains how her doing so has also been helpful to others,

This woman came up me and she said, 'I know who you are and I've just wanted to reach out to you and say like, two years ago my husband killed himself, and at the time, I remember thinking, if she can get through what she got through, I can get through this.' And that has been one of my driving motives for trying to get my story and the girls' story out there.

Participant 2 connects these ideas in a single word,

The word that pops into my head is *legacy*. It is very important to me for them to be remembered, again, for who they were, not how they died. And, as a reminder that we all have an impact.

4.3: Participant 3

Participant 3 is in her mid-60s, a wife, and a mother of one. Her teenage daughter committed suicide; Participant 3 is six years into her bereavement. Participant 3's GPI results indicate she is

mostly an intuitive griever. She scored four out of five on the intuitive questions and 2.66 out of five on the instrumental questions.

She describes her life-perspective, “You know, I always say, [...] I've already had my worst day. You know, so it doesn't really matter.” My impression of Participant 3 is that of a funny, loving person. She jokes about serving as a grief counselor, “I kind of want to say, ‘But you know, my daughter died right? I mean, I did my best, but maybe I'm not a great resource.’ I mean, it's kind of silly, but it's true.”

Participant 3 explains her sense of purpose in working as a counselor, “It's just kind of the thing that you do, you know, just to honor your person.” She describes her perspective on memorialization, “There are so many things you can do to sort of make meaning of your person's life.” She explicates her motivation to memorialize her daughter, “I wanted people to know about her as much as I could know about her, you know? I mean, as much as I could tell [...] about her.”

Participant 3 credits digital media as being particularly helpful in conveying the breadth and depth of her daughter,

It's a feeling that you're trying to portray, you know? You're trying to, like, show the kinds of things that mattered to her, the kind of person that she was. It's passing on like, feelings we have when we think of her [...] You're kind of trying to also portray your grief a little as to why this is so sad for you [...] She was this, and she was wonderful. And we are all so sad about it because of all these wonderful things [...] So it's like all of those things together. You're trying to portray the grief that you've been having because

of what's *not* going to happen, too. And I think that that comes across in a [...] montage [...] better than in just words.

Participant 3's digital memorialization activity has included creating slideshows and consistent social media posting, mostly on Facebook. She believes digital media "can help us immensely in our grief." She elaborates on her ongoing use of digital media to memorialize her daughter,

It means when people think of her, what do they think of? That's the legacy. The legacy for me is to, well, [...] that's how I got the tattoo. It has a semicolon at the end. A semicolon usually stands for 'your story isn't over.' That means don't take your own life. It's like a pause instead of a period. But for me, it meant her story isn't over yet. [...] And then we've switched it to 'her story will never be over,' [...] because we'll keep fighting. And that's why I did this so I wouldn't forget. That was my goal. So that, you know, as obnoxious as people might think I am, I want that to be her legacy. That mental health matters, that you know what? There's going to be a tomorrow and that you can get through it. [...] That people are here to help you once you do get through it.

4.4: Participant 4

Participant 4 is in her mid-40s and a mother of one. Participant 4 lost her daughter due to complications from a congenital disorder when she was approximately 70 days old. Participant 4's GPI results indicate she is a blended griever. She scored 2.83 out of five on the intuitive questions and 1.83 out of five on the instrumental questions.

Participant 4 is seven years into her bereavement. She describes her ongoing relationship with her daughter, “She's still an everyday constant for us.” My impression of Participant 4 is that of a calm and reflective human being. She describes how she explained her calmness to another parent, “When you've lost a child, none of the rest of this really matters.”

Participant 4 also created a slideshow for her daughter’s funeral. However, most of her efforts to memorialize her daughter have been on social media. Participant 4 describes her use of Facebook to memorialize her daughter as “therapeutic.” She explains, “It helps to remember her, but also yeah, it says a lot about who I am as a person and why I am the way I am.”

Participant 4 shares the sense of meaning she’s derived from her daughter’s short life, “Okay, she came. She did her part to save my life. Now I got to do something for myself. So, I started working out doing all the things to make sure I'm healthy for my son.” She elaborates, “I don't post a lot of my weight loss journey now, but when I do that is at the heart [of it].”

She describes a particularly powerful image that she shares,

The one picture that I share probably the most often is me holding her. She's gone. But I'm holding her up on my shoulder because I never got to hold her there because she always had her tubes, so I always had to cradle her. But like my aunts and people have just said like, ‘That is the most painful picture I've ever seen,’ because I'm just bawling.

Participant 4 explains how doing so continues to benefit her as “just to see how far I've come.” She hopes her posting is received as “a message to people that like, you can make it through hard things.”

Participant 4 describes her images of her daughter, “In those [approximately 70 days] that she was there, I saw her every day. And I always took a picture every day.” She explains how the changes she sees in these images has helped her heal,

I think just knowing that she wasn't okay, you know? Because there's obviously guilt that, you know, you feel like, okay, I kind of gave up but [...] reminding myself that there's nothing to feel guilty about.

Participant 4 describes her current posting practice, “Most of what I share now is to celebrate her birthday [...] Well, yeah, and just to make sure she's not forgotten.”

4.5: Participant 5

Participant 5 is in her late 30s and lives with her boyfriend. She lost her son due to complications from cancer when he was a teenager. Participant 5’s GPI results indicate she is a blended griever. She scored 4.66 out of five on the intuitive questions and four out of five on the instrumental questions.

Participant 5 is just over a year into her bereavement. My impression of Participant 5 is that of an open, loving person. Participant 5 is still dealing with heavy grief. She describes being at a difficult part in her journey,

My routine still haven't got back the same. Because I feel like I had a routine with my son, but now I'm just going like, I just wake up and just go. Now I don't even have a routine for every day no more.”

Participant 5 explains how a recent opportunity to share her son's story changed her life,

I got to share his story then. So, I think that's where my healing process started. Because once I had the story inside of me, that I was afraid to tell, or I didn't think no one wanted to hear it. So, once I was able to tell it, [...] I don't have to be shut in isolated. Because that's what I was used to. Like, 'You just sit in the corner and you get it together.' You know what I mean? Now, I don't have to sit in the corner no more.

Participant 5 uses Facebook almost exclusively to memorialize her son. Initially, she created a slideshow. Since then, she has posted hundreds of combinations of images, text, and music in his honor. She describes her sense of self when posting, "I feel like *me* sharing it. It's like, 'Share your testimony. Share it! Share your feelings!'" She says,

It helps me heal, you know? It gave me a little relief. Even though I know that he's not here, it's like, he lives on still. Even though he's gone. And to share with people that didn't know him how great a person he was, you know?

She explains her resulting sense of growth, "I'm able to do it with a smile now and, I cry all the time, but I'm more stronger than what I was."

Participant 5 reflects, "For some reason I feel like I can relate and help a lot of people." She explains her interest in helping others,

I also want them to understand that, even though you go through things like that, it's okay to talk about [it]. It's okay to express your feelings. It's okay to cry. People think crying make you look crazy or stupid or weak.

She describes her message to those learning how to grieve, “That it’s okay to grieve and be happy. It's okay to cry sometimes. It's okay to cry and then pick yourself back up and keep it moving.”

She reflects on her continued memorialization of her son, “I was angry enough at first about it. But now his legacy is beautiful. And I feel if I keep sharing it, it would be more beautiful and beautiful.”

4.6: Participant 6

Participant 6 is in her early 30s and a wife. She lost her son due to complications from a heart defect when he was three months old. Participant 6’s GPI results indicate she is primarily an intuitive griever. She scored 4.33 out of five on the intuitive questions and 1.5 out of five on the instrumental questions.

Participant 6 is only seven months into her bereavement. She says of her journey, “There's less and less moments where I'm like, crumbling on the ground from grief, but there are still moments where it happens.”

My impression of Participant 6 is that of a kind and gentle human being. She shares her philosophy on life, “I really, genuinely believe that the point of life is to love and connect with other people.” She explains how sharing her son’s story and personal grief journey relates to her

philosophy, “This is the way I know how to do it in the deepest way. This is how I know how to love people the deepest.”

Participant 6 initially created a slideshow for her son’s funeral. She explains, “The slideshow was, I knew right away I needed pictures of him, for us and the people who love him, for anybody that was there to see.” Since then, Participant 6 has been sharing her grief journey on social media, mostly Facebook and TikTok. She describes her reason for choosing TikTok, “because it was like, right here, right now. How am I feeling? And I'm just talking to a phone so I don't feel like I have to be poised.”

Participant 6 commonly supplements her videos with other media. She explains,

I think adding music and words and pictures to it almost gives it more of like an all-encompassing view of it [...] Being able to add that all-encompassing view of it can help other people understand. And it makes me feel like I'm representing it more accurately.

She believes her social media use has supported her grief journey. She describes,

From the perspective of a bereaved mom, social media has been—media in general: music, writing on my computer, sharing the story—has been a very helpful tool for me to take steps in the grieving process.

She elaborates on how her doing so is intended to help others in difficult situations,

I want to be as helpful as I can for those people [...] I know what it feels like, how alone you can feel, but also I know what it feels like to have that hope [...] The point of me being so vulnerable and open is to help other people.

She describes her sharing activity as “doing something with the energy that I have. It also feels like I'm doing something with the energy that [my son] had, or has still.” She explains her and her husband’s perspective as, “Anything that we've decided to do after [our son’s] death to memorialize him feels like [...] we get to parent him a little bit.”

Participant 6 describes her sense of motivation to memorialize her son, “It doesn't feel I have an option. It doesn't feel like there is an option. It feels like I said, imperative.” She elaborates on her sense of responsibility to maintain her son’s legacy,

He lived a big life. Even though it was very short, it was very hard. I think the responsibility that I feel to carry on his strength and his legacy is, again, it doesn't feel like an option. It's part of me. It feels like a limb.

4.7: Participant 7

Participant 7 is in her mid-30s, a wife, and a mother of two. She lost her son due to complications from a heart defect when he was six months old. Participant 7’s GPI results indicate she is a blended griever. She scored 3.83 out of five on the intuitive questions and 2.16 out of five on the instrumental questions.

Participant 7 is five years into her bereavement. She says of her first year of bereavement, “So we spent the next year without any children trying to figure out what to do with our lives.”

She describes the realization she and her husband came to, “There's got to be a better way to get grief support into parents’ hands.” She also describes the non-profit they created with another bereaved couple, “Our whole goal is that we want to make sure parents get information and support as quickly and as efficiently as possible after the death of their child.” She explains why, “You just, you don't have a lot of energy to be doing a lot of stuff.”

My impression of Participant 7 is that of a strong, contemplative person. She explains her early use of Facebook to memorialize her son,

Just a way to kind of share my favorite things about his life and let other people see him since there was no other, you know, there's not going to be a future of seeing him anymore.

Participant 7 has found sharing her son’s life story to be helpful to her grief process, “It's helpful for me to know that he's going to be out there [...] It just, it makes me happy.” She explains, “Sharing helps, I think, to get some of the feelings out instead of holding everything in.” She elaborates on the benefits of sharing his story, “It also helps me feel like [...] He's still serving other people [...] there's still something good that he's able to contribute to other people through his life, even if it was so short.”

Participant 7 explains how her sharing has also been helpful to others, “There's been people who said they've been inspired by us. ‘You inspire me because I couldn't imagine going through that.’” She describes how these experiences led to her and her husband realizing, “There's always going to be the grief and the waves that come with it, but we want to do something positive with that. And I want to make sure that his life was not for nothing.”

This sense of wanting to do something positive and their son's life not being for nothing led to the creation of their non-profit organization. In their roles with the organization, Participant 7 and her husband use a diverse array of digital media types and technologies. Participant 7 explains one dimension of their experience doing so, "Incorporating him into what we're doing with our foundation [...] is kind of our way to continue parenting him, really."

She sums up their perspective on their endeavor, "So we say, like, 'This is the legacy.'"

4.8: Participant 8

Participant 8 is in her mid-40s, a wife, and a mother of one. She lost her daughter in a car accident when she was four years old. Participant 8's GPI results indicate she is mostly an intuitive griever. She scored 3.16 out of five on the intuitive questions and 1.33 out of five on the instrumental questions.

