

REDESIGNING GRIEF: DIGITAL DESIGN'S IMPACT ON
GRIEVING ONLINE AND ITS RESPONSIBILITY
TO IMPROVE THE EXPERIENCE

by

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DEDICATION

To my father, Eduardo Raul Di Sarli, who instilled in me a lifelong desire to keep learning, thank you. I never would have imagined the challenges I would face during the writing of this thesis. However, the last four months spent caring for you made me even more passionate about this cause. I will always remember your pride, stories, and songs.

“Y tal vez a la noche, cuando el viento abanique su copa, embriago de gozo, le cuente—Hoy a mi me dijeron hermosa.”

— Juana de Ibarborou

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“No hay que llorar, que la vida es cruel. Nunca estará solo. Dios está con él.”

— Celia Cruz

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ABSTRACT

Grief, while one of the most universal human experiences, can lead to long-lasting mental health issues for some if the loss was sudden or violent. Even in so-called “normal” grief, an individual will experience a huge disruption to their life. Web 2.0 marked the evolution of users from passive consumers of content to active participants who generate content and dialogue with other users through social media. In this digitally mediated age, a person will generate massive amounts of data in the form of photos, videos, audio, documents, chats, and other files, which will become their digital legacy postmortem. The objectives of this research were to 1) understand the foundation of modern grief theory; 2) investigate the ways in which the internet and computing have transformed archiving rituals post-loss; and 3) critically analyze the designer’s role in shaping the experience of grief online. In this ethnographic study, participants were asked questions surrounding their current mourning practices and how they handle the digital legacy of their loved ones. Fieldwork with bereaved users revealed that in addition to physical crafting, digital crafting has emerged as a frequent practice due to many conversations and interactions being digitally

mediated. Digital crafting in the context of bereavement can be described as the act of gathering, editing, curating, and archiving digital materials for the purpose of record-keeping, remembering, sharing, and future bequeathing. A speculative design project is presented to bring attention to the role that designers play in the experience of the bereaved and challenge them to consider new ways to facilitate connections between the bereaved and deceased through digital media.

Keywords: Bereavement, Grief, Mourning, Thanatosensitive Design, Human-Computer Interaction, Speculative Design, Digital Design, Digital Crafting, Digital Legacy

I. INTRODUCTION

No matter your age, affliction, economic or social status, grief is likely to affect you at some point in your life. At the start, it is important to clarify some terms. *Grief* is described as the internal feeling and experience of losing someone important while *mourning* is the outward behavior that society will expect of you (Walter 2012). *Thanatology* is an interdisciplinary field studying the medical, psychological, and sociological experience of death and dying (“Medical Definition of Thanatology” n.d.). Although we all might experience grief, we will not experience it in the same way because the experience of grief is unique to everyone. While most can return to their emotional baseline within a year, some types of losses including sudden and violent losses put the bereaved at risk for mental health issues (Kristensen, Weisæth, and Heir 2012). Prolonged Grief Disorder (PGD)—recently added to the American Psychiatric Association’s (2013) *Diagnostic and Statistical Manual of Mental Disorders* (5th ed; DSM-5)—can lead to a long-lasting and traumatic bereavement experience if not addressed. Violent and sudden loss can lead to mental health issues like Post Traumatic Stress Disorder (PTSD) and Major Depressive Disorder (MDD), alongside or independently of PGD. Even with so-called normal or uncomplicated grief, the average person experiences a huge disruption to their daily life. When we lose someone important, we also experience a loss of self as our identity is partially

formed by our relationship with others. The bereaved will be “different” for a while and experience mental distress, as well as physical, behavioral, and spiritual responses. Whether someone experiences PGD, MDD, PTSD, or “normal” grief responses, they will experience a negative impact on their mental health. In clinical terms, the person’s ability to prepare for the loss and their response to their grief will dictate whether they eventually return to normal function or need further medical intervention.

As computers, smart devices, and the internet continue to permeate our lives, a new topic to consider is what happens to our data after we die. Considering the far reach of Social Network Sites (SNSs) like Facebook, Instagram, and Twitter, the average person will live a large part of their lives mediated through these platforms. In the digital age, the average person will subsequently amass vast amounts of data stored on these platforms including photos, videos, posts, comments, chats, and interactions. When a user dies, this data stays on these platforms and servers, prompting some companies like Facebook to introduce features like the Legacy Profile, which switches a user’s profile postmortem into a memorialization status complete with new rules of interaction. While tech giants like Facebook are starting to consider new features for postmortem data issues, there is still not enough education for designers on their roles in the creation of these systems. Although important research on this

topic has occurred in the last 20 years and innovative solutions to this issue are starting to take shape, they exist at the periphery of mainstream design conversations. The term Thanatosensitive Design (TSD) will be used throughout this thesis to refer to the critical design tool that recognizes the needs of the bereaved, the dying, and the dead in the creation of interactive systems (Massimi and Charise 2009).

The purpose of this thesis is twofold. The first is to bring attention to the vital role that designers play in the experience of the bereaved. The second is to challenge designers to consider new ways to facilitate connections between the bereaved and the deceased through digital media. I challenge designers to do this by proposing a speculative design solution that uses digital crafting and archiving practices to help the bereaved continue bonds with the deceased.

This thesis is organized into six chapters. Chapters I and II describe the current problems with the grief experience in digital spaces and introduce the role of designers in this ecosystem. Chapter III will include a literature review covering relevant topics of research in the arena of death studies, Human-Computer Interaction (HCI), and digital design. Later in Chapter III, a selection of harmful user experience (UX) observations and case studies of TSD solutions will be cataloged. Chapter IV will cover the methodological approach for the speculative project and primary research observations. A speculative digital

design project will be presented in Chapter V using a human-centered design framework by nonprofit design studio IDEO. The sixth chapter will conclude this thesis with final observations on the relationship between digital design and the grief experience as well as future activations and investigations for the thesis project. Additionally, for designers wishing to be more death-sensitive in their practice, a list of recommendations will be presented.

II. STATEMENT OF THE PROBLEM

Death is unavoidable. Benjamin Franklin popularized the now well-known idiom that nothing in this life is certain, except death and taxes as he neared his own demise in 1790 (“Death and Taxes” 2019). While dying represents the one true experience we will all have to face alone, grief and mourning on the other hand are as much social experiences as they are personal ones. In a 2012 issue of *OMEGA: Journal of Death and Dying*, Professor Tony Walter of the Centre for Death and Society and a group of researchers outline several ways in which the internet has changed how we die and mourn (Walter et al. 2012). They present their argument in two parts. First, they analyze the many new online practices surrounding the funeral experience, memorialization, inheritance, and archaeology that have sprung up since the internet has become a daily part of life. They then make connections between these new practices and key concepts in death studies including the sequestration of death from everyday life, complicated grief, disenfranchised grief, and continuing bonds with the dead (Walter et al. 2012). It is safe to say, that nine years after this article was published, the internet has *certainly* changed the way that we live, die, and experience grief.

So, what is the problem? While the internet has offered new spaces for public memorialization, communities for disenfranchised grievers, and a digital

legacy that can be accessed by the bereaved, death and grief remain fringe HCI topics in the design profession. I argue that the tech industry has been slow or reluctant to respond because of its members' age and prejudices which leads to beliefs, values, and taboos that disregard the needs of the bereaved and the dying. For young tech workers, death remains a far-off topic. Tech workers are, on average, much younger than workers of other industries. A recent study completed by PayScale determined that out of the 32 tech companies it surveyed, only six had a median age greater than 35 years old (Hardy 2013). Compare that to the overall median age of the American workforce of 42 years old ("Median Age of the Labor Force, by Sex, Race, and Ethnicity: U.S. Bureau of Labor Statistics" n.d.). It is a fact that as we age, we will experience more death and subsequently, grief. The over-representation of young designers and developers in the tech industry who have less experience with grief in the tech industry has led to a lack of education and interest in the needs of the dying, the dead, and the bereaved. In a 2021 study by Spanish Communication Professor Andrea Rosale and Swedish Media and Communications Professor Jakob Svensson, 18 tech workers from around the globe were interviewed to learn about their perceptions of age and how those perceptions influenced the culture of contemporary tech (2021). The study revealed that ageism—the discrimination of people based on age—was embedded in the industry and leading to the marginalization of older

people. Participants of the study expressed “a common assumption that most users are young, and hence that the design and development of products and services are best handled by young tech workers (Rosales and Svensson 2021, 87).” Additionally, tech workers’ beliefs and taboos surrounding death can become imbued into the structures of the systems they build. Professors Cristiano Maciel and Vinícius Carvalho Pereira at the Federal University of Mato Grasso’s Laboratory of Interactive Virtual Environments in Brazil documented this phenomenon in a 2012 study. In the study, they interviewed eighty-three Brazilian software developers about their opinions on what should happen to their digital legacy after death. Their study showed that “communications were observed to be permeated by beliefs, moral, religious and ideological values, which may influence the development of ‘thanatosensitive’ design solutions (Pereira and Maciel 2012, p.7).”