Participant 8 is nine years into her bereavement. She describes her early grief journey, "The pain is so acute it almost like, bisects you from reality." She elaborates, "Just like this, huge grief vacuum. And she was our only child. And so there wasn't the rest of the tending to." She explains her and her husband's experience as "exist[ing] in the void with our own, you know, within our own shock." She describes existing in the void of grief,

I loved my kid so much, and like, by all means, in all reality, I should have just exploded when she died. I should have just vanished into thin air and to falling apart, and to never, ever be recovered again. You know, like many bereaved parents [...], if I could have stopped breathing, I would have stopped breathing. You know, it's not about killing

myself, but just like, 'Fuck! Do I have to keep waking up? Could I just stop waking up?'
But you know, we don't. Here we are. We keep waking up, every fucking day.

My impression of Participant 8 is that of a straight-talking, level-headed human being. She describes remembering her vision for the slideshow that was to be played at her daughter's funeral, "I remember wanting to do a digital memorial or, you know, a video for the funeral and I wanted to put it together into a video very specifically cut to music, cut to a soundtrack that I put together."

Participant 8 describes how this early use of digital media led to her sharing her daughter's story on social media,

It was just so painful after she died [...] We'd share her life, the stuff that we did and her pictures. And she just took such beautiful pictures, just a beautiful kid. And I just couldn't imagine a world without her in it. And without people seeing her. So, I would post pictures of her, sometimes a couple times a day. You know, just kind of sharing her life. And it became a thing.

She elaborates on her belief that digital media was helpful early in her grief process,

I was [...] just so in love with my kid. [...] We were so attached and connected, and I just loved her so much. [...] We would, you know, share pictures of her. They just, like, filled my whole spirit to even just look at pictures.

She describes doing so as, “a form of self-expression of my own grief.” She explains her motivation for doing so, “It allowed me to continue that relationship.”

Participant 8’s use of social media has changed over the years. She describes realizing the potential value her story held for others as “providing visibility, and hopefully comfort for somebody who may need to hear that somebody else is thinking or feeling the things that they're going through.”

Participant 8 leads a regional grief group. She explains her motivation for getting involved, “I realized the need to speak about the experience of grief and bereavement and loss. Not so much for myself, but for other people. Creating a dialogue and transparency as to what people will go through.” Participant 8 sees social media as a means for her message “to be visible to other people.”

She explains her current perspective, “Part of my journey now is, ‘How do I choose to experience my grief? As an act of love for myself? For sharing that out?’ That's how I keep her keep her alive.”

4.9: Master Themes

Following the IPA methodology, this section is a discussion of the main themes identified during the study’s analysis process. This includes, as Smith and Osborn (2004) describe, the study’s “master themes [...] presented in a table, with examples of each theme to support it” (p. 234). The discussion below contains multiple tables, as the themes are organized by the study’s three research questions. Further, all three research questions produced themes in multiple subject areas.

4.9.1: Research question 1: How are bereaved parents using digital media to create memorials for their deceased children?

I divided the discussion of the main themes related to this research question into two subject areas. The first subject area is *technology*. The second is *media type*.

Table 3 is a summary of the technologies used by the study’s participants to memorialize their children. Based on my analysis of the ideas expressed during participants’ interviews, I organized these technologies into five categories: *social media*, *presentation software*, *dedicated websites*, *graphics applications*, and *audio application*.

Table 3

Technologies

Participants	Social Media (e.g., FaceBook, TikTok, etc.)	Presentation Software (e.g., PowerPoint, Keynote, etc.)	Dedicated Websites (e.g., WordPress, GoDaddy, etc.)	Graphics Applications (e.g., Photoshop, Canva, etc.)	Audio Synthesis Application s (e.g., Audacity, iTunes, etc.)
1	×	×		×	
2	×	×	×		
3	×	×	×	×	×
4	×	×	×		

5	×		×	
6	×	×	×	×
7	×	×	×	
8	×	×	×	

The dominant category amongst these is *social media*, with all participants using it in some manner. For many participants, social media has been especially helpful. As Participant 1 describes, “I felt like it kind of gave me the power to tell my story how I wanted it to be told.” Participant 6 shares a similar perspective, “Being able to connect with people and find community without having to leave the house was beneficial for me in so many ways.” She later adds, “If social media wasn't here, I don't know how what it would look like for me. That sounds dramatic, but it's sincere.” Participant 8 explains, “The social media postings allowed me a contained space to express and access those emotions, even if only for the 90 to 180 seconds it took me to put them up [...] It gave me an outlet to do that.”

Another category participants expressed strong opinions of is *presentation software*. All but one participant used some type of presentation software to create a memorial for their children. As Participant 2 explains, slideshows help her “remember stories about [my girls].” Participant 3 recalls the slideshow she and her family put together for her daughter’s funeral, “It was beautiful. It had this music that she loved. You know, the stuff that either she loved or that we felt represented her to us, or some of each [...] And, you know, all the pictures of her.”

One technology category that only two participants expressed strong opinions of is *audio applications*. Participant 3 created a mental health podcast series with a friend and colleague. She reflects, “I really think the podcast was good. A good thing to do.” Participant 6 maintains a grief blog that centers on a music playlist she made for her son the morning he died. She recounts later realizing the importance of the playlist,

So, I don't think it in the moment I realized how important it was, especially the playlist [...] I've still added songs to it since he's passed too. So, it feels very important now. But in the moment it definitely did not register that it was going to be that important.

Table 4 is a summary of the media types used by the study’s participants to memorialize their children. These media types include text, images, audio, and video. The dominant categories amongst these are *text* and *images*, with all participants using them in their memorialization processes. Participants expressed strong opinions about the special powers of audio and video.

Table 4

Media Types

Participants	Text	Images	Audio	Video
1	×	×	×	×
2	×	×	×	×

3	×	×	×	×
4	×	×		
5	×	×	×	×
6	×	×	×	×
7	×	×	×	×
8	×	×	×	

All but one participant reported using audio to memorialize their children. Participant 1 and Participant 6, both TikTok users, expound on the benefit of adding audio to their posts. Participant 1 explains, “Being able to pick your music really can, like set the tone or set the mood that you're trying to give off.” Participant 6 elaborates on this idea, “There's an energy, I think, that comes with music that you can't get anywhere else.”

Six of 8 participants reported using video to memorialize their children. Participants’ comments on video were mixed. As Participant 3 describes,

Here's my problem with video: every time I've heard her voice since she's died, it's been really hard for me, even though it's [been] eight years. And so I haven't really gotten that into video [...] It's just hard. [...] I can see the pictures. That part's fine. But the video makes her real.

Participant 5 expressed a different reaction to video. She describes her elation in receiving new videos from friends and family, “Thank you for sharing this memory with me! I didn't know he did this video. It's like, oh, my God, where did this come from?” She adds, “The videos make me feel like he's still here.”

For Participant 7, video presents a different challenge. She explains, “Now we can't go back and watch a video without noticing that he's got insanely heavy breathing [...], and that's really hard.” She adds, “The videos are hard because they remind us of what we missed and the guilt of not catching it.”

From the discussion above, it is clear the study's participants have used a diverse range of technologies to memorialize their children. Key amongst these technologies are social media and presentation software. Participants have also used a variety of media types in their memorialization activities. The most common are text and images. In addition to these, participants ascribed unique emotional potential to audio and video.

4.9.2: Research question 2: What are the experiences of bereaved parents when using digital media to create memorials for their deceased children?

I divided the discussion of the main themes related to this research question into two subject areas. The first subject area is *ordinary* user experiences. The second is *extraordinary* user experiences.

Table 5 is a summary of the types of ordinary user experiences reported by participants. Guided by over twenty years' experience as an interaction designer, I arranged the experiences into two rather benign categories: *ease-of-use* and *appreciation for features*. Not surprisingly, every participant described having experiences in both areas.

Table 5

Ordinary Experiences

Participants	Ease-of-Use	Appreciation for Features
1	×	×
2	×	×
3	×	×
4	×	×
5	×	×
6	×	×
7	×	×
8	×	×

For example, Participant 2 describes her first Web-based file transfer experience,

It was actually really easy to transfer huge amounts of data. [...] I used it pretty much on my own without tutoring. I could just click a couple buttons and upload things and it went smoothly.

For Participant 3, the convenience of ubiquitous availability is a significant benefit, “Boy, I just I’m such a fan. I’m just a Web-based fan because I just feel like, you know, that’s where it’s so easy.” Participant 6 describes her experience succinctly, “Yeah, it was easy, I think. I’m an Apple user.”

More in-line with the goals of this study, Table 6 is a summary of the types of extraordinary user experiences reported by participants. My determination of these experiences as extraordinary is based on how I understood these experiences as inextricable from the participants’ bereavement. I arranged the experiences into seven categories: *frustrating*, *stressful*, *collaborative*, *comforting*, *painful*, *cathartic*, and *beyond rational*.

Table 6

Extraordinary Experiences

Participants	Frustrating	Stressful	Collaborative	Comforting	Painful	Cathartic	Beyond Rational
1	×	×	×	×	×	×	
2		×	×	×	×	×	×
3		×	×	×	×	×	×
4		×		×	×	×	
5	×	×	×	×	×	×	×

6				×	×	×	×
7	×	×	×	×	×	×	×
8	×	×	×	×	×	×	×

Four of 8 participants described frustrating user experiences in their memorialization efforts.

Participant 1 describes her experience using TikTok,

Oh, that pisses me off, actually. My shit gets blocked because it's called sensitive content. Pisses me off [...] So, this is my story. I don't like that they blur my stuff because it's like, it's real!

Participant 8 describes discovering that the format of her daughter's memorial was incompatible with the funeral home's media system,

We were trying to get it in their DVD player. I'm picturing being in the funeral home at the back corner where they have the media station or whatever and [we were] trying to get it to play and it just wouldn't play and just being very frustrated with it. [...] It was really very, very frustrating. It was very frustrating and disappointing. In wanting to share this like piece of my soul, this like essence of my child and her life and the things that went along with her in the pictures that were chosen, the story that we were telling the music of our life that she loved that. That said, 'her,' you know, to her father and I. And

wanting to give that to [...] memorialize her [...] to the people who were there. [...] If I had more room to give the emotions of frustration and anger and, you know, like disappointment, if I had more room for that, I would have felt more of those things. But it wasn't the priority of the day and being upset about it wasn't going to [...] do anything.

All but one participant expressed becoming stressed in some fashion while using digital media to memorialize their children. Participant 1 describes trying to organize and archive her images of her son, "I actually had to have a family member do it for me. My sister had to do it. I could not, I could not go in there and do it." Similarly, one of Participant 2's most stressful experiences is also related to archiving her images of her girls. She describes realizing that her images of her girls were "all the pictures I had and there would be no more new pictures. That was a hard moment." She then recounts her frantic search for reliable storage for her media, "There was definitely [...] just the emotionally kind of terrifying aspect of like, you're trying to transfer things to like, save them to a hard drive!"

Six of 8 participants reported working collaboratively to memorialize their children. Collaboration ranged from small family groups to community-wide projects. Participant 3 explains how she worked with her family to memorialize her daughter, "Me and my sister and my brother and his wife and everybody was there planning the funeral. We all had laptops out. We had photos out. We were just working together." Participant 3 elaborates on her experience,

You know, [it's] kind of overwhelming [...] I would say, like here's what I want. Here's what I want you to do. And then they'd have to figure it out because [...] grief just makes you too, you know, you've got too much going on in your head.

Participant 8 describes her experience working on a memorial with her family, “Everybody else had fallen apart. And so, I wasn't going to fall apart. And so, I had a very specific vision and the way that I, you know, the way that I wanted things to be done.”

Every participant expressed feeling comforted in some way in their digital memorialization experiences. Participant 2 describes the solace she found in images of her daughters during her early grieving, “At the time, I was, I mean, I'm trying to think of the right word, desperate [...] I needed those pictures.” Participant 4 explains what she receives from looking at images of her daughter, “So, her end-of-life photos compared to what she looked like prior. I didn't really remember that. And so, like I do look at those pictures just to remind me.”

Likewise, every participant expressed experiencing painful feelings at some point in their digital memorialization activities. Participant 3 describes her early grieving experience, “At first, [...] I see myself sitting at the computer at night, just sobbing.” Participant 5 describes the outright devastating experience of losing all of her images of her son,

My crazy self went to Target and, of course, I used the bathroom and laid my phone down. Came back to the sink and before you knew it, somebody had took my phone. And I'm like. ‘Somebody took my phone! I need that phone!’ That's all that I had. And you know, [...] the pictures, you can't get pictures back. You know, so, it broke me.

When asked about cloud-based backups, Participant 5 explains, “No, that's what broke me, because when I got to T-Mobile, my iCloud didn't have none of them backed up. So it broke my heart.”

Thankfully, Participant 5 was able to collaborate with her friends, family, and broader community to develop a new collection of images and videos of her son. She explains, “And I told everybody, and before you know it people was coming out of the woodwork like, ‘I got this picture! I got this picture of him, auntie! Here you go.’ I’m like, ‘Okay!’”

Every participant also described their memorialization experiences as cathartic in some way. Participant 6 explains her experience, “It was cathartic because I was dragging and dropping and looking at each picture as I put it in there.” Participant 7 describes memorializing her son, “I think it was just, honestly, it was like a cathartic way for me to go through and have like, a purpose.”

Six of 8 participants described their memorialization practices in terms that transcend rational explanation. Participant 7 describes the motivation behind her memorialization practice, “Like I don’t have a future where I get to continue sharing photos, so I’m going to share these photos and videos now so that I can keep him alive.” Participant 8 explains her experience,

It let me connect to her in an active way. Every day. In an active like, action-based way. So, I was always connected to her all the time in the pain and the grief. In like every fiber of your being, right? And social media was like a fiber of your doing. So, being versus doing. So, let me do!

From the discussion above, it is clear the study’s participants have had a complex mix of ordinary and extraordinary experiences using digital media to memorialize their children. Amongst the ordinary, participants expressed appreciation for ease to use technology and described liking particular features. Amongst the extraordinary, participants described

frustrating, stressful, collaborative, comforting, painful, cathartic, and metaphysical experiences. Participant 7 provides poignant insight into the complexity of her experience using digital media as a bereaved parent,

There's a whole lot of emotions going on. I'm not really sure what to feel. I feel angry that I'm having to do this. I feel sad that he's not here anymore, that we're not going to get any more of these photos. I feel happy because this [image] was a really happy funny moment and I'm glad that I've got these photos. So, I do feel happy that I have something. At least I have some sort of, you know, imprint of his life. [I feel] angry at other people, a lot of guilt [...] just like every feeling you could possibly think of, I think came up while going through [the images of him].

4.9.3: Research question 3: Why are bereaved parents using digital media to create memorials for their deceased children?

I divided the discussion of the main themes related to this research question into two subject areas. The first subject area is *meaning-making*. The second is *healing*. The themes discussed in these areas are key master themes in the study.

Table 7 is a summary of the ways participants described their memorialization activities as meaning-making. Based on my analysis of the ideas expressed during participants' interviews, I organized these ways into three categories: *understanding one's experiences*, *commemoration*, and *sense of purpose*. Every participant described experiencing each way.

Table 7

Ways of Meaning-Making

Participants	Understanding One's Experiences	Commemoration	Sense of Purpose
1	×	×	×
2	×	×	×
3	×	×	×
4	×	×	×
5	×	×	×
6	×	×	×
7	×	×	×
8	×	×	×

Understanding one's experiences is a key main theme in the study. Participant 1 describes her use of digital media to memorialize her son, "It made me feel like [my son's] loss had some meaning behind it. Because the whole time, I feel like, when you lose a child you're always searching for meaning." Participant 2 describes a realization she came to through her grief process, "Maybe there are some things we're just not meant to be able to hold on to forever." Participant 7 describes her experience with social media, "So, I mean, going through it forced me, like putting things on there kind of forced me to look at the happy side of things."

Commemoration is another key main theme in the study. Participants' commemoration ranged from personal remembrance to community engagement. Participant 1 describes her relationship to a specific digital image taken the day her son died, "I think from my perspective it's one of the most powerful photos. [...] Because I feel like it sums up everything and all of the emotion from that day." Participant 2 explains how creating a slideshow supported her grieving process, "It helped me remember good times and it helped me remember being their mom." Participant 3 expresses a similar sentiment, "It would help me remember, you know, all the things about her." Participant 5 shares her reasons, "I don't want to forget about him or, you know, some people forget."

Other commemoration activities reported by participants were more public. Participant 2 describes her use of social media to interact with the grief community, "It's a way to show people that you can do it and it can be positive." Participant 6 explains how her commemoration has evolved, "I think my sole motivation to start out with was me saying I need to get it out, and then the *biggest* motivation has been other people." Participant 6 describes her experience sharing her grief story, "I feel like I'm naked, you know, in front of other people. And by doing that, it's helped them feel less alone." Participant 8 explains the significant support she and her husband experienced in reaction to her sharing their story on social media early in their grief journey,

Really and truly, the social media support we received after her death from, you know, from the far-flung widespread corners of [the] history of our lives. That energy helped buoy us up and carry us through for a long time. So, that like, energetic connection and love and caring really helped us get out of bed, you know? So, I don't go to a church or pray or subscribe to religion, but I do know that there is energetic human connection.

And that the thoughts and prayers that were coming from all of these people who either knew us at some point in time or knew of us really, really made a difference. [I] could feel, you know, could feel it in the body!

Sense of purpose is another key main theme in the study. Participant 3 explains simply, “I do it because I want to say something and do something that honors her.” Participant 6 describes her early activity to memorialize her son, “And then once we got back to kind of, like reality, I had to do something with [my grief]. And I’m a writer, and so I wrote a lot just in my personal journal. And then, I knew I needed to do something with that.” Participant 8 describes her perspective on her daughter’s life,

That continues to be the point for me. In representing love. Her as love. Our relationship, my feelings, my grief. Because that’s what grief is. Grief is the other side of love. You can only grieve as deeply as you've loved. And the loss of a child is so uniquely tragic and altering [...] Some people believe in God. I believe in love. And that's what that is, and how you manifest that into the world is the point.

She adds,

That love was only possible with her in the first place. And it's my job is to transform that into the world, that love for other people [...] through her death and how I help other people get through there lives, whether it's in grief or in regular life.

Table 8 is a summary of the ways participants described their memorialization activities as healing. Based on the participants' interviews, I organized these ways into two categories: *self-healing* and *healing for others*. Every participant described experiencing each way.

Table 8

Ways of Healing

Participants	Self-Healing	Healing for Others
1	×	×
2	×	×
3	×	×
4	×	×
5	×	×
6	×	×
7	×	×
8	×	×

Self-healing is a key main theme in the study. Participant 1 reflects on her grieving process, “I’ve just kind of really been an open book, which has allowed me to heal. But it’s also allowed other people to heal along with me, I think.” When asked how sharing has helped her heal, she replies

“I think being able to share it personally helps me heal. It helps me heal because, I don't know why. It just helps me heal. [...] I feel like because it helps me to find meaning.” Participant 7 explains how sharing her son’s story on social media has allowed her to heal,

I think being able to share his photos and his memories with other people helps me—*helps force me*—like, with the videos for example, like it helps force me to not make it such a taboo thing to go back and look at it.

Participant 8 describes her early social media posting in honor of her daughter,

It was reaffirming and uplifting! And like I said, [...] she was still a part of the world. She hadn't died! I mean, you know, obviously she died. But her life and spirit were still a part of what was happening.

Healing for others is another key main theme in the study. Participant 5 explains how she hopes her posting is helpful to others, “Just by looking at a picture give them hope. By just reading a couple words. May lift them up!” She explains her belief, “Each time by sharing the memory, uplifting words, pictures, videos, we’ll lift someone up! Day by day!” Participant 6 confirms how her memorialization activity has been helpful to others, “I've had several people comment or message me saying. ‘I have a heart baby that died’ or ‘my son died’ or ‘my daughter died’ or whatever, ‘and it's refreshing to see somebody so vulnerable.’”

From the discussion above, it is clear the study’s participants have experienced ways of meaning-making and healing through their memorialization activities. Chiefly amongst these,

participants described significant personal healing. Participants also unanimously explained having a goal of helping others, as well as described believing that their memorialization activities have been helpful to others.

4.10: Additional Insights

This section is an overview of additional insights that were identified during the analysis process. These additional insights include special cases and themes that are aligned with the purpose of the study, but that do not directly relate to the project's research questions.

The first special case is that of *sibling relationships*. Participants who were mothers of young siblings expressed appreciation for digital media as means for helping their children understand the death of their sibling(s). Participant 2 explains,

They're grieving these people they've never gotten to meet. To a certain extent, they're holding themselves up to the standard of these dearly departed sisters. And so, it's important to me to be able to show them like, look, they got in trouble, too!

Participant 4 explains why she has looked through images of the time surrounding her daughter's death with her son, "When you're 5, like death is such a foreign concept, but especially in that first year." Participant 7 talks about using digital images to help create a bond between siblings,

I'm very grateful that I have them digitally because [...] it makes it incredibly easy to be able to show her and discuss him every night. Like, I wouldn't probably have [...] if I didn't have a phone with photos on it of him. I probably wouldn't be showing her

photos— *and different photos, in particular*—every night. So, I'm really grateful that I have the opportunity to have those [...] She'll say, 'What was I like at 3 months?' Or, 'What was [my brother] like at 3 months?' And I can go back and pull up a picture and show her. [...] It just it means a lot to me because they didn't get to share a bond, in person together. And so, I feel like we're helping her to create at least somewhat of a bond with him.

The second special case is that of *potential adverse effects*. Two participants expressed experiencing complications in their use of digital media. Participant 2 explains digital media affecting her memories,

There are times where I felt like, my memories of them have been replaced by my memories of looking at pictures [...] It takes some work to kind of dig back into my own memory [...] my real memories of being with them in those moments versus the pictures and the videos and the things that I've looked at so much since. That's been a hard balance [...] I think it is helpful at times. And then there are other times where they're almost replacing my memories [...] There are times like, and this isn't as common anymore, but there are times where I would get lost in the, and it's so unending, and like you can just go through so much that you can just lose hours and hours, just almost drowning in the memories. So that can be, maybe a problematic side [...] if you don't have the support to kind of help pull you out of that.

Participant 8 describes her decision to stop posting in memorialization of her daughter, “I did it every day, or almost every day, but probably every day up until 2021, when I finally stopped.”

She shares why she stopped,

It became too much and too painful to continue to post because, to take the time to go through to find the photographs, to mine, you know, to mine through the experiences, to pick what I was going to put up that day, it just it hurt too much. It was really very painful. And so it went from being something that was more cathartic to something that became more burdensome [...] The catharsis from the earlier times, coming out of the numbness and coming into the more like, reality of life. And it just was so painful. Quite frankly, scrolling through my Google photos, it starts getting really fucking far away. It's not 2015 anymore [...] Now it's 10, 12, 15 scrolls instead of a couple of scrolls and [...] that is a really painful reminder.

The first theme aligned with the purpose of the study, but not directly related to the project's research questions is that of *significance of media*. Participants' opinions of the significance of their media assets ranged. But for several participants, these media assets were extremely important. Participant 1 explains,

I don't even think you can put words to it because it's priceless [...] When you experience grief like that, a lot of times you like, black it out. And so having photos can help you piece together memories that you otherwise wouldn't have [...] Literally those pictures are [...] It's, it's all we have! [...] It's literally all that we have! So, it's everything.

Participant 2 shares a similar opinion, “It's irreplaceable [...] It's tantamount to a house fire [...] You can't recreate those memories.” Participant 8 describes her decision to create multiple backups, “Just to make sure that it's in several other places so that if something happens to this computer or, you know, God forbid it didn't back up before something happened, it would be backed up.”