As mentioned above, TSD remains a fringe topic in the education of designers; however, this topic provided the foundation for the problems explored in this thesis. HCI Researchers Michael Massimi and Andrea Charise introduced this concept of *thanatosensitivity* in their paper presented at the 2009 Conference on Human Factors in Computing Systems (CHI). They describe TSD as a “humanistically-grounded approach to HCI research and design that

recognizes and actively engages with the facts of mortality, dying, and death in the creation of interactive systems. (Massimi and Charise 2009).”

How can we describe the integral role that SNSs play in our relationships with each other? As design problems become increasingly complex, the need for designers to understand complex social behavior grows. Respected author, UX researcher and former Director of the Design Lab at the University of California, San Diego, Don Norman points to this gap in education saying, “design schools do not train students about these complex issues, about the interlocking complexities of human and social behavior, about the behavioral sciences, technology, and business. There is little to no training in science, the scientific method, and experimental design (2010).” Design author and critic A. Telier puts forth Heidegger’s *thing* theory as a framework for viewing the practice of design (Telier et al. 2011). Telier argues that designers should not focus on the designed artifact but its “thingness,” which describes the users’ social behavior interacting with the artifact and the material qualities of said artifact. SNSs can be described as objects of design but they are more than that. Using thing theory, we can see the integral role that SNSs play in our lives. SNSs act as a gathering of people, rich with the lives and interactions of both living and dead users. Designers are intrinsically tied to how these *things* look, feel, and function and are therefore uniquely positioned to craft new environments that consider the needs of the

user, both living, and dead. Additionally, they should recognize, that in addition to minimizing trauma felt by users, they have a responsibility when creating products and services to consider how these networks can be “activated in new ways after death” (Pitsillides 2019, 427).

III. PRELIMINARY RESEARCH

Literature Review

Theories of Grief

To understand how we have arrived at this moment where the digital spaces we inhabit are poorly designed for the messiness of death and grief, it is important to describe the sociological development of contemporary grief theory. A key aspect of this is the evolution of mourning from the 19th century as a condition of the soul (Freud 1917/1959) to a pathological condition in the twentieth century. HCI and thanatological researchers Selina Ellis Gray and Dr. Paul Coulton argue in the book *Digital Legacy and Interaction: Post-Mortem Issues* (2013) that after the Victorian era, mourning went through a period of decline and displacement in the twentieth century. They then contend that in the 21st-century mourning has transformed into brand new rituals that have fallen through the cracks of traditional memorialization research. (Gray and Coulton 2013).

Modern interpretations of the Victorian era position mourning as a public ritual in society where connections with the deceased were celebrated (Walter 1999). However, this does not mean that the Victorians were not without their own oppressive social protocols. The turn towards private grief began with socio-cultural shifts which include “the secularization and diversification of

religion, geographical and social mobility, the growth of consumerism, changing concepts of hygiene, new configurations in the domestic setting, the rise of individualism, the professionalization of care for the dying and disposal services for the dead (Gray and Coulton 2013, 34).” These shifts were further documented by early pioneers of modern death studies including Geoffrey Gorer who wrote that death was increasingly becoming less public and more private (Maddrell and Sidaway 2010). Another early contributor to early 20th-century death studies was psychiatrist John Bowlby, whose attachment theory of grief examined the way humans create bonds with others and how they react when those bonds are threatened or severed (Worden 2009, 13). Bowlby also identified several attachment styles including secure, avoidant, anxious, and disorganized (Bowlby 1961). Proponents of attachment theory draw correlations between grief resiliency and attachment style to the deceased (Wayment and Vierthaler 2002).

The father of psychoanalysis, Sigmund Freud, widely contributed to the modern era’s understanding of grief in his seminal essay, “Mourning and Melancholia” (1917/1959), where he made a distinction between mourning and *melancholia*, which warranted further study as it was an illness of the mind (Granek 2010). It is at this point that grief started to evolve into a “pathology to be privatized, specialized, and treated by mental health professionals (Granek 2010, 46).”

German American psychologist and author Erich Lindemann continued this trajectory with his 1944 study *Symptomatology and the Management of Acute Grief*, in which he established three viewpoints that have remained central tenants to modern psychology's understanding of grief to this day (Granek 2010). The first is the categorization of grief as a medical disease with observable physical and psychological symptoms. Secondly, Lindemann listed the symptoms of what he called abnormal grief which placed its management in the purview of health professionals. Thirdly, he argued that "psychiatrists could, and should, be involved in the management of grief since they were experts in the field and knew the right techniques to help the patient with their grief work (Granek 2010, 58)." Lindemann's study also introduced grief work as a process by which the bereaved needed to work through their grief to return to normal function and that this type of self-care could be properly done with the help of a psychiatrist (Granek 2010). In its integration into mainstream culture during the 20th century, the bereaved were now faced with a new anxiety – "am I recovering from the illness of grief at a proper rate? (Gibson 2006, 257)"

Psychiatrist and author Elizabeth Kübler-Ross is the most prominent figure in the foundation of end of life and grief studies in the United States. Her seminal work *On Death and Dying* (1969) formed the basis for the modern education paradigm of healthcare professionals. In it, she proposed that people

go through five stages at the end of life: denial, anger, bargaining, depression, and acceptance (Kübler-Ross, 1969). Additionally, her five stages model has become so influential that it has shaped society's understanding of grief and the dying experience (Corr 2019, 9). While her work was influential in understanding the various needs of the dying, it has been wrongly prescribed by many as a framework to understand grief. While Kübler-Ross tried to correct this misconception of the five stages model in *On Grief and Grieving* (2004) it had already been entrenched in the United States healthcare education system as canon.

While the five stages model has served as the foundation for many of the therapies used today for the bereaved, newer models position grief as oscillating, non-progressive, and non-linear. In the 1990s Professors Margaret Stroebe and Henk Schut proposed the dual-process model, a theory that critiqued the linear and simplistic nature of the five stages model and instead described grief as a “dynamic, regulatory coping process of oscillation, whereby the grieving individual at times confronts, at other times avoids, the different tasks of grieving” (Stroebe and Schut 1999, 197). Thanatologists Dennis Klass, Phyllis R. Silverman, and Steven L. Nickman continued this criticism of the five stages model with their continuing bonds theory. This theory proposes that continuing bonds with the deceased is a healthier way to live with grief (Klass et al. 1996).

Central to this theory is the concept of the self as relational and supported by others, therefore the relationship between two people does not end when someone dies (“HCI at the End of Life and Beyond” 2020). Attachment style to the deceased plays a large part in predicting whether continuing bonds will be beneficial to the bereaved. In certain relationships the bereaved will move towards replacing physical proximity with psychological proximity to the deceased, creating greater grief resolution using continuing bonds (Field, Gao, and Paderna 2005). Critics of attachment theory argue against it being applied broadly to the population without considering an individual’s culture and socioeconomic status (Duschinsky et al. 2020).

As mentioned previously, between the 19th and 20th centuries, mourning is said to have gone through a transformation from public mourning into private, or silent mourning (Gray and Coulton 2013). Once a public sociological ritual, mourning was now a private affair that needed to fit neatly into a two-week bereavement period. Although mourning had been “silenced” in the physical realm, the introduction of cyberspace in the late 20th century gave griever a new space to mourn “publicly” that was safe from the sequestration of death in modern life. New memorialization rituals occurring in cyberspace are being studied in real time. Gray and Coulton argue that these rituals have fallen out of the dominant filters of mourning studies and are being “used in rich ways to

store, record, retrieve and, importantly, make visible experiences of loss, memories of death and the spectral presence of the dead (2013).”

Currently, scholars, researchers, and clinicians are looking at a combination of new theories to explain the varied and highly individualistic experience of grief. While the concept of “letting go” and “moving on” still permeate popular culture, those familiar with death studies realize the clinical response to the bereaved must be more nuanced to account for this variance (Neimeyer and Thompson 2014). For example, studies have shown that 40–50% of individuals will exhibit low levels of depression, PTSD symptoms, and will face the experience of grief with resilience (Bonanno 2004). In contrast, around 10–15% of people will suffer from PGD evidenced by symptoms such as longing for the deceased, inability to accept the death, and trouble functioning in normal life (Kristensen, Weisæth, and Heir 2012, Prigerson et al. 2009). Between these two types of grievers fall many people who will adaptively come to terms with their loss after a brief period of disruption (Neimeyer and Thompson 2014). Another model of grief frames it as “a process of reaffirming or reconstructing a world of meaning that has been challenged by loss (Neimeyer and Thompson 2014).”