The second theme aligned with the purpose of the study, but not directly related to the project's research questions is that of *user experience-related insights*. Participants offered several suggestions for technology designers interested in supporting bereaved parents' memorialization activities with digital media. Participant 1 explains what, for her, would be a fundamental ideal,

I don't know how technology can be gentle, but it needs to be like, gentle. But I don't, I don't know how technology can be gentle. I don't know how to describe how technology would be gentle, but it needs to be gentle.

Participant 1 elaborates,

It needs to be simple, and it needs to be easy to use, because when you're grieving, you don't have the emotional capacity and the physical capacity to put a lot of effort into things like, you just, you just don't.

Participant 8 describes her opinion of the importance of an application using familiar functionality,

It can be really hard to add on new skills when you're, you know, when you're in the middle of grief—*of heavy and early grief*. And so, the best access people have to memorialize their loved one is through using [what is] already available [...] If it functions like PowerPoint, I would have been able to have [...] done that. But trying to integrate a new mental framework would have been really tricky [...] You have to make it something that's [...] accessible [...] When thinking about people in grief and getting something done—*whatever the something might be*—recreating current mental frameworks is the best chance. So, if it's a new product, a new product modeled after old product might be [...] what's helpful.

Several participants described wanting a template-based application to memorialize their children. Participant 1 explains her ideas,

It would be really handy to have some sort of like, slide deck where it's all put together for you and you just, literally, it's like a template, and you just like, insert the pictures and it goes right along [...] and it syncs to music that [users] can choose. That would be very handy [...] If the technology had like, maybe quotes or sayings [...] Sometimes if you can't find the words yourself, it's nice to have someone who's walked in your shoes have those words. You're like, 'Wow, that literally is exactly what I'm feeling!' That would be nice!

Participant 3 describes her ideas,

You plug it in and it says, ‘What pictures do you want?’ And you throw them all in there, and then [you say] ‘Find me more.’ And it goes and finds more and then it says, ‘What songs?’ And you just say, ‘These songs.’ And it does it for you, and you're done. That would be beautiful!

Participant 1 advocates for connecting a digital application like those described above to print-based distribution. She explains her vision, “You can just [...] convert it to like, a paper copy to be mailed out to my grandma and grandpa. That would be sweet [...] That would be next level.”

The third theme aligned with the purpose of the study, but not directly related to the project’s research questions is that of *artificial intelligence-related insights*. Several participants offered opinions on application functionality that would be facilitated through some type of artificial intelligence (AI). Based on my analysis of the ideas expressed during participants’ interviews, I organized these ideas into three categories: user support, image analysis, and virtual simulation.

Participant 1 explains what she thinks would be helpful,

You know that annoying little paper clip that used to pop up on [MS] Word? Like, even if there was just something that would be [...] Because making these, like going through pictures and stuff is extremely difficult. You're basically reopening old wounds, so if there was like, a little annoying paper clip that popped up just like, giving words of

encouragement or something like that! Or, like ‘By you creating this, [...] you are helping memories last a lifetime!’

Participant 3 expressed a different perspective on support avatars,

Here's what I hate: those chat things that come up and say, ‘Are you having trouble?’ Because I just want somebody to tell me what to do [...] How about some ideas like [...] ‘Is this what you're trying to do?’

Participant 2 explains similar functionality,

Netflix has this like, ‘Are you still watching?’ Like, something that automatically comes up? A program for those who are grieving could be like, ‘How are you doing? Have you been doing this too long?’ Like, just something that pops up [...] after a certain amount of time that checks in, maybe offers like, ‘Do you need to talk to somebody?’

The second category is comprised of ideas related to AI’s image analysis capability. I divided these ideas into two subject areas. The first subject area is *media resolution*. The second is *person identification*.

Participant 1 describes the challenge she experiences looking at some images, “For me, a lot of these pictures, they're impossible for me to look at still. But I like, want to go through them and have them organized nicely, but I just, I can't do it.” She describes wanting to temporarily reduce the resolution of images,

If there was a way to, I don't want to say, like 'hide,' but like blur pictures when you're organizing them. So, it's like, you know what they are, but you don't have to constantly look at them. That would be nice.

Participant 2 describes wanting to increase the resolution of her images, “[A] technology that allows us to take maybe some of those older [low resolution] pictures and update them today’s standards!”

Participant 3 describes wishing her photo management application could recognize her daughter’s face in images, “It would be really nice if my phone knew it was her and could just put them in [a group] automatically.” Participant 2 would use facial recognition to “scrub [...] the presence of [a person].”

The final opinion I will share is the only mention of virtual simulating one’s child in all eight interviews. In an effort to convey the subtlety of this opinion, I offer below an extended exchange between Participant 3 and myself,

Participant 3

What I'd really like is an app that would create her again, like an AI or something.

Which, that would be really creepy. So, I'm not sure it would really work. But when you think about it, that's all you really want is your person back.

RF

Recognizing that this is sensitive material, can I ask for a little bit more clarity?

Participant 3

Sure.

RF

You talked about wanting that, but then described it as, 'That's creepy' [...] Even if you could imagine it being done well, is it something that you would be interested in?

Participant 3

Probably not, it's the first thing that comes to my head. Of course, because you want your person back. But on the other hand, it's too creepy for me. It's not unlike going to a medium. To me, it's like, I wouldn't do that. That doesn't, I mean, I don't care if anybody else does. I could care less, but I wouldn't. That's creepy to me because I don't want to know that stuff. So no, I don't think I would.

From the discussion above, it is clear the study's participants offered many additional insights not directly related to the project's research questions. These insights ranged from the use of digital media for sibling relationships to potential adverse effects of digital media use. These insights also included opinions related to the significance of media assets, user experience, and artificial intelligence.

In this chapter, I have presented the results the study's analysis as a narrative of my experience. My primary goal for this narrative has been to provide the descriptions required to answer the study's research questions. My secondary goal for the narrative has been to establish a

set of emotionally powerful statements that have the potential to inspire a sense of empathy within designers of digital media technologies, and thereby grant them a deeper understanding of their work. A tertiary goal for the narrative has been to capture insights that represent opportunities for improving the technologies employed by bereaved parents. Each of these outcomes represents an expansion of TSD practices.

In the next chapter, I discuss these results.

Chapter 5: Discussion

The purpose of this chapter is to discuss the results reported above. As Smith and Osborn (2004) explain, “After the results section, the [IPA methodology’s] discussion relates the analysis to some relevant literature and discusses the implications of the study” (p. 234). Thus, the discussion that follows addresses the study’s findings in relation to five research areas: grieving patterns, continuing bonds, meaning-reconstruction, thanatosensitive design (TSD), and memorialization. My discussion of each research area includes brief speculations on the implications of the study for future related research. The chapter concludes with a discussion of the limitations of the study and a reflection on my experience conducting it.

5.1: Grieving Patterns

As explained above, the protocol established for this study includes use of Martin and Wang’s (2006) Grief Pattern Inventory (GPI) (Appendix A)—a 14-question survey designed to identify patterns within people’s grieving experiences. This tool is based on Martin and Doka’s (2000) work considering grieving patterns and gender stereotypes. Central to this work is a spectrum extending from the *intuitive* grieving pattern to the *instrumental* grieving pattern.

Intuitive grievers invest more of their energy into affective strategies for coping with grief, such as expression of their emotions. Instrumental grievers invest more of their energy into cognitive strategies for coping with grief, such as planning and organizing activities. However, as Doka and Martin (2011) explain, “Few people display the ‘ideal’ intuitive or instrumental response. Most grievers are a blend of both styles” (p. 53). As means for better understanding these patterns—and ultimately, the potential of digital media to support grievers—I describe below Doka and Martin’s model for explaining grief.

Underlying Doka and Martin's grieving patterns is a comprehensive model of grief (Figure 9). For Doka and Martin (2011), one's foundation for understanding grief is recognizing that it involves both "inner experience and outward expression" (p. 38). A griever's inner experience begins with appraisal, or the cognitive (and semiconscious) process in which one attributes meaning to the loss event. This triggers the griever's "preprogrammed biological response" (p. 40) in the form of psychic energy. Each griever's psychic energy response capacity is an individualized characteristic and affects all subsequent processes. Likewise, the stimulation provided by this energy initiates an individualized mix of adaptive systems, or response tendencies. These include affective, cognitive, physical, and spiritual systems. As Doka and Martin explain, "[A] person's response tendencies are molded by powerful, often imperceptible influences [...] Two of the most influential forces are the individual's culture (both societal and familiar and their influence on gender-role development) and personality" (p. 39). In turn, these response tendencies influence the types of adaptive strategies a griever chooses to respond to the loss, and thereby, as Doka & Martin's explain (2011),

manage both [one's] internal experience of grief and the outer expression of that grief. Whether one is more cognitive or affective in [one's] response tendencies and [one's] adaptive strategies determine whether [one] is more instrumental or intuitive in nature (p. 40).

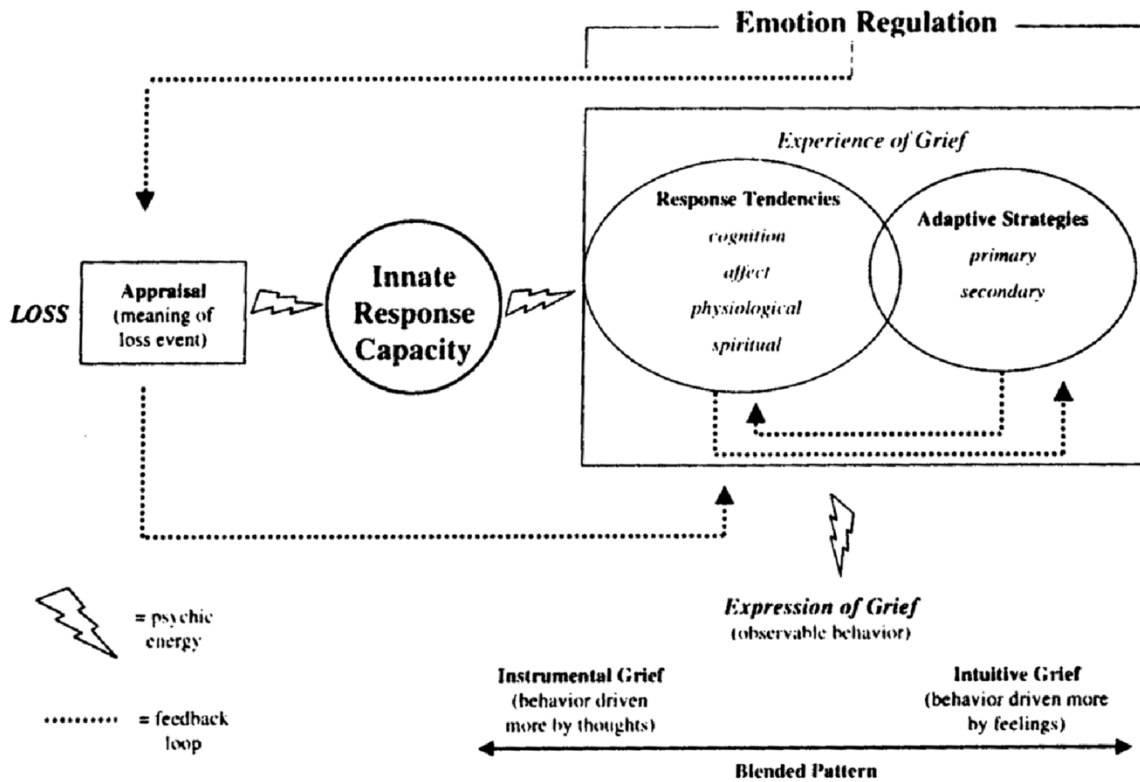


Figure 9. Comprehensive model of grief (Doka & Martin, 2011).

Mediating both a griever’s response tendencies and adaptive strategies is the effect of an individual’s emotion regulation. This regulation often seeks to resolve differences in an individual’s cultural influences and one’s personality. Moreover, as Doka and Martin (2011) explain,

The proposed comprehensive model is not closed. In other words, actions that happen later in the process can produce a change in the appraisal process, resulting in different arousal levels of psychic energy, different response tendencies, different adaptive strategies, different expressions of grief, and so on (p. 40).

With this model of grief as a basis, Doka and Martin (2011) describe where their understanding leaves off...

What is not clear is exactly what is being regulated. Is emotion regulation primarily concerned with the management of expressions of emotion or the underlying arousal of processes leading to those expressions—or both? The answer to this question lies at the heart of understanding grief as well as implementing effective interventions with grievers (p. 43).

The study described in this document does not focus on grieving patterns as a key component to any of the research questions. Yet, the collection of participants' GPI scores—and attention to participants' explanations of why they have used digital media to memorialize their children—provides some insight related to the goals of the study.

As reported above, participants' GPI scores indicate that, as a group, the study's sample skews toward intuitive grieving. Participants provided a range of explanations for their use of digital media in memorializing their children. Toward one end of this range are descriptions of various forms of emotional expression, such as catharsis, meaning-making, and personal identity. Toward the other end of this range are descriptions of more cognitive rationales, such as maintenance of children's legacies, support of others in one's community, and dissemination of practical information. Based on my interviews with the study's participants, I believe that all participants employed both intuitive and instrumental grieving strategies to some extent.

Unfortunately, due to the design of the study, further correlation amongst participants' GPI scores, use of intuitive and instrumental grieving strategies, and explanations for their use of digital media is difficult. However, Doka and Martin (2011) offer guidance for researchers interested in investigating new interventions for griever, "The griever with the greatest number of available and useful strategies has a distinct advantage over the griever limited to just a few" (p. 55). They elaborate,

Both intuitive and instrumental grievers must find additional ways to express themselves that may be unfamiliar. For instrumental grievers, this means they must find outlets that allow them to vent whatever internal levels of affect they experience. On the other hand, intuitive grievers need to discover ways to facilitate expression of their cognitions as well as their feelings. Thus, effective adaptive strategies must accomplish two goals:

- A. They must facilitate the expression of the griever's dominant inner modality of experience (affect for the intuitive griever, cognition for the instrumental style).
- B. They should also expedite expression of the subordinate modality of experience. This means expressing feelings for the instrumental griever and cognitive-based activity for the intuitive pattern (p. 57).

In light of this—as well as the responses reported by participants, digital media offers unique potential to support bereaved parents in their grieving processes. This argument is based on the flexibility inherent to digital media in how it can be used to convey both emotional expression

and cognitive activities. In this way, digital media can be a tool for facilitating both dominant and subordinate modalities for both intuitive and instrumental grievers.

Therefore, one direction for future research in this area could use the GPI as a filter for participants' inclusion in a study like the one described above. Use of the GPI as a filter would allow researchers to identify people who are more purely intuitive or instrumental grievers. Identifying more purely intuitive or instrumental grievers could facilitate comparison between more extreme grievers' responses. This comparison as to how and why more extreme grievers use digital media in their grieving may produce insights related to Doka and Martin's question above regarding the role(s) of emotional regulation in grieving.

Another direction for future research in this area would consider digital media use in what Doka and Martin (2011) consider to be dissonant responses to grief. They describe dissonant responses as the ways grievers may choose to express their grief that are "at odds with the griever's primary internal experience" (p. 91). While most people are motivated to grieve in ways that minimize dissonance, for some, a "lack of harmony between an inner state and an outer expression persists, resulting in dissonance" (p. 91). Better understanding how and why dissonant grievers use digital media in their grieving may also produce insights related to the role(s) emotional regulation in grieving. My interest in this direction for future research is inspired, in part, by the complications reported by participants and the identification of potential adverse effects of using digital media in one's grieving process (discussed in §4.10).

5.2: Continuing Bonds

One of the most influential theoretical perspectives discussed in this document is that of Continuing Bonds theory (Klass et al., 1996; Klass, 1993). This theoretical perspective draws

upon Volkan's (1971; 1981) concept of linking objects and argues that mourners can and do maintain relationships with deceased people. Further, doing so is not indicative of maladaptive mourning. To the contrary, many mourners who have maintained a relationship with a deceased person report the continued bond as being helpful to their grieving process.

As explained above, central to Continuing Bonds theory is the concept of a mourner's inner representation of the deceased. With respect to bereaved parents' grieving experiences, Klass (1993) explains that bereaved parents seek solace in their inner representations of their deceased children. He proposes three categories of ways bereaved parents seek this solace and maintain these relationships: religious devotion, interaction with linking objects, and focused memory.

As explained above, religious devotion is not restricted to the ideas or practices of organized religion, but is meant to convey bereaved parents' sense of being connected to—and embracing—something bigger. Linking objects can be the things, places—even experiences—that connect the bereaved to the deceased (Klass, 1993; Volkan, 1971; 1981). Focused memory time can become the foundation for personal ritual.

Five of 8 participants described their use of digital media for memorialization as resulting in a continued bond with their children. Phrases such as, “still here,” “still alive,” and “continue parenting [them]” were common. Much of participants' memorialization activity occurred through social media, predominantly Facebook.

Based on these ideas, I believe the popularity of social media as a tool for bereaved parents to continue bonds with their children can be better understood by considering three characteristics of social media. These characteristics align with Klass' (1993) three ways of seeking solace and maintaining relationships, as briefly described above.

1. Connection: Users' interactions with social media platforms like Facebook provide a sense of being connected to a larger entity.
2. Linking object: A social media interface—for example, a Facebook user's profile—is simultaneously a tactile thing and a virtual place.
3. Focused memory: Posting images on social media to inspire memories is a regular and ritualistic experience for many.

Perhaps what makes social media so effective for continuing a bond with a deceased person is that it allows users to engage in all three at once.

From the discussion above, it is clear that bereaved parents' continued bonds with their children can have social dimensions. Klass et al. (1996) offer insight related to how a bereaved parent continues a bond with their child in a social context,

The end of grief is not severing the bond with the dead child, but integrating the child into the parent's life and into the parent's social networks in a different way than when the child was alive (p. 199).

They elaborate on the importance of sharing this bond,

Sharing a bond with the child begins with sharing the pain that the death of the child has brought [...] As the dead child is integrated into the social network, the experiences by which parents maintain contact with their children can be social validated (p. 206).

Based on these observations, one direction for future research related to Continuing Bonds theory and digital media could involve designing, developing, and evaluating a Web-based media sharing application. The purpose and function of this system would be guided by user experience goals related to solace seeking and social validation. The process of designing, developing, and evaluating a system that prioritizes these ideas would provide insights related to both interaction design practice and bereavement theory.

Another direction for future research related to Continuing Bonds theory and social media would consider other social contexts that allow for simultaneous engagement in the solace seeking ways described above. Here they are again:

1. Connection: A sense of being connected to something bigger
2. Linking object: The things, places, and experiences that connect the bereaved to the deceased
3. Focused memory: Reflection on memories as personal ritual

Identifying additional social contexts which share these characteristics—for example, the practice of prayer in church—may elucidate other shared characteristics between these contexts. Further, better understanding these shared characteristics could provide insights related to both grievors and the solace they seek.

Another direction for future research related to Continuing Bonds theory and digital media would consider how bereaved siblings might use these tools to maintain their own bonds

with their deceased siblings. Klass et al. (1996) explain the unique challenges related to sibling bereavement,

The death of a sibling alters the constant, interactive, dyadic, comparison through which personal identity is learned reciprocally by siblings during adolescence. In addition, bereaved siblings coping with the developmental crisis of adolescence must now cope with the accumulated stresses of the situational crisis of sibling death and its aftermath (p. 236).

In Packman, et al.'s (2006) investigation of the uniqueness of sibling bereavement, they identify several factors that influence sibling reactions and discuss the clinical implications. Amongst these, one stands out as potentially significant in light of this discussion,

Parents (and other adults) must also realize that some siblings may not be as verbal as adults in expressing their feelings and memories, or may not be as willing to talk about the deceased sibling (p. 833).

Thus, the nonverbal nature of digital images, audio, and video offers special communication potential for bereaved siblings to express their feelings and engage in continued relationships with their siblings. Research considering the strategies of a younger demographic would also help inform the design of the next generation of related tools.

The final direction for future research related to Continuing Bonds theory and social media I will discuss is based on *transcorporeal communication*, or as DeGroot (2018) describes,

“communication to people who do not maintain a physical presence.” This type of communication is not intended to include the work of psychics or mediums, but instead describe the communication that bereaved individuals use to continue their bonds with deceased loved ones.

DeGroot (2018) describes this as “communication toward/with/to the deceased” (p. 43). She explains a model she developed based on how people characterize their communication with the deceased,

This communication includes the components of sender, inner representation of the deceased as receiver, message, feedback based on what the sender believes the deceased would say, and a metaphysical element. (p. 43).

DeGroot’s work is foundational to recent investigation of how people communicate transcorporeally on social media, particularly Facebook. Blower and Sharman (2021) consider how people interact with the deceased on Facebook. Akinyemi and Hassett (2023) look at how people continue bonds with the deceased on Facebook. Common to both research projects is the observation that mourners use deceased people’s Facebook profiles to communicate toward/with/to them.

This is an area of research of which I became aware in preparation for conducting the study’s interviews. However, in these interviews, none of the participants described using social media to communicate toward/with/to their deceased children. I attribute this, in part, to the study’s eligibility criterion of only allowing bereaved parents of children (aged zero–17) to participate in the study. Facebook requires users to be 13 years or older to activate an account.

To my knowledge, none of the participants' deceased children had a Facebook account. Thus, I infer that, if participants were not in the habit of using social media to communicate toward/with/to their children before their deaths, their beginning to do so after their children's deaths would seem unlikely.

Therefore, one direction for future research related to transcorporeal communication, parental bereavement, and social media could consider the communication practices of bereaved parents of adolescent or adult children who did have Facebook accounts. Considering the post-bereavement digital communication practices of this group may illuminate participants' perceptions of, motivations for, and rationales regarding their doing so. In turn, the information produced through this research would provide insights related to both interaction design practice and bereavement theory.

5.3: Meaning-Reconstruction

As explained above, I adopt Neimeyer's Meaning Reconstruction Model (Neimeyer, 1998; Neimeyer, 2001; Gillies & Neimeyer, 2006) as key to informing my understanding of the grieving process. My decision to do so is based primarily on two factors. First, this model is the product of efforts by Neimeyer (and many collaborators) to synthesize multiple theoretical perspectives into a single coherent framework by which grieving processes can be better understood. Second, the importance that this model places on an individual's meaning-making process aligns well with the methodology of this study.

As Neimeyer (2019) describes, "A meaning reconstruction approach to grief embodies an implicit metatheory, in this case, psychological constructivism." As described above,

constructivism rejects the idea of an objective reality in favor of relativism, or the belief in multiple equally valid perspectives on reality. Neimeyer (2001) elaborates,

Pervading constructivist metatheory is a position of epistemological humility, a recognition that, whatever the status of an external reality, its meaning for us is determined by our constructions of its significance, rather than the “brute facts” themselves.

As described above, Neimeyer proposes the Meaning Reconstruction Model as a tool for both understanding the grieving process and guiding grief therapy. Up until this point, my discussion of the model has prioritized the former, with little consideration of the latter. In this section, I begin by exploring the tenets of this model in light of the study’s findings. This leads to a discussion of the study’s results in terms of Gillies and Neimeyer’s (2006) categories of activities that grieving individuals use to reconstruct meaning. Following this, I discuss recent research in meaning construction. The purpose of this discussion is to illuminate opportunities for using digital media in grief therapy.

As outlined above, the Meaning Reconstruction Model is comprised of five tenets. The first tenet is *narrative truth*, or the concept that truth is an individualized construction. All participants described perspectives that align with this tenet of the model. For example, Participant 2 shared her philosophy for surviving the deaths of her three daughters, “You need to hold the good and the bad and you can’t have one without the other.”