Often, especially in the cases of those experiencing abnormal grief, finding meaning can be a challenging task due to the nature of the loss. Clinicians in

these cases will work to help the griever practice *meaning-making*. Meaning-making is a critical step in the reconstruction of the self following loss, especially in cases of sudden or violent loss. Still, it can be a crucial step for anyone grieving. To understand the fissure of identity that the bereaved can experience post-loss, it is helpful to examine Dialogue of Self Theory (DST). DST, developed by Dutch psychologist Hubert Hermans, combines the concept of the self, which is traditionally internal, with the concept of traditionally external dialogue to form a more dynamic understanding of ourselves (“Dialogical self” n.d.). DST uses concepts of spatiality and positionality to describe the many “I’s” that live within us. This is referred to as a “society of mind” where these many versions of the self can occupy various positions and dialogue with each other. During meaning-making, the bereaved individual comes to terms with the shift in these “I’s” that have been shaken by loss (Elzen 2021). Expressive Writing is a form of emotional and personal writing that psychologists use as a tool for those who have dealt with trauma. This type of therapy is useful because it helps the bereaved reconstruct their narrative and re-establish their mind society (Elzen 2021). David Kessler, described as “one of the world’s most foremost experts on healing and loss” is an author, public speaker, thanatologist, and healer (“David Kessler” n.d.). He is most well-known for coauthoring *On Grief and Giving* with Elizabeth Kübler-Ross (2004). Kessler writes about the importance of meaning-

making in his book, *Finding Meaning: The Sixth Stage of Loss* (2019). Kessler discusses the intervention of reframing to help the person transform the story that they are telling themselves about their loss. This can include changing the language we use in our own heads to tell our story, i.e., “*this death happened to me* becomes *death happens*. *I’m a victim* becomes *I am a victor because I have survived this loss* (Kessler 2019, 71).”

Death in the Age of the Internet

The recent freedom of mourning from the confines of modernity into 21st-century cyberspaces presents a direct challenge to what was previously termed the “sequestration of death from everyday life (Clark 1993; Giddens 1999; Rees 2001; Willmott 2000).” Sociologist Jessica Mitford wrote about the sequestration of death or death denial that was prevalent in the 20th century in her book *American Way of Death* (1969). In it, she points to America’s consumerism and growing secularization as the main causes. Mitford argued that death was being hidden away and discreetly taken care of by death professionals like funeral directors, nurses, doctors, and hospice care workers—the result being that the average person could be ignorant of the realities of death and grief when it came their time. This commodification of death by the funeral and medical industry also meant that people were spending substantial amounts of money on caskets,

gravestones, embalming, and funerals, to truly “honor” their loved ones (Mitford 1969). Fast-forward to today and the effects of a digitally mediated culture are seen in drive-thru and virtual funerals, curbside services, cyber-cemeteries, and online obituaries (Walter et al. 2012).

The internet has changed how we die and how we mourn. Before the World Wide Web, a person’s social sphere was limited to people who knew them directly in the physical realm. Now, through the prevalence of SNSs like Facebook, Twitter, Instagram, this social sphere has grown to include a vast network of digitally mediated relationships. When a person dies, their digital self can remain in cyberspace forever, or at least as long as the network and servers are still functioning. This digital self can remain as a buoy of comfort or a reminder of pain for the bereaved, depending on circumstances of the loss and relationship to the deceased. The internet also provides a “safe space” for grievors who do not feel heard in their “real” lives. Many studies have documented the internet as a contemporary space for mourning (Roberts and Vidal 1999–2000; Brubaker and Hayes 2011; Walter et al. 2012; Cumiskey and Hjorth 2018; Gibson 2018). The transition of the World Wide Web 1.0 to 2.0 marked another important shift of the internet as a contemporary space for mourning. Web 2.0 refers to the evolution of the role of users from passive consumers of content to active participants who generate their own content and

interact with others through social media dialogue (“Web 2.0” 2005). This general shift is thought to have occurred in the early 2000s and marked a fundamental change in how the internet impacted everyday life. The result of this evolution means that throughout our lifetimes we will produce, store, and share massive amounts of data that remain distributed across feeds, profiles, hard drives, and smartphones. In addition to conventional items like digital photos and videos exists a rich variety of other data including interactions, chats, texts, and voicemails. This highly varied data will eventually become the digital assets or *digital legacy* that we leave behind (Carroll and Romano 2010). A new problem has thus emerged: what becomes of all the data left behind after we die?

Research shows that collecting, curating, disseminating, and editing this data is burdensome on the bereaved and leaves open ethical questions on how and by whom this content shall be managed (Massimi and Charise 2009; Odom et al. 2010). Additionally, physical objects containing digital data become sacred postmortem like the smartphone containing a final voicemail or the laptop loaded with personal documents. Researcher and Professor of Philosophy Debra Bassett has documented a new type of anxiety that the bereaved are experiencing due to the fear that objects containing digital legacies will become obsolete, or that the data will become lost or damaged (2018). Bassett identifies this new internet-age experience as ‘second loss’ and shares an example of a friend who

has avoided upgrading her mobile phone in over 5 years because it contains a voicemail of her daughter who died suddenly (Bassett 2018). Even though there are methods of extracting the voicemail, “she is too frightened to try them and fears that somehow she will lose some of the ‘essence’ of her daughter (Bassett 2018).”

SNSs like Facebook, Instagram, and Twitter are now intimately tied to a person’s social ecosystem. SNSs are distinctly different from grief-specific sites as they already contain an active community and are used in similar ways pre- and post-mortem (Pitsillides 2019). Using Heidegger’s thing theory where SNSs can fluidly change from communicating with the living to communicating with the dead we can see how important these spaces are for the bereaved (Pitsillides 2019). Kasket (2012) interviewed several administrators of Facebook legacy pages and found that the prevalent use of ‘you’ when addressing the deceased in their communication shows the platform’s power in standing in as a proxy for the relationship.

Design Things and the Importance of Crafting for the Bereaved

An important item to consider is the role that users, designers, developers, and other technologists play in how a design *thing* is used in practice. A helpful framework for understanding this topic was proposed by Social Design Professor

and Director Lucy Kimbell (2009) as an alternative to the ubiquitous and polysemous phrase, 'design thinking.' Coined by Kimbell as design-as-practice, this framework proposes that the structure of a design 'thing' is not in the way a designer designs it, or how the technology functions, but in how end-users use it in practice (Kimbell 2009). How is this useful for designers? Kimbell explains, "...the implication for understanding design is that it transcends the boundaries of the individual and his or her cognitive style and offers a way to see design activity as distributed across a number of different people and the artifacts they interact with (Kimbell 2009, 8)." SNSs can be described as a design artifact, but as previously shown through their diverse use in practice, they have become something more. If one views SNSs through a sociomaterial lens as not merely a digital artifact but also as a gathering of people, then designers are uniquely positioned to craft new environments that facilitate continuing bonds with the deceased (Telier et al. 2011).

When we lose someone, what remains are their digital and physical legacy and our memories of that person. These digital and physical items take on new meaning and importance postmortem for the bereaved. *Crafting*, in the context of grief, is the act of assembling or creating a personalized artifact containing belongings or mementos of the deceased which is meant to symbolize an important event or stand in place of the relationship (Massimi and Rosner 2013).

Crafting can be an important practice for the bereaved as part of their grief work and can be a way to create a proxy of the physical relationship that was lost. Psychologist William Worden in the seminal book, *Grief Counseling and Grief Therapy* identifies Four Tasks of Mourning that must be completed before the bereaved can return to equilibrium. Task Four is to “find an enduring connection with the deceased while embarking on a new life (Worden 2009, 50). Crafting new objects to symbolize an enduring connection to the deceased falls under this task. Michael Massimi and Professor Daniela Karin Rosner interviewed nine self-identified “crafters” in a 2013 study to learn about how these artifacts are used, created, and imbued with meaning. They found that important life events marked by ritual—like birth, weddings, and death—were commonly associated with crafting and end up representing the event itself. They also found that craft artifacts symbolize relationships and that the timing of crafting is especially important. There is a window during a major life event where “this excess of affection, time, and effort are permitted, but this expectation is a double-edged sword: it is an opportunity for grand acts of craftwork and expression, but it is also an opportunity to fall short of expectations (Massimi and Rosner 2013, 5).”