Neimeyer (2001) explains the role of narrative creation in meaning-making, “[A] life story disrupted by loss must be reorganized, rewritten, to find a new strand of continuity that

bridges the past with the future in an intelligible fashion” (p. 263). Participant 3 provided an extended explanation of her experience creating a narrative for her daughter; she also described why she chose digital media to do so,

It's a feeling that you're trying to portray, you know? You're trying to, like, show the kinds of things that mattered to her, the kind of person that she was. It's passing on like, feelings we have when we think of her [...] You're kind of trying to also portray your grief a little as to why this is so sad for you [...] She was this, and she was wonderful. And we are all so sad about it because of all these wonderful things [...] So it's like all of those things together. You're trying to portray the grief that you've been having because of what's *not* going to happen, too. And I think that that comes across in a [...] montage [...] better than in just words.

Participant 1 described her reason for choosing TikTok to share her bereavement journey, “I felt like it kind of gave me the power to tell my story how I wanted it to be told.” Participant 6 explained her perspective on sharing her bereavement journey as

doing something with the energy that I have. It also feels like I'm doing something with the energy that [my son] had, or has still [...] Anything that we've decided to do after [our son's] death to memorialize him feels like [...] we get to parent him a little bit.

Neimeyer (2001) confirms that sharing one's narrative is common in therapeutic contexts, "Bereaved people often seek safe contexts in which they can tell (and retell) their stories of loss" (p. 264).

The second tenet of the model is *discourse and rhetoric*, or the notion that the meaning of one's narrative is reinforced through recognition by one's social contexts. All participants described experiences that align with this tenet of the model. For example, Participant 1 explained how sharing her grieving process on TikTok has been helpful for both her and her community, "I've just kind of really been an open book, which has allowed me to heal. But it's also allowed other people to heal along with me, I think." Participant 2 described learning to share her grief with her community,

Your grief is the last thing you have to hold, and to be able to share that and let other people carry it for you, that's hard. But I knew it was important and it was the only way I was going to survive.

Participant 6 described how social media allowed her to participate in a discourse early in her grief journey, "Being able to connect with people and find community without having to leave the house was beneficial for me in so many ways." Neimeyer (2001) explains how discourse with one's community creates shared understanding of the loss,

Each person constructs a unique response to bereavement that distills the meanings of loss current in [one's] family, community, and culture. Each of these ways of

‘linguaging’ about loss, in turn, provides a partial prescription for how loss is to be accommodated by the individual and the social world (p. 264).

The third tenet of the model is *tacitness*, or the idea that not all thoughts and feelings are verbally expressible. All participants described experiences that align with this tenet of the model.

Although, the extent to which participants described tacit communication varied. For me, Participant 1 provided one of the most profound descriptions of tacit communication regarding a particular image taken the day her son died and how it helps convey her truth, “I think from my perspective it's one of the most powerful photos. [...] Because I feel like it sums up everything and all of the emotion from that day.” Participant 4 also provided a profound description of a picture from the day her daughter died,

The one picture that I share probably the most often is me holding her. She's gone. But I'm holding her up on my shoulder because I never got to hold her there because she always had her tubes, so I always had to cradle her. But like my aunts and people have just said like, ‘That is the most painful picture I've ever seen,’ because I'm just bawling.

Neimeyer (2001) describes the purpose of therapeutic interventions to support tacit understanding, “At an abstract level, all of these entail helping clients more adequately symbolize their experience as a precondition to its reflexive examination” (p. 266).

The fourth tenet of the model is *relational self*, or the concept that one’s sense of self shifts during bereavement in relation to various social contexts. Many of the experiences reported by participants align with this tenet of the model. Although, the extent to which

participants described their senses of self shifting in various social contexts differed. Many participants described related activities—such as understanding one’s role leading memorial services with one’s community—but did not explicitly explain their sense of self during the experiences. For me, Participant 8 provided the most profound description of a shifting sense of self in her explanation of how sharing her daughter’s story on social media affected her fundamental sense of existence,

It let me connect to her in an active way. Every day. In an active like, action-based way. So, I was always connected to her all the time in the pain and the grief. In like every fiber of your being, right? And social media was like a fiber of your doing. So, being versus doing. So, let me do!

Neimeyer (2001) describes how one’s sense of self shifts during one’s grieving process,

In the wake of bereavement [...] we are forced to renegotiate our identity as a survivor in interaction with others, seeking an audience that will validate the new version of self we enact. This process typically is both conservative and revolutionary, entailing a search for that which remains viable in our previous lives and an invention of new roles and ways of being that are appropriate to our changed worlds.

The fifth tenet of the model is *evolutionary epistemology*, or the notion that one’s self-narrative evolves over time and in different social contexts. Many of the experiences reported by participants align with this tenet of the model. Although, the extent to which participants

described their self-narratives evolving varied. Many participants alluded to related phenomena—such as understanding a new purpose in life—but did not explicitly explain their experiences in terms of narrative construction. For me, Participant 5 provided the most profound description of an evolving self-narrative in her explanation of how sharing her son’s story allowed her to begin healing from his death and fundamentally changed how she related to others in her life,

I got to share his story then. So, I think that's where my healing process started. Because once I had the story inside of me, that I was afraid to tell, or I didn't think no one wanted to hear it. So, once I was able to tell it, [...] I don't have to be shut in isolated. Because that's what I was used to. Like, 'You just sit in the corner and you get it together.' You know what I mean? Now, I don't have to sit in the corner no more.

Neimeyer (2001) describes the therapeutic benefit of reworking one’s self-narrative after loss,

When bereaved individuals are unable to negotiate this transition they may feel constrained by a life story that is radically incoherent, leaves important experiences “unemplotted” [...] However, a progressive evolution of the self-narrative is also feasible, suggesting the possibility of posttraumatic growth and the development of richer, more elaborate texts of identity following adaptation to loss.

With the tenets of the Meaning Reconstruction Model as a foundation, I now discuss the activities in which grieving individuals engage to reconstruct meaning for themselves. As

explained above, Gillies and Neimeyer's (2006) describe three categories of activities that grieving individuals use to reconstruct meaning: *sense making*, *benefit finding*, and *identity change*. Below, I exemplify and explain how the study's participants used digital media in activities related to these categories.

Sense making is the foundation of meaning reconstruction. The experience of parental bereavement can result in confusion and disorientation regarding many aspects of one's life. For Participant 1, using social media to share her bereavement journey means being able to do so on her own terms, "I feel like it has been my own type of therapy to talk through things on my own." For Participant 2, creating multiple digital memorials to process her daughters' deaths has led to a deep understanding of the human experience, "Maybe there are some things we're just not meant to be able to hold on to forever." For Participant 4, reviewing digital images of her daughter's last days provides a poignant reminder of why she chose to have life support removed,

I think just knowing that she wasn't okay, you know? Because there's obviously guilt that, you know, you feel like, okay, I kind of gave up but [...] reminding myself that there's nothing to feel guilty about.

Benefit finding is a key dimension of meaning reconstruction, but it may take time to emerge (Neimeyer & Anderson, 2002). Not surprisingly, many bereaved parents are resistant to the notion of benefit finding in the period immediately following their children's death. Yet, as time passes, this can change. For Participant 1, one of the benefits that stems from her son's death is related to the inspiration she believes his story provides to the broader community,

Sharing his story has helped others grow in their faith as well, and has helped a lot of people through some very hard situations [...] I get messages every day saying like, 'Thank you so much for sharing your story. Because, like, we couldn't find anything like [it].'

For Participant 3, sharing her daughter's story means creating a legacy dedicated to supporting others' mental health,

I want that to be her legacy. That mental health matters, that you know what? There's going to be a tomorrow and that you can get through it. [...] That people are here to help you once you do get through it.

For Participant 5, one benefit of enduring her son's death and sharing her experience is how she has grown in ways that allow her to help others in her community,

I also want them to understand that, even though you go through things like that, it's okay to talk about [it]. It's okay to express your feelings. It's okay to cry. People think crying make you look crazy or stupid or weak.

Identity change is an immediate aspect of most parents' bereavement experiences. Unless an individual is already a bereaved parent due to a previous loss, the death of one's child brings with it unfortunate membership to a new association. Stemming from this experience, the

processes of sense making and benefit finding also commonly affect one's sense of self.

Participant 2 describes how using digital media to share her daughters' lives has influenced her evolving sense of self,

[I'm] trying to understand myself and who I am now because it's it is changing on an almost molecular level. Just like becoming a mother changed me down to my marrow, losing them changed me yet again, and now this person who is, you know, grieving with gratitude is also a new person.

Participant 5 likened her sense of identity when using social media to share her son's story and her grieving process to having a spiritual experience, "I feel like *me* sharing it. It's like, 'Share your testimony. Share it! Share your feelings!'"

Many researchers are interested in the development of research programs that integrate meaning reconstruction activities into grief therapy (Neimeyer, 2019). Neimeyer argues that a meaning reconstruction-based therapeutic model should facilitate two functions: *processing the event story* and *accessing the back story of the relationship*. He describes how the clinical protocol should be a "procedure in which a trained mental health professional supports a bereaved client in closely reviewing and relating the story of the death under conditions of high safety but low avoidance" (p. 84). Current research in this area has included both psychotherapeutic and expressive arts modalities (Thompson & Neimeyer, 2014; Torres et al., 2014).

Neimeyer (2014) offers a therapeutic technique he developed called *Chapters of Our Lives*. The process begins by the therapist prompting the client to create a "'table of contents' of

their unique self-narratives, outlining how they would organize their significant life transitions across time” (p. 80). This activity can be done together in the session or as therapeutic homework.

Neimeyer (2014) offers another therapeutic technique developed by Hedtke (2012) called *introducing the loved*. The process begins by the therapist asking the client to describe the deceased. Neimeyer describes this activity is primarily verbal, but acknowledges using “images to prompt comments on the special qualities of each [person introduced]” (p. 87).

Rolbiecki et al. (2021) describe a study of bereaved people using digital storytelling to narrate meaning making. The research team hosted five workshops for 14 people to learn the basics of digital storytelling with Apple’s iMovie. The team also supported participants’ meaning-making processes in the creation of digital narratives. They describe the purpose of the study,

The focus of this particular study was not on the effectiveness of Digital Storytelling in preventing or reducing problematic bereavement outcomes. Rather, we sought to answer the following research question: *What meaning-making processes are evident in bereaved individuals’ personally-created digital stories?* (italics in the original) (p. 2).

They report, “Findings support prior research and enrich emerging understandings of arts-based interventions as tools to facilitate and communicate meaning-making processes” (p. 1).

Based on this work—as well as the responses reported by participants, one direction for future research related to meaning reconstruction and digital media could consider further

integration of digital media into existing therapy-based storytelling activities. Neimeyer (2014) describes narrative work in the therapeutic context as

the use of various facilitative questions that bear on [one's] significant settings, characterizations of self and others, plots, themes, and implicit goals in either conversation or as prompts for personal journaling (p. 80).

Thus, activities like *Chapters of Our Lives* and *introducing the loved* could be expanded to use digital images, video, and audio. I believe the increased richness provided by digital media would enhance communication between therapists and clients.

Another direction for future research related to meaning reconstruction and digital media could take a longitudinal approach to considering bereaved people's meaning reconstruction processes. Rather than the single "meaning-centered intervention" (p. 2) explored by Rolbiecki et al. (2021), a longitudinal study would involve multiple meaning-centered interventions and could use different media types. Information created through this activity could provide insights related to both interaction design practice and bereavement theory.

5.4: Thanatosensitive Design

As explained above, the ideas underlying TSD are fundamental to the study described in this document. TSD involves "the multidisciplinary study, design, and evaluation of computing technologies which actively engage with issues of human mortality, dying, and death" (Massimi, 2010, p. 2952). The central goals of this project are guided by Massimi and Charise's (2009) goals with TSD.

Massimi and Charise's (2009) goals with TSD are, first, to persuade those working in human-computer interaction to see the importance of considering mortality, dying, and death in technology design, and second, to call for additional work in these areas. One of the project's central goals is to identify a collection of emotionally powerful statements from bereaved parents regarding their experiences memorializing their children. My purposes in collecting these statements extend from Massimi and Charise's (2009) goals.