In a world where a person’s digital legacy can match or even outgrow their physical legacy, systems will need to respond to this important need to craft with both digital *and* physical belongings. Massimi and Rosner’s findings offer

several implications for designers when creating modern technology to support crafting for bereavement. The first is to imbue technology with symbolic value (Massimi and Rosner 2013). There is an inherent paradox in using technology for crafting in that technology in its core function is about making identical copies and the act of crafting is about making a one-of-a-kind (Massimi and Rosner 2013). Tools for digital crafting then need to offer open-ended ways for users to author highly personalized artifacts of remembrance (Massimi and Rosner 2013). They can also be opportunities for the user to learn something new, and the tools can support that by pushing the user to step outside of their comfort zone. The second uncovered theme surrounded “revealing and object’s provenance (Massimi and Rosner 2013).” The crafters often authored a new object that held a shared history between the crafter and recipient and designed the object with the intent of keeping it “for the scrapbook (Massimi and Rosner 2013).” The last theme of their findings concerned designing for repurposing and maintenance of objects. The researchers found that crafters liked to repurpose and repair old objects of significant value into new objects with new symbolic meaning. The practice of repurposing objects in new ways is already often done in the grief support community. One common example is the creation of a quilt out of the clothes of the deceased. How might this concept of repurposing objects be used in digital crafting? Massimi and Rosner add, “layering interactive experiences on

top of the sensual experience of the craft object can be a productive and powerful way to restore, reinterpret, or augment an object's material value (Massimi and Rosner 2013, 6)."

To understand the role that material items play in providing meaning for the bereaved, it is helpful to examine Symbolic Interaction Theory (fig. 1). Coined by Herbert Blumer (1900–86), this sociological theory is built on three key premises. The first is that human beings relate and act towards objects based on the meanings that these objects have for them. The second is that these meanings arise from interactions with other humans. The third is that the meanings are carried and modified through an interpretative process between a human, the object, and society. The things left behind after loss seldomly hold their value in their material qualities. For the bereaved, their value lies in their ability to act as a vehicle transporting them back to memories shared with the deceased. For designers, Symbolic Interaction Theory can be used as a paradigm to understand the complex and dynamic relationships between the bereaved, the deceased, and material things.

Symbolic Interaction Theory

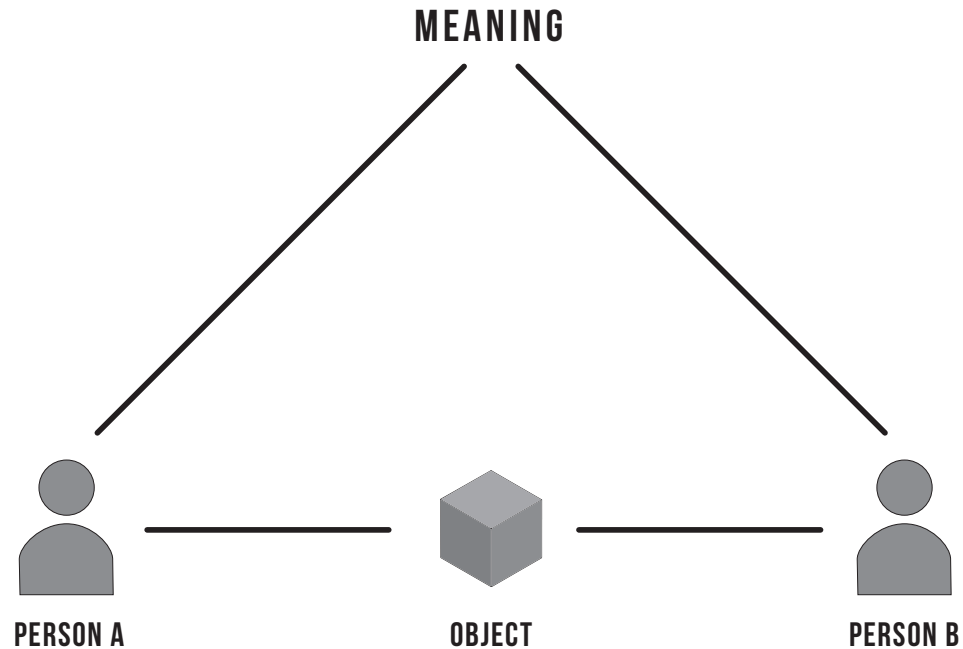


Figure 1. *Di Sarli, Gabriela, Symbolic Interaction Theory Diagram (2021). This theory can be used as a paradigm to understand the complex and dynamic relationships between the bereaved, the deceased, and material things.*

Harmful User Experience Observations

In this section, three collected observations of harmful user experience design are presented that demonstrate the ongoing need for TSD. The objective is to offer a practical example of how the spaces and artifacts that designers create, from SNSs features to productivity tools, can affect a user who is experiencing grief or is in a state of crisis. As a pairing to the theory presented above, this is

helpful to the everyday designer to see how their practice is deeply embedded in complex sociological processes.

Observation 1: Facebook's Year in Review Feature

There are many examples of poorly thought-out social media feature rollouts that are harmful to the bereaved. Facebook, being the largest and the most far-reaching of the SNSs, takes a fair share of these egregious mistakes. For example, Facebook's *Year in Review* feature, meant to celebrate the previous year, garnered a wave of backlash in 2015 after controversially featuring illustrated figures dancing around photos of user's deceased loved ones. One user, Eric Meyer, described how he felt in a blog after Facebook's algorithm served him his *Year in Review* featuring photos of his deceased six-year-old daughter's battle and eventual loss due to brain cancer (see fig. 2). Meyer writes, "...for those of us who lived through the death of loved ones...we might not want another look at this past year" (Meyer 2015). Shortly after writing it, Meyer's blog went viral, and many other users shared their own traumatizing *Year in Review* stories. In the book *Design for Real Life* (2016), Meyer and co-author Wachter-Boettcher point out how the narrowness in the design team's vision behind the *Year in Review* feature led to this harmful outcome. They write, "they didn't look beyond that ideal persona, in that ideal circumstance, and ask, 'How will someone in another

context perceive this (Meyer and Wachter-Boechtter 2016, 9)?” To repair the public relations nightmare, Facebook invited Meyer in to consult with their design team on how to be more thanatosensitive. The new *Year in Review* now includes neutral copy and does not mix a user’s images with illustrations (Meyer and Wachter-Boettcher 2016). The language in the pop-up now says, “We thought you might like looking back,” which removes assumptions about the user’s year being positive (see fig. 3).



Figure 2. Meyer, Eric, Module Promoting Facebook's Year in Review Feature That Uses a Photo of Eric Meyer's Deceased Daughter Surrounded by Dancing Figures. (New York: Jeffrey Zeldman, 2016) 8, fig. 1.1.



Figure 3. Meyer, Eric, Facebook's 2015 Year in Review After the Redesign (New York: Jeffrey Zeldman, 2016) 14, fig. 1.2. The new design features neutral copy that does not make assumptions about the user's year. Illustrations no longer mix with the user's images.

Observation 2: Design for Stress Cases

While Eric Meyer was not a bereaved user yet, his story of trying to find vital information on a hospital website while rushing to meet his daughter at the hospital is relevant because it shows the cognitive overload that a bereaved user might be experiencing while in a crisis. On that fateful night, while a stranger

was driving him and his wife to Children’s Hospital of Philadelphia as his daughter was being life-flighted by helicopter, he visited the hospital website on his iPhone. As he frantically searched, he could not find a phone number or any information on where to go in the case of emergencies. Meyer describes the website design:

“Not only was the site not mobile-friendly, I couldn’t find anything explaining what to do in an emergency. I kept looking for a box or banner or something that would tell me what to do, where to go, who to ask once we got there. I never found it because, as I discovered later, there was no such resource. There was no page to help. Our literal life-or-death situation was completely ignored (Meyer and Wachter-Boechtter 2016, 41).”

While there was a phone number on the website, it was in a low-visibility sidebar and so was completely missed by Meyer. In a 2016 presentation, Meyer showed a screen capture from the hospital’s website with content blurred to simulate what he saw when looking for information during his crisis (see fig. 4). In *Design for Real Life*, Meyer and Wachter-Boechtter offer a different terminology for what is typically considered an edge case—they advocate for the term *stress case* (2016). An edge case is a programming industry term to refer to scenarios that affect an inconsequential number of users (Meyer and Wachter-Boechtter 2016). To move these cases from the fringes to the center of the designer’s purview, Meyer and Wachter-Boechtter change the language from a word of insignificance to one that more accurately describes what the user might be feeling. In the book, *Badass: Making Users Awesome*, Programming Instructor Kathy Sierra demonstrates the

phenomenon of cognitive overload in an experiment (2015). In this experiment, participants were put in two groups and presented with memorizing a sequence of either two or seven numbers. They were then offered a snack, either cake or fruit. Those that had the harder task were more likely to pick the less healthy treat because they had exhausted their cognitive resources (Sierra 2015). When users are experiencing a crisis, they are cognitively overloaded resulting in a mental fog that impedes their ability to think straight. Designers must diversify their user personas to account for someone who may be using a product while in this fog.