The first purpose for collecting these statements is to inspire a sense of empathy between the designers of digital media technologies and this user group. As described above, empathy is a key element of design practice. As cited above, Wright and McCarthy (2008) elaborate, "empathy has been used as a defining characteristic of designer-user relationships when design is concerned with user experience" (p. 637). The second purpose for collecting these statements is to (thereby) grant designers in this field a deeper understanding of the importance of their work. The third purpose for collecting these statements is to identify opportunities for improving the technologies employed by bereaved parents to memorialize their children. The discussion below prioritizes this third purpose.

As described above, Massimi and Charise (2009) identify five areas of HCI research that hold potential for incorporating TSD: user-centered design, user modeling, intelligent agents, research methodology, and privacy. My discussion of this study's findings has overlapped many of these. Based on participants' responses, this discussion has emphasized user-centered design, user modeling, and intelligent agents. Below, I offer a summary of participants' responses as confirmation of these ideas as timely research topics.

Participants' comments related to user-centered design ranged from insight into the complexity of bereaved parents' user experiences to vivid description of a template-based application to memorialize one's child.

Participant 7 described the complexity of interacting with one's digital images as a bereaved parent,

There's a whole lot of emotions going on. I'm not really sure what to feel. I feel angry that I'm having to do this. I feel sad that he's not here anymore, that we're not going to get any more of these photos. I feel happy because this [image] was a really happy funny moment and I'm glad that I've got these photos. So, I do feel happy that I have something. At least I have some sort of, you know, imprint of his life. [I feel] angry at other people, a lot of guilt [...] just like every feeling you could possibly think of, I think came up while going through [the images of him].

Participant 1 explained her vision for a Web-based application for memorializing a loved one,

It would be really handy to have some sort of like, slide deck where it's all put together for you and you just, literally, it's like a template, and you just like, insert the pictures and it goes right along [...] and it syncs to music that [users] can choose. That would be very handy [...] If the technology had like, maybe quotes or sayings [...] Sometimes if you can't find the words yourself, it's nice to have someone who's walked in your shoes have those words. You're like, 'Wow, that literally is exactly what I'm feeling!' That would be

nice! [...] You can just [...] convert it to like, a paper copy to be mailed out to my grandma and grandpa. That would be sweet [...] That would be next level.

Participants' comments related to user modeling ranged from conceiving of new emotional dimensions for this user group to recognizing possible limitations within this user group due to cognitive impairment.

Participant 1 pondered a new underlying concept for technology designers to consider when designing for bereaved parents,

I don't know how technology can be gentle, but it needs to be like, gentle. But I don't, I don't know how technology can be gentle. I don't know how to describe how technology would be gentle, but it needs to be gentle.

Participant 8 explained why interaction designers should consider using existing user interface and user experience conventions when designing for bereaved parents,

It can be really hard to add on new skills when you're, you know, when you're in the middle of grief—*of heavy and early grief*. And so, the best access people have to memorialize their loved one is through using [what is] already available [...] If it functions like PowerPoint, I would have been able to have [...] done that. But trying to integrate a new mental framework would have been really tricky [...] You have to make it something that's [...] accessible [...] When thinking about people in grief and getting something done—*whatever the something might be*—recreating current mental

frameworks is the best chance. So, if it's a new product, a new product modeled after old product might be [...] what's helpful.

Participants' comments related to intelligent agents ranged from ideas for assistive technology to complex image analysis features. Participant 6 offered the idea of a chatbot that checked in on users,

Netflix has this like, 'Are you still watching?' Like, something that automatically comes up? A program for those who are grieving could be like, 'How are you doing? Have you been doing this too long?' Like, just something that pops up [...] after a certain amount of time that checks in, maybe offers like, 'Do you need to talk to somebody?'

Participant 2 described wanting advanced facial recognition and image manipulation to "scrub [...] the presence of [a person]" from one's images.

As described above, Massimi and Baecker's (2010) TSD-related focus is on the use of technology to remember and identifying how "digital artifacts [can] support or replace more material ways of remembering" (p. 1822). From this investigation Massimi and Baecker's (2010) offer a list of ten opportunities for TSD (discussed in §2.2.4). Amongst these, number seven stands out as most germane to this discussion.

7. *The Support Problem*: This problem acknowledges the dearth of social support technologies available to the bereaved.

Below, I discuss this problem area in light of my experience conducting this study. Social support technologies encompass a wide array of resources. Due to this study's focus, my discussion of this problem prioritizes the experiences of bereaved parents practicing digital memorialization.

I attest to a lack of technological resources deliberately designed to accommodate the dynamic and complex needs of this user group. Based on my understanding of participants' memorialization activities, use of social media exceeds all other technologies. However, in terms of participants' experiences, much room for improvement was acknowledged. My impression is that participants wish they had access to tools designed more specifically around the dimensions of memorialization.

Therefore, one direction for future research in this area could involve designing, developing, and evaluating a Web-based media sharing application based on the ways of meaning-making reported by participants: understanding one's experiences, commemoration, and sense of purpose. The purpose and function of this system could be guided by the ways of healing reported by participants: self-healing and healing for others. The process of designing, developing, and evaluating a system that prioritizes these ideas would provide insights related to both interaction design practice and bereavement theory.

5.5: Memorialization

The final research area to which I relate the study's findings is memorialization. As cited above, Hallam and Hockey's (2001) central argument is "that material dimensions of memory making are significant not just in the marking of deaths, but also in the social and cultural processes

through which lives are remembered and futures are imagined” (p. 20). A key insight I experienced in conducting this study is that of a broader and deeper understanding of this statement.

Admittedly, I began the study with a comparatively narrow definition of memorialization, that of creating a digital memorial. This narrowness is reflected in the wording of the project’s research questions, “to create memorials.” My understanding of memorialization began to shift almost immediately.

My first interview—with Participant 1—extended my understanding of memorialization to include an ongoing practice. My understanding continued to broaden during my second interview. Participant 2 shared her perspective of, “memorializing my girls in every step I take.” In my third interview, Participant 3 echoed this idea, as cited above, “There are so many things you can do to sort of make meaning of your person’s life.”

In light of these perspectives, I began to understand memorialization differently. I began to understand my previous research activities differently. I began to understand the very act of completing this dissertation as a means of memorializing my own daughter, Julia Erin. That understanding was a profound phenomenon to experience.

From the dawn of the verse epitaph to the emergence of the newspaper obituary, from post-mortem photographs and gramophone recordings to the early memorial websites, and now to contemporary social media-based memorialization, the form of memorialization has evolved. Another aspect of memorialization that is evolving is its social presence. As cited above, Arnold et al. (2018) state, “Social media memorialisation [...] celebrates a repositioning of the dead very much within the everyday flow of daily life” (p. 54).

Thus, one direction for future research related to social media memorialization could consider the new social structures that emerge as the social presence of death evolves, and the role(s) that digital media plays within these structures. The information created through this activity may provide insights related to both interaction design practice and bereavement theory.

5.6 Limitations of the Study

As Bell and Korzybski (1934) famously asserted, “The map is not the territory” (p. 570). That is to say, a description of a thing cannot be as detailed as the thing it describes. This idea is commonly used to explain interface design. A computer interface is not to be as detailed as the information it offers. Some abstraction and/or reduction must occur.

This assertion is also valid when considering any representation of knowledge. (Even quantitative information—for example, eight apples—undergoes several abstractions in its representation.) This assertion is of course true for qualitative knowledge. Thus, such is the case with the findings of this study.

A key limitation to this study is how the insights derived from participants’ interviews simply cannot be shared in totality. Both my interpretations and descriptions must involve some abstraction and/or reduction.

Other limitations to this study relate to the scope and nature of its investigation. The scope of the study is limited to three research questions. Further, each of these research questions is qualitative in nature. Thus, the findings discussed in the study are limited by the foci of these questions *and* the subjectivity of the information they produced.

Therefore, the findings of this study can be understood as inherently incomplete and entirely subjective. However, that is not to say that are without value. My representation of the

study's findings is based on my efforts to realize a rigorous investigation process. As Mason (2012) describes, rigorous qualitative inquiry involves

data generation and analysis [that] have not only been appropriate to the research questions, but also thorough, careful, honest and accurate (as distinct from true or correct—terms which many qualitative researchers would, of course, wish to reject). At the very least this means that you must satisfy yourself and others that you have not invented or misrepresented your data, or been careless and slipshod in your recording and analysis of data (p. 188).

Lincoln and Guba (1985) expand on these ideas by defining four evaluation criteria for qualitative findings: *credibility*, *dependability*, *confirmability*, and *transferability*.⁶

Thus, to achieve this credibility, dependability, confirmability, and transferability, I have sought to adhere to standard interpretive strategies, including articulation of my relevant presuppositions and diligent use of the hermeneutic circle. My efforts to meet these expectations for qualitative rigor have also been guided by my following the multiphase analytical process of the IPA methodology.

⁶ Malterud (2001) attempts to map these qualitative criteria onto quantitative criteria, arguing that credibility, confirmability, and transferability can be likened to validity, objectivity, and generalizability.

My goal in achieving credible, dependable, confirmable, and transferable findings is to attain a sense of trustworthiness in the information. As Rodham (2015) explains, “The relevance of traditionally positivist terms such as ‘reliability’ and ‘validity’ has been questioned [for qualitative findings] and the term ‘trustworthiness’ has been suggested as being more appropriate (p. 60).” To that end, as suggested by Yardley (2008) and Rolfe (2006), I have sought demonstrate sensitivity to the research context and transparency in my process.

Another limitation to this study is the transferability of its findings. The purpose of this study is to understand and share the experiences of the study’s participants. However, the findings developed from this investigation may only be said to be trustworthy for this group of people. Said another way, the ontological pluralism inherent in qualitative inquiry (and the IPA methodology) preclude absolute extension of these findings to other groups—for example, *all* bereaved parents.

Yet, as described above, one of the defining features of the IPA methodology is that it is inductive, or develops understanding from the particular toward the general. Which is to say, the study’s findings should be generalizable to some extent. As Creswell and Creswell (2018) describe,

The generalization occurs when qualitative researchers study additional cases and generalize findings to new cases. It is the same as the replication logic used in experimental research. However, repeating a case study’s findings in a new case setting requires good documentation of qualitative procedures (p. 202).

In addition to requiring good documentation of one's procedures, the transferability of this study's findings to other groups will also be influenced by the characteristics these groups share with the study's sample. For example, I suspect this study's findings are transferable *to some extent* to most bereaved parents. Similarly, I expect this study's findings are transferable *to some extent* to most bereaved siblings, etc. However, what is not known is which shared characteristics are most influential to the transferability of the findings.

Another limitation to the transferability of this study's findings may be the self-selective nature of the study's sample. All participants self-selected to participate in the study. Clearly, the study's participants are not the only bereaved parents using digital media to memorialize their children. What is not understood is why these people chose to volunteer and others did not.

In light of these limitations to the transferability of the study's findings, I am curious to know how a similar study, but prescribed—for example, as part of a grief therapy protocol—may produce corresponding and differing results. This prescribed study could include—and *compare*—people of different genders, people with different grieving patterns, people from different cultural backgrounds, people experiencing different types of bereavement, etc. Such a study may provide insights related to which participant characteristics are most influential to the transferability of the findings.

5.7 Personal Reflection

As I reflect on my process conducting this study, my thoughts are filled with learning experiences. These experiences range from *aspects that went well* to *things I wish I knew before I started*. I discuss these learning experiences below.

Beginning with the focus and scope of the project, I learned about the challenges of conducting a research project directed at a deeply personal and emotional topic. I had anticipated some emotional challenges along the way, as I have previously conducted TSD-related research. However, the rigor of the IPA methodology provided a new level of research experience.

One example of an emotionally challenging experience I had is the process of conducting the study's interviews. As someone who does not have a counseling background, the richness and depth of the information that participants shared was a bit of a surprise. I am immensely grateful to the study's participants. Without their courage and honesty, this project would not have been possible. But initially, I found that the intensity of the interview experience challenged me in ways for which I was not prepared. I did my best to adjust to this requirement of the study. The pages above are a testament to my intent to honor participants' courage and honesty.