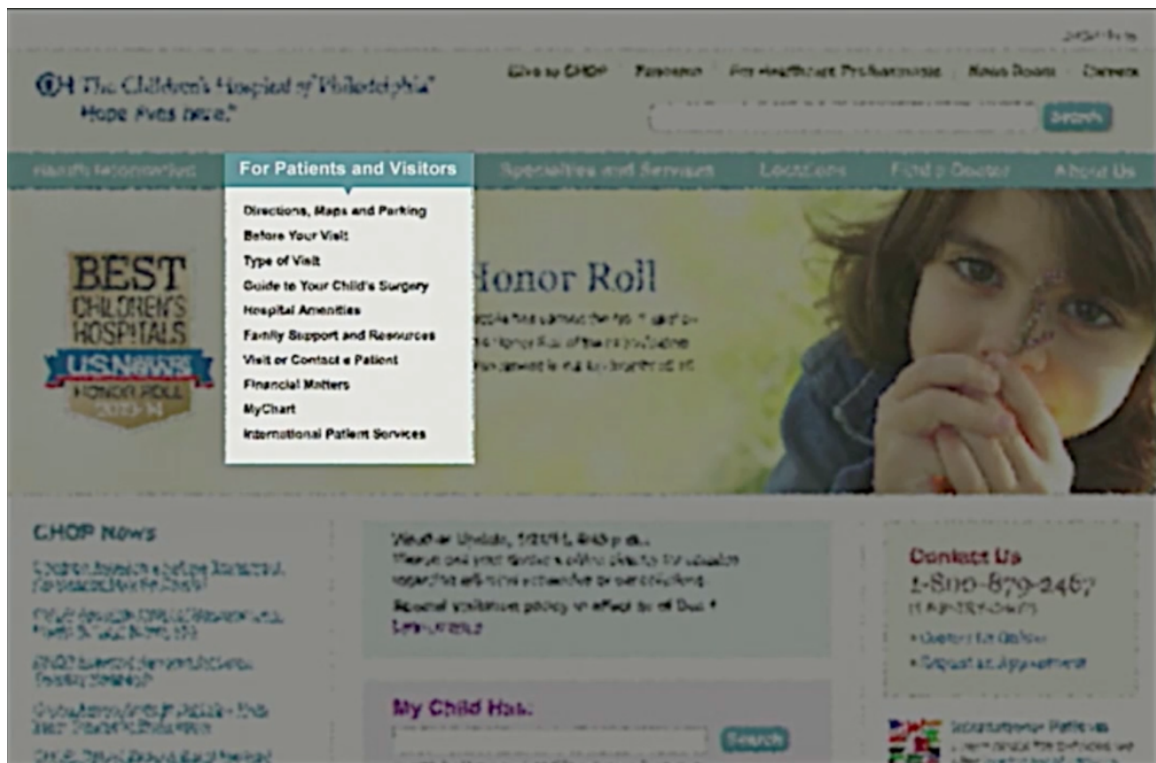


Figure 4. Meyer, Eric, Children's Hospital of Philadelphia Website with Blurred Type to Simulate What Eric Meyer Saw During His Crisis (Washington, DC: Apart, an Event, 2015).

Observation 3: Notion's Kanban Board Feature

In the seven years since experiencing my own loss, I have experienced many poor design choices on SNSs and other digital platforms that are insensitive to the bereaved. My journey to this thesis topic started when after suddenly losing my mother in an accident, I saw her profile being re-animated on my Facebook feed. The simple decision of Facebook using user's friends to

advertise pages and products they might like ended up producing a very traumatizing user experience for me in the acute stages of my loss. At the time, the Legacy Profile feature had not been created, and now that they have, there are at least more tools for the bereaved to avoid these kinds of traumas on Facebook. Unfortunately, this kind of insensitive design is still happening, case in point—Notion. Notion is a web-based application that is a kind of one-stop-spot for all things organization, note-taking, personal task management, and data management. Users have many features at their disposal, including Kanban boards. Kanban boards come out of the world of software development and were originally used as tools for project management at Microsoft (see fig. 5). A Kanban board “visually depicts work at various stages of a project using cards to represent work items and columns to represent stages of the process (“Kanban board” 2021).” I adopted Notion as my thesis project management tool and have found it especially useful. However, upon creating a new task list using a Kanban board, I noticed something strange—on my board, Notion had included a pre-populated task with the label “Call Mom” (see fig. 6). While this might seem like a trivial thing to highlight, a simple design decision with this oversight could be deeply traumatizing to a bereaved user and makes a lot of assumptions. Like in the Facebook *Year in Review* observation the design team at Notion behind this decision “did not look beyond that ideal persona, in that ideal

circumstance (Meyer and Wachter-Boechtter 2016, 9).” Instead, they should have asked themselves, “how will someone in another context perceive this (Meyer and Wachter-Boechtter 2016, 9)?

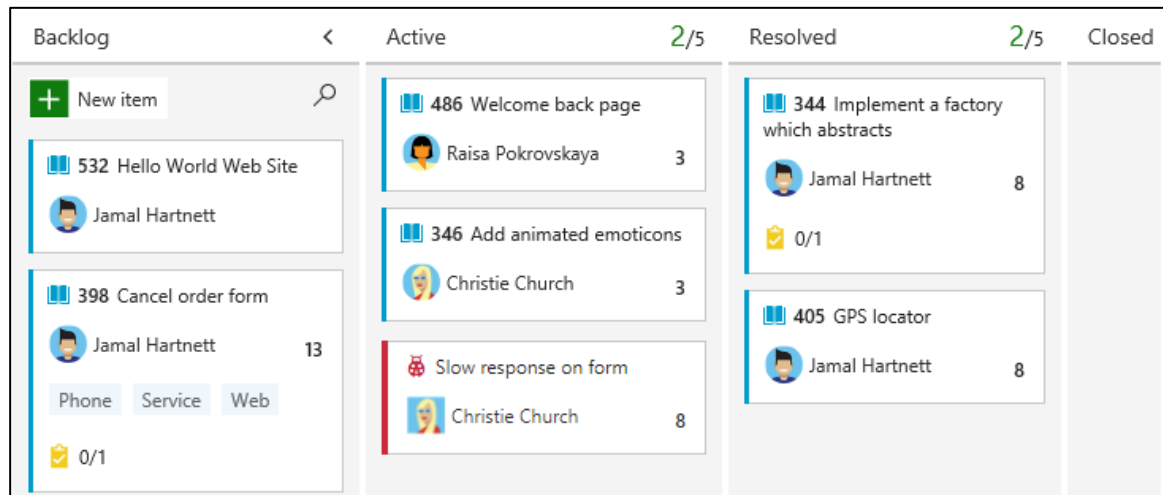


Figure 5. Microsoft, *Example of a Kanban Board* (“Kanban basics,” 2018). Kanban boards, originally developed by Microsoft, are a tool to help visualize and manage workflow.

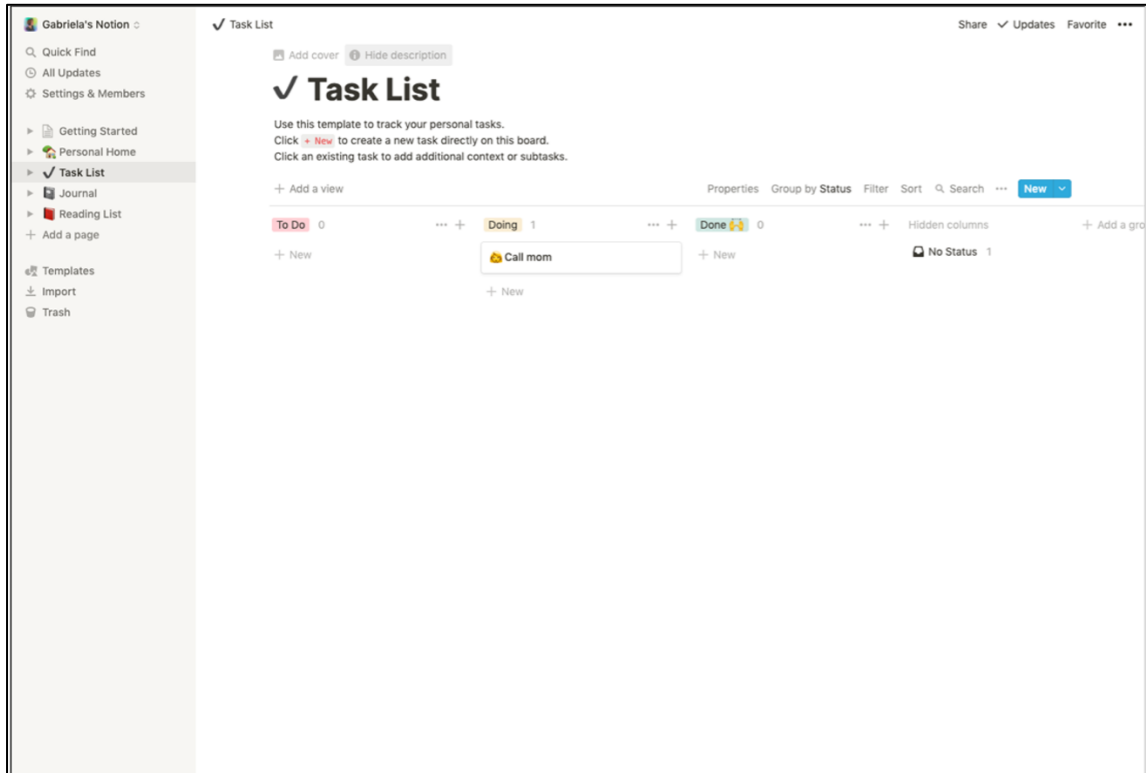


Figure 6. *Di Sarli, Gabriela, Notion Page Showing a Pre-populated Kanban Board With “Call Mom” As One of the Tasks (2020).*

Thanatosensitive Design

In this section, I will delve deeply into the topic of TSD and cover the current rhetoric by designers and researchers at the forefront of this field.

Massimi and Charise use a critical humanist tradition to analyze the relationship between humans and computers after the human has died. They use the philosophical concept of authorship by Michael Foucault (1926–1984) to demonstrate how in the age of the internet and infinite word-processing, we author vast amounts of data that can become of interest to other parties after our death (Massimi and Charise 2009). They pointed out that the cyberspace system

(in 2009) was not yet built to handle the death of the author. They introduced TSD as a critical and humanistically grounded tool to evaluate how current systems operate and issues in their design. They describe the ethical dilemma surrounding families having to decide what to do with the data their loved one leaves behind. In addition to introducing TSD, they make a call to action for designers and researchers to use it as a critical tool in their daily practice. They also uncover several questions for future researchers in subfields of HCI such as:

- *User-centered design*: Is the eventual end of life considered when discussing the needs of the user?
- *User-modeling*: Does the ultimate death of the user factor into the collection and organization of user data in current systems?
- *Intelligent agents*: Can entities like AI, smart assistants, and robots be permitted to operate so that a user can take action after their biological death?
- *Research methodology*: What is the ethical boundary around taking data from a deceased user?
- *Privacy*: Since death changes what is “private” information, what then makes up “inheritable” data? What are the boundaries around what is private and what is not after the death event? Conversely, whom shall the task of maintaining the privacy of that data fall upon? What kinds

of lifelong changes do we need to make to the data-creating process that allows us to maintain privacy posthumously?

In 2010, Simon Fraser University Assistant Professor William Odom and a group of researchers published a study that examined how the bereaved process their grief and manage a new asymmetrical relationship with the deceased. As this new relationship is navigated, the bereaved find new ways to communicate with the deceased and decide which aspects of the relationship persist and which are put to rest. Their findings continue the long-studied trajectory of the significant role of objects in these relationships and expand it to include digital materials (Odom et al. 2010). They document how the act of bequeathing serves as a way the dead communicate with the living and how the bequeathed objects go beyond reflecting the relationship to effectually constituting it (Odom et al. 2010). Their research documents the burden that many of the bereaved experience after receiving bequeathed items that are ambiguous in meaning, and how this effect is continuing in the digital realm. A behavior, they note, is that when the bereaved inherit artifacts, there is great care taken into preserving those artifacts, but also hiding them so that they are not confronted when they are not ready (Odom et al. 2010).

Odom et al. highlight two areas of concern for designers working in this arena. The first is for designers to consider the “moral endurance of an archive”

when designing systems and products (2010, 1838). This means that systems should support “more nuanced practices of owning, storing and managing materials, in ways that enable appropriate relinquishment beyond the life of the owner” (Odom et al. 2010, 1838). They suggest that interactive systems need to evolve to support deeper and more nuanced methods of storage. For users, it is important to be able to differentiate certain content for safe storage in the system while also maintaining control over its visibility. The second suggestion is to design for “richer forms of contextualization,” meaning the capacity for a user to ascribe an explanation to an object so that it may be of more significance to the receiver when it is passed on (Odom et al. 2010, 1839). Because digital archives can store infinite amounts of trivial items alongside significant items, bereaved users, and users at the end of life need designs that allow for the ability to differentiate which items are important and which items can be thrown away.

The book *Digital Legacy and Interaction: Post-mortem Issues* (2012) edited by Maciel and Pereira offers a wealth of current research on the intersection of HCI and death studies. Based off of empirical research, the book sets forth various guidelines and implications for designers hoping to remain sensitive to death in their work. A selection of these guidelines are presented here:

1. Allow users to disconnect and choose isolation and silence if needed

because talking about death is complicated.

2. Support meaningful making. The practice of crafting and making new artifacts out of old supports the bereaved in their grief work.
3. Allow for the control of mourning symbols. Users are not just their grief, so they should not be forced to advertise their grief status.
4. Design for a highly diverse experience. Each person's loss is colored by their own beliefs, culture, psychology, and relationship type. Designs should never impose on the user the right way to grieve.
5. Consider that there is not a solution to bereavement and that this can be considered a "wicked" design problem (Rittel and Weber 1973).

Wicked problems are large, complex, systematic, and unsolvable problems. For the bereaved, the goal is less about avoiding pain, and more about needless pain due to insensitive systems.
6. Design with people in mind. Since this is an ethically sensitive topic, design methods that place people at the center of the design process—such as participatory design and human-centered design—are essential.
7. Acknowledge your own values and assumptions when designing. As Pereira and Maciel (2012) uncovered, our beliefs and taboos about death will color how we design systems that are used by a diverse set

of people with a diverse set of beliefs.

Previously, I have written about Eric Meyer, the software developer who caused real change at Facebook due to the documentation of his poor experiences with their *Year in Review* feature. In *Design for Real Life*, Meyer and Wachter-Boettcher offer some practical guidelines for the everyday designer and developer that are pertinent to list here (2016). Their perspective is unique as they sit outside the academia and research arena as opposed to the other researchers listed. Meyer is a web developer, while Wachter-Boettcher comes from the world of content strategy and UX consulting. They urge designers to consider stress cases—those use cases where the user is in crisis—as key use cases to consider when in the design process. Additionally, user personas should not only show users in an ideal, relaxed mood, but also in other moods and crisis scenarios. In an online article titled “Designing New Products with Empathy: 50 Stress Cases to Consider,” member of the NPR Digital Media Design Team Libby Bawcombe uses Meyer and Wachter-Boettcher’s book to summarize six main guidelines for practitioners (Bawcombe 2016):

1. Consider the context and personal story of the user that might affect their experience when using your design
2. Think of all the ways that the experience could go wrong for the user
3. Never abuse the user’s time. Time is the most valued resource that a

user has, and they will be juggling a dozen tasks while using your product.

4. Do not ask for unnecessary information. Ask yourself when designing forms for obtaining data: why is this information necessary?
5. The intention of the product should always be clear to the user.
6. Copy is important. Consider how the tone of your copy can be perceived by a user in crisis.

Thanatosensitive Design Case Studies

In the following section, several TSD case studies will be presented. These projects represent innovative approaches for products targeted at the unique needs of bereaved users.

Case Study 1: Enabling Ongoingness Project

A group of multi-disciplinary researchers is documenting their project Enabling Ongoingness: Content Creation & Consumption in the New Digital Age in the UK (United Kingdom). Their prototypes are aimed at users who are at

the end of life, living with dementia, or who are bereaved. Three experimental artifacts, *ReFind*, *Ivvor*, and *Trails* (fig. 7) make use of inherited archives by



Figure 7. (left to right) *Enabling Ongoingness*, *ReFind*, *Ivvor*, and *Trails* (Honolulu HI USA: ACM, 2020).

offering ways to contextualize and engage with data that might be ambiguous to the user (Wallace et al. 2020). These projects deal with the issue of inheriting substantial amounts of data that lacks context either due to the owner's cognitive decline (as in the case with people living with dementia) or lack of explanation by the owner before passing

ReFind is a circular media viewer made of brass and corian (acrylic and mineral mixture) that holds only six media items at any time. One item is from the bereaved and five are from the deceased. You can explore the items by rotating the object. *ReFind* uses a system of semantic tags in metadata to find relationships between the bereaved's media items and the deceased. The object

seeks to “offer new perspectives and narratives on the relationship between the bereaved and deceased facilitated by a continued dialogue through media and semantic metadata (Wallace et al. 2020, 37).” *Ivvor* is a smart locket that keeps a small collection of images permanently within it and uses significant times and dates for the wearer to reveal linked content from an inherited archive. *Ivvor* also keeps the media locked and hidden until the wearer raises it towards their face, allowing the moment to remain private between the wearer and the object. (Wallace et al. 2020). *Trails* is a handheld device made of brass and leather with a map textile printed on it. Inside, there is a small Bluetooth speaker that connects to a background service on your smartphone. *Trails* plays audio and soundscapes when you are in a location that is meaningful to the relative. The inherited audio recordings offer a way for the user of *Trails* to feel closer to their lost relative (in this case the relative had dementia) and “the listener is encouraged to stop, experience and reflect on the audio in relation to their current context (Wallace et al. 2020, 38).”