One aspect of the project that I think went well is the literature review. I found the process of conducting the project's literature review to be a transformative learning experience. Before conducting the review, I was not entirely confident in my readiness to realize the dissertation project I was envisioning. However, the learning I experienced reading, analyzing, and writing about the literature that I reviewed for the project provided a significant boost in my confidence. After conducting the review, not only did I feel more confident in conducting the study, but I was sincerely excited to do so.

Another aspect of the project that I think went well is my execution of the methodological process. If there is merit to be found in the pages above, that merit owes heavily to the IPA methodology. This was my first experience using the IPA methodology. I found its structure and activities to align well with the goals of my inquiry. My overarching goal with this inquiry was to conduct the most in-depth user research of which I could conceive. As described

above, the IPA methodology certainly provided in-depth user research. I am not aware of any other interaction design research projects that have applied the IPA methodology. I think this methodology offers a lot of opportunity for the design research community.

One thing that I think represents a miss with the project is better understanding how participants' time since bereavement impacts their memorialization activities. I did not consider this variable in defining the project's research questions. Neither did I have any open-ended questions related to time since bereavement in the interview script (Appendix B). During the process of conducting the study's interviews, I sensed opportunity for deeper understanding of how memorialization activities evolve as bereaved parents' time since bereavement increases. But unfortunately, participants' ideas related to their times since bereavement and memorialization activities remained implicit. This aspect of the study is the first thing I would change if I could redo it.

I believe that better understanding how grief changes over time is crucial to better supporting mourners in their grieving processes. At times, my experiences conducting this study brought me face-to-face with the unique bitter and burning pain of early parental grief. These moments caused me to wonder if some participants were ready to have the conversations we did. In the end, all participants expressed appreciation for the opportunity to volunteer for the study. But these experiences begat questions related to whether those in heavy grief—especially early parental bereavement—should constitute a new category of vulnerable individuals, and thus have special protection in research studies.

Moreover, my experiences conducting this study also involved total rejection from some grief organizations due to policies of not allowing researchers access to their membership. There were many instances that caused me to wonder if this rigid protectionist stance was best serving

their members, much less broader humanity. How many opportunities have been missed to share the profound learning that has been realized by living through profound tragedy?

In summary, my experience conducting the study described above has bolstered my faith in the influence of research and education on the human experience. It has been a privilege and honor to conduct the project explained herein. I offer this dissertation to the University of Minnesota (and broader academia) as a candidate for their highest degree. Thank you.

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Appendix A: Grief Pattern Inventory

Please rate each of the following statements based on how you responded after your loss MOST of the time. Choose the most SIGNIFICANT and RECENT personal death-related loss you've experienced as the basis for your answers.

1. I am more emotional than most people I know. 1 2 3 4 5
2. It seems natural for me to cry and show my feelings to others. 1 2 3 4 5
3. It helps me to express my grief through tears. 1 2 3 4 5
4. Although I know that I am grieving in my own way, others may think that I am cold and unfeeling. 1 2 3 4 5
5. I don't seem to feel things as deeply as most other people I know. 1 2 3 4 5
6. I appreciate it when others encourage me to share my innermost feelings about my loss with them. 1 2 3 4 5
7. I have been told that I am avoiding my grief even though I don't think that I am. 1 2 3 4 5
8. Even though I have returned to my normal routine, I continue to be overwhelmed by strong and painful feelings. 1 2 3 4 5
9. I believe that a bereavement support group is (would be) very helpful to me. 1 2 3 4 5

10. I resent efforts to get me to show feelings that I really don't have. 1 2 3 4 5
11. I would rather talk about "issues" related to my loss than feelings about my loss. 1 2 3 4 5
12. I would describe myself as more intellectual than emotional. 1 2 3 4 5
13. I don't like others knowing how upset I am by my loss. 1 2 3 4 5
14. I often disguise how I'm really feeling inside. 1 2 3 4 5

Appendix B: Interview Questions

Getting to know the participant

Tell me about yourself.

Gender?

Age?

Ethnicity / cultural affiliation (e.g., Hispanic, Jewish, Chinese, etc.)?

Relationship status (e.g., married, single, etc.)?

Spiritual orientation (e.g., Catholic, Lutheran, Buddhist, etc.)?

Highest education level (e.g., high school, technical education, college, etc.)?

Can you describe the relationships in your life that are most important to you?

Household composition (e.g., father, mother, son, daughter, etc.)?

Would you tell me about [child's name]?

Circumstances of their child's passing

Could you describe your life in the period leading up to [child's name]'s passing?

Could you describe the circumstances around [child's name]'s passing?

Expected?

Cause?

Deceased child(ren)'s age(s)?

Could you describe your life in the period following [child's name]'s passing?

Time(s) since bereavement?

Digital memorial

Tell me about the memorial you created for [child's name].

How did you make it?

How would you rate your computer skill level (e.g., 1: novice, 10: advanced, etc.)?

Which tools / technologies / software / applications did you use?

Could you describe your experiences making the memorial?

How did the process feel to you?

Are there any aspects of the tools / technologies / software / applications that stick out in your mind?

Would you be willing to share [child's name]'s memorial with me?

Aspirational technology use

Are there any ways in which you wish the tools / technologies / software / applications worked differently?

Are there any ways in which you wish you could work differently with the tools / technologies / software / applications?

Grief and meaning

Could you describe what motivated you to make this memorial?

Could you describe how [child's name]'s memorial serves you in grieving?

Could you describe what [child's name]'s memorial means to you?

Appendix C: Recruitment Flyer

PARTICIPANTS WANTED FOR RESEARCH STUDY

Exploring the Experiences of Bereaved Parents Who Have Created Digital Memorials

We are looking for:

- parents aged 18+
- who have lost a child between 0-17 years of age
- who have created a digital memorial for their child

A digital memorial can be any type of memorial that includes digital photos, videos, audio, and/or words.

This includes slideshows, video montages, image galleries, blogs, etc.

Participation includes a short survey and an interview.*[∞]
Estimated time commitment is one hour.

If you are interested in participating in this study, please contact Robert Fraher at frah0005@umn.edu or 715.505.4848.

* This interview can be conducted in your home, a quiet place of your choosing, or virtually.

[∞] The audio of this interview will be digitally recorded.

This research study has been approved by the University of Minnesota's Institutional Review Board (STUDY00019981).



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Appendix D: Consent Form

Consent Form

Title of Research Study: Exploring the Experiences of Bereaved Parents Who Have Created Digital Memorials HRP-580

Investigator Team Contact Information: Brad Hokanson

For questions about research appointments, the research study, research results, or other concerns, call the study team at:

Investigator Name: Brad Hokanson Investigator Departmental Affiliation: Design, Housing, and Apparel Phone Number: 612 624 4918 Email Address: brad@umn.edu	Student Investigator Name: Robert Fraher Phone Number: 715 505 4848 Email Address: frah0005@umn.edu
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Supported By: NA

Financial Interest Disclosure: NA

Key Information About This Research Study

The following is a short summary to help you decide whether or not to be a part of this research study. More detailed information is listed later on in this form.

What is research?

- The goal of research is to learn new things in order to help people in the future. Investigators learn things by following the same plan with a number of participants, so they do not usually make changes to the plan for individual research participants. You, as an individual, may or may not be helped by volunteering for a research study.

Why am I being invited to take part in this research study?

We are asking you to take part in this research study because you are an adult bereaved parent who has created a digital memorial for your child.

What should I know about a research study?

- Someone will explain this research study to you.
- Whether or not you take part is up to you.
- You can choose not to take part.
- You can agree to take part and later change your mind.
- Your decision will not be held against you.
- You can ask all the questions you want before you decide.

Why is this research being done?

This study aims to produce a set of insights derived from exploring bereaved parents' experiences creating digital memorials that can be used to inform the future design of similar technologies.

Consent Form

How long will the research last?

We expect that you will be in this research study for one hour.

What will I need to do to participate?

You will be asked to complete the Grief Pattern Inventory, a 14-question one-page form, and participate in a semi-structured interview. During the interview, you will also be asked, if you wish, to share your memorial with the researcher. The audio of this interview will be digitally recorded.

More detailed information about the study procedures can be found under "What happens if I say yes, I want to be in this research?"

Is there any way that being in this study could be bad for me?

Participation in this study involves talking about the loss of your child. This may cause you to experience feelings associated with grief. A follow-up grief resource information sheet will be offered to you if you would want to access additional local personal support.

Will being in this study help me in any way?

We cannot promise any benefits to you or others from your taking part in this research. However, some parents report positive effects from participating in bereavement research. These include opportunities to reflect on their children and contribute to improving the experiences of other bereaved parents.

What happens if I do not want to be in this research?

There are no known alternatives, other than deciding not to participate in this research study.

Detailed Information About This Research Study

The following is more detailed information about this study in addition to the information listed above.

How many people will be studied?

We expect about 10 people will participate in this research study.

What happens if I say "Yes", but I change my mind later?

You can leave the research study at any time and no one will be upset by your decision.

If you decide to leave the research study, contact the investigator so that the investigator can withdraw your data from the study.

Will it cost me anything to participate in this research study?

There will be no cost to you for any of the study activities or procedures.

What happens to the information collected for the research?

We may publish the results of this research or sharing the resulting data. However, we will keep your name and other identifying information confidential.

Additional sharing of your information for mandatory reporting

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Consent Form

If we learn about any of the following, we may be required or permitted by law or policy to report this information to authorities:

- Current or within the preceding three years child or vulnerable adult abuse or neglect;
- Communicable, infectious or other diseases required to be reported under Minnesota's Reportable Disease Rule;
- Certain wounds or conditions required to be reported under other state or federal law; or
- Excessive use of alcohol or use of controlled substances for non-medical reasons during pregnancy.

Data or Specimens Collected

The records of this study will be kept private amongst the research team. All paperwork will be kept in a locked office. The digital recordings of the study's interviews and the transcripts will remain on password-protected computers. These computers will be the property of the research team. The report from this research will not contain any information by which you could be identified. All personal identifiers will be removed from your identifiable private information.

What will be done with my data and specimens when this study is over?

Your data will not be used for any future research after this study is complete.

Whom do I contact if I have questions, concerns or feedback about my experience?

To reach the research team: Please see the "Investigator Contact Information" section at the beginning of this form.

To reach someone outside of the research team: This research has been reviewed and approved by an IRB within the Human Research Protections Program (HRPP). To share feedback privately with the HRPP about your research experience, call the Research Participants' Advocate Line at [612-625-1650](tel:612-625-1650) (Toll Free: 1-888-224-8636) or go to z.umn.edu/participants. You are encouraged to contact the HRPP if:

- Your questions, concerns, or complaints are not being answered by the research team.
- You are having difficulty reaching the research team.
- You want to talk to someone besides the research team.
- You have questions about your rights as a research participant.
- You want to get information or provide feedback about this research.

Will I have a chance to provide feedback after the study is over?

The HRPP may ask you to complete a survey that asks about your experience as a research participant. You do not have to complete the survey if you do not want to. If you do choose to complete the survey, your responses will be anonymous.

If you are not asked to complete a survey, but you would like to share feedback, please contact the study team or the HRPP. See the "Investigator Contact Information" of this form for study team contact information and "Whom do I contact if I have questions, concerns or feedback about my experience?" of this form for HRPP contact information.

Consent Form

Your signature documents your permission to take part in this research. You will be provided a copy of this signed document.

Signature of Participant

Date

Printed Name of Participant

Signature of Person Obtaining Consent

Date

Printed Name of Person Obtaining Consent

WITNESS STATEMENT:

The participant was unable to read or sign this consent form because of the following reason:

- The participant is unable to read the information
- The participant is visually impaired
- The participant is non-English speaking
- The participant is physically unable to sign the consent form. Please describe:

Other (*please specify*):

For the Consent of Non-English Speaking Participants when an Interpreter is Used:

As someone who understands both English and the language spoken by the subject, I represent that the English version of the consent form was presented orally to the subject in the subject's own language, and that the subject was given the opportunity to ask questions.

Signature of Interpreter

Date

Printed Name of Interpreter