Case Study 2: Haptic Remembrance Book

Winner of the CHI2019 Student Design Competition, the *Haptic Remembrance Book* by Elaine Czech is a technology-integrated book for persons living with dementia (PLWD). The project uses multi-sensory design and art

crafting to create a personalized book for PLWD to engage in remembering and facilitate conversations with loved ones (Czech, Shibasaki, and Tsuchiya 2019) Czech co-designed the book with staff from Mediva, Inc. and long-term care facilities as well as the PLWD themselves (Czech, Shibasaki, and Tsuchiya 2019). Figure 8 shows a page where fake fur in the shape of a dog's face paired with a photo of the PWLD's dog is used to stimulate memory and encourage interaction with the book.



Figure 8. Cech, Elaine, *Haptic Remembrance Book* (elaineczech.com, 2020).

Case Study 3: Storyworth and Zapptales

In recent years, there has been an uptick in products and services that are aimed at users who are looking to document and archive meaningful stories and artifacts. One of these companies is Storyworth, whose service sends weekly

prompts to the user's loved one that are meant to elicit meaningful stories about that person's past. At the end of a year, Storyworth sends the user a hardcover book presenting these collected stories and pictures in a beautiful memento meant to be a physical archival of that person's life story. Another similar, yet unique service is Zapptales. Zapptales is a web and mobile app service that offers users a way to document that intangible, yet hugely important artifact after the loss of a loved one—chat histories. After walking the user through the process of downloading the data of their choice from a select variety of platforms including Facebook, Instagram, and WhatsApp, the user is then prompted to upload that data to the Zapptales service. After some controlled editing and payment, Zapptales sends a hardcover book containing chat histories beautifully archived in a tangible form. The book provides the user a way to archive and remember these conversations long after chat logs are swiped, and profiles shut down (Fig 9). QR codes are printed on the pages so the user can also watch chat video content.



Figure 9. *Zapptales, Example Book* (zapptales.com 2021).

IV. METHODOLOGY

Thanatosensitive Design and Slow Technology

Influential to the research and design process of this thesis were two findings from Odom et al.'s 2010 study. The first is concerning the “moral endurance of an archive (Odom et al. 2010, 1839).” This refers to the process of owning, storing, and managing materials postmortem and the need for technologies that support these practices. Archiving refers to the process by which materials are preserved somewhere for historical record. Archiving is integral to the museum industry, which works to collect histories, narratives, and artworks for present and future interaction. While the internet is often hailed as an endless archive, its contents are often contained within the servers of social media platforms or other entities where its access and endurance remain questionable (Grau, Hoth, Wandl-Vogt, 2019). This means archiving digital data is more complicated because of its intangible and mediated qualities. The second is “designing for deep storage, sedimentation & graceful decay (Odom et al. 2010, 1839).” Odom et al. suggest that interactive systems should contain deeper and more nuanced levels of storage (Odom et al. 2010). Systems should allow users to “demarcate particular content for deep storage and explicitly treat it differently from other data stored within the system (Odom et al. 2010, 1839).” This is where I believe slow technology can be used innovatively. Coined by

Swiss Interaction Design Critics Lars Hallnäs and Johan Redström in 2001, slow technology posits that interaction design must expand its purpose beyond solely making people's lives more efficient to creating technologies that are integrated environmentally and experientially into the lives of people. Odom et al. in 2012 expanded the agenda of slow technology to include bereaved users needs such as "supporting experiences of pause, contemplation, and reflection (Odom et al. 2012, 817)." How can new slow technologies be designed that support this need to demarcate and safely store precious data for future remembrance?

Exploratory Research

Throughout the exploratory design research phase on this topic, central to my methodology were two principles: the first was working as closely as I could to the bereaved in the research and design of projects and the second was considering design outcomes that supported the bereaved in reflection and remembrance.

Verstehen, or interpretive understanding, is a sociological concept introduced by Max Weber in the early 20th century the describes the process by which we empathize with another group outside of our own in order to understand it (Guy Oakes 1977). As designers, we are trained to practice this interpretive understanding by learning ways to empathize with our users or

audience. Designers will use design thinking frameworks to try to understand what it is like in the shoes of their users or audience. Part of my journey into this thesis topic started in 2014 when I felt the sting of poor user experience in the acute stages of my grief. I only knew then that what I was experiencing was hurtful, and something I wanted to avoid going through again. It was only until the beginning of my graduate college studies that I started to realize that I did not have to accept poor user experience as an outsider. I could be part of the infrastructure that changes it for the better. While no two grief experiences are alike, I knew from day one of my graduate studies that my thesis would be about grief and user experience, and I felt that my personal story of loss would be integral to working with other bereaved users. My lived experience and passion for this topic led me to explore the experiences and pain points of the bereaved through a body of work in the intersection of grief and design.

The Grief Connections Project

In my first graduate year, as part of a course titled Design for Social Impact, I began a collaborative project with a local grief support nonprofit called The Christi Center. The house-turned-community center is a safe space for the bereaved to receive free, ongoing, peer-based grief support and was founded after the tragic loss of the founders' daughter Christi in 1985. I came to the Christi

Center in 2018 to learn from the staff and their members about their processes and pain points. I started with an audit of the services that the Christi Center offers. I made observations by attending grief support groups myself and talking with the staff and volunteers of the Christi Center. I completed photo ethnography and structured interviews with key stakeholders to discover key problem areas. Addressing access to support and representation for marginalized groups became a key area of focus.

Through my research, I discovered that the language surrounding grief support was important. I learned that even though the services offered by the Christi Center were free, they were not accessible to everyone who needed them. Through their thirty-plus years serving the area, they learned that although they offered free and ongoing grief support to the community, often, people of color were still unable to access their services due to several reasons. Transportation, time off, and childcare were barriers to access, as well as these communities inherent trust in organizations outside of their own cultural group. One particularly poignant moment came during an interview with Program Director Erin where she recalled a community member telling her, “your gift to us is not coming into our communities and facilitating groups, it’s training people who are already part of our communities to facilitate our groups.” This is where the idea for a new program named Grief Connections was born. The program’s

purpose was to train members of the community in peer-based grief support facilitation so that they could hold their own groups in their own community. This was an important initiative for the Christi Center in offering more accessibility to grief support for underserved communities in the central Texas area.

I learned that the Grief Connections program was currently only managed by one person and consisted of a 12-hour program where trainees came to the center to receive their training on-site. At the end of the training, the trainee receives a 3-ring binder filled with a training handbook that they could review and reference in the future if they had any questions arise in their groups. During my interviews with the program director Erin, she expressed that the program needed a new professional face to attract new trainees. The 3-ring binder for trainees was also an outdated tool that was impossible to update once the handoff happened at the end of the training. If trainees had more specific questions, they would have to call the Christi Center, taking away precious mental resources that the Christi Center staff needed to save for the bereaved. I proposed designing a website that would be a marketing tool for the program and house the training manual to be accessible by facilitators of the Grief Connections program. I held a UX workshop with the stakeholders of the Christi

Center to determine the value proposition, brand voice, and build user personas trainees of the program (see fig. 10 and 11).

I then designed a logo for the program that followed the same visual design system as the Christi Center logo. I designed wireframes and after some initial user testing, created a hi-fidelity website that was user tested with three past trainees of the program. The landing page features diverse illustrations of people in grief support groups and explains what the Grief Connections program is and how visitors can learn more (see fig. 12). The brand voice is of the program is warm, personal, secular, and expert driven. Due to the short timeline of this project, the website was split into two phases, the first phase being the landing and contact page and the second phase being the training manual. Phase II will resume in 2022 when in-person support groups can take place again.

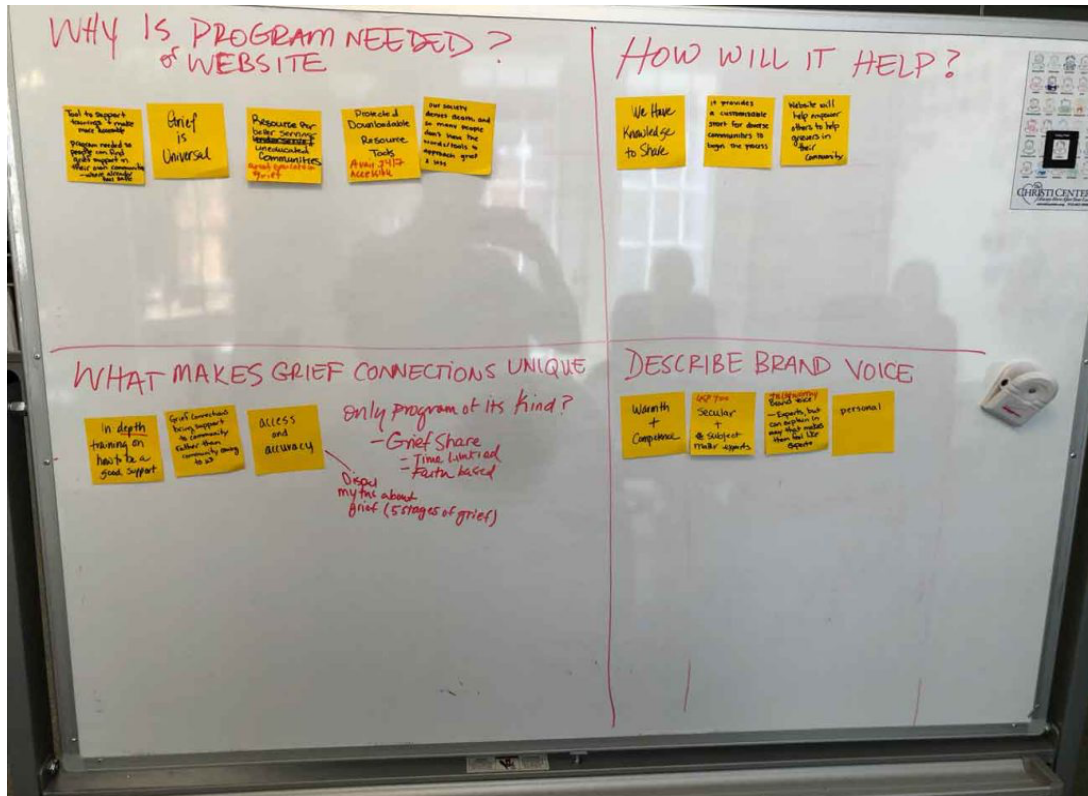


Figure 10. Di Sarli, Gabriela, UX Workshop with the Christi Center (Austin, TX, 2019).




 <p>Abbi <i>Engaged, Griever</i></p> <p>NEEDS</p> <ul style="list-style-type: none"> * Info about grieving process * Facilitation skills * Tools to talk about grief <p>FEATURES/BENEFITS</p> <ul style="list-style-type: none"> * Searchability * Online training manual * Crisis intervention resources <p>OBJECTIONS</p> <ul style="list-style-type: none"> * Tech illiterate * Where do I go for help? * Too much jargon <p>KEY MESSAGE</p> <ul style="list-style-type: none"> * <i>You are empowered to use this tool to help others</i> * <i>It's okay to not know all the answers</i> * <i>We've got your back</i> 	 <p>Father Will <i>Skeptical, Churchleader</i></p> <p>NEEDS</p> <ul style="list-style-type: none"> * To see the value for his congregation * How to find and vet trainees * Need to know about liability <p>FEATURES/BENEFITS</p> <ul style="list-style-type: none"> * Guide for locating trainees * Data to educate him + cong. about grief * Data about effectiveness of Grief Connections * Reviews of those that have gone through the programming of CC. <p>OBJECTIONS</p> <ul style="list-style-type: none"> * Liability fear * Does language reflect my religious beliefs? <p>KEY MESSAGE</p> <ul style="list-style-type: none"> * <i>This will help your ministry and your congregation</i> 	 <p>Leslie <i>Curious, Leader of Collaborative</i></p> <p>NEEDS</p> <ul style="list-style-type: none"> * Info on who it's appropriate for * Quick, easy info * How is it useful in variety of different agencies? <p>FEATURES/BENEFITS</p> <ul style="list-style-type: none"> * Time estimates on readings * General topics covered <p>OBJECTIONS</p> <ul style="list-style-type: none"> * Lack of time + resources * Can it be combined and used across multiple agencies? <p>KEY MESSAGE</p> <ul style="list-style-type: none"> * <i>You don't have to be a professional to help</i> * <i>You can learn to do this</i>
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Figure 11. Di Sarli, Gabriela, User Personas of Trainees of the Grief Connections Program (Austin, TX, 2019).

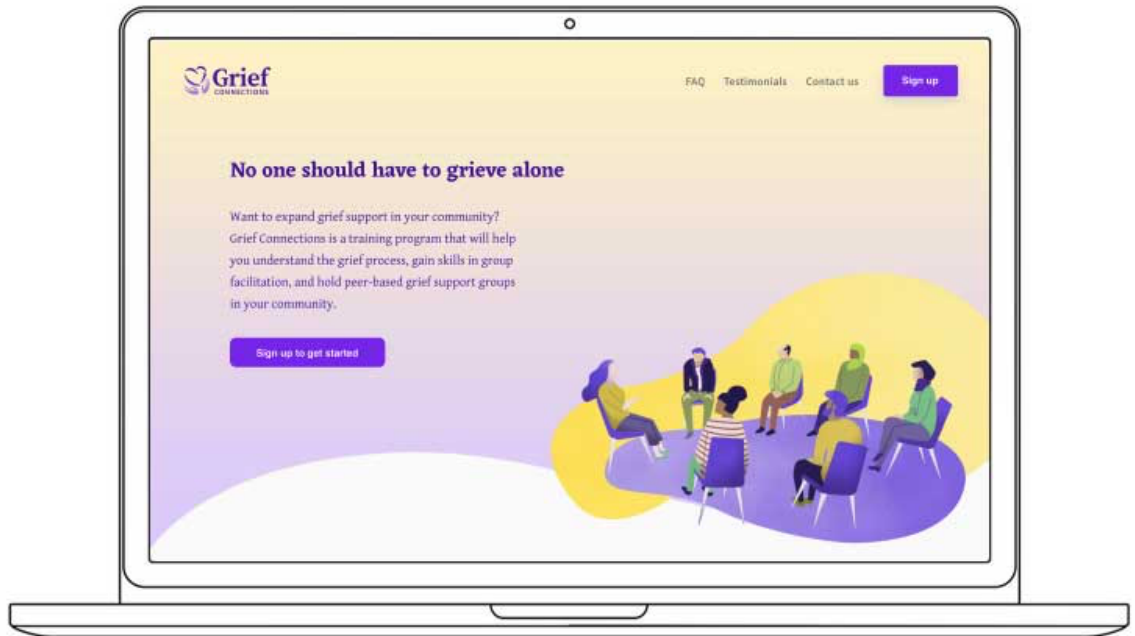


Figure 12. *Di Sarli, Gabriela, Grief Connections Landing Page Design (Austin, TX, 2019).*

This project was an important immersion into the human-centered process where I learned how to listen and empathize with people to address the need I felt was greatest from my user research. I also learned about designing and copywriting around sensitive topics such as death and loss. Although I have lived experience with grief, everyone's experience is different and needs to be considered. My solution revolved around giving the Christi Center the tools they needed to support this important program. Because cultural, racial, and economic differences affect how we experience death and process loss, designers

need to practice cultural competency to learn how to design with empathy for groups other than their own. These differences also affect how diverse groups view grief support services and can lead to barriers to access for these important resources.

The Shipwreck Project

Another project created as part of my exploratory research into this topic was an experimental book titled *Shipwreck*. I began wanting to explore the effects that memory has on grief and how the distance in time from trauma can shape one's recollection of that event. As a vehicle for this exploration, I was brought back to a post that I had seen on Reddit by an anonymous user that simply said, "*My friend just died. I don't know what to do* (Reddit 2011)." Reddit, aptly self-described as "the front page of the internet," is a website where online communities can discuss and share posts from relationship advice to cat photos ("Reddit" n.d.). This post took place on r/Assistance, a subreddit where people ask for help with various needs. In response to the user's request for advice, another user by the name of GSnow typed a powerful anecdote about loss, life, and shipwrecks. The comment garnered many upvotes, Reddit gold, and responses from other users remarking how helpful his words were. GSnow's comment has since been shared across the internet and quoted in many blogs,

articles, and podcasts. The post had such an impact on me, that several years later, I thought it the perfect textual material to use as a metaphor for the effects that memory has on grief.

According to a 2012 study by Donna J. Bridge and Ken A. Paller, two professors in the Interdepartmental Neuroscience Program and Department of Psychology at Northwestern University, each time you recall an event, your brain distorts it. Bridge and Paller write, “a memory is not simply an image produced by time traveling back to the original event—it can be an image that is somewhat distorted because of the prior times you remembered it (Northwestern University).” If every time we retrieve a memory, we alter it slightly with an updated version is this an essential part of grief work? In the case of those experiencing PGD clinical depression and cognitive impairments are more likely to develop (Hashim et al. 2013). Memory loss is also considered one of the mental symptoms experienced by those in the acute stage of grief. To represent the distortion and ultimate transformation of memory after loss, over the course of a few weeks I recalled GSnow’s comment and transcribed it from memory. I went through this process five times to symbolize the years it had been since my own loss. To represent the transformation from the original text to my replaced memory of it I printed the words out on paper and then use various tools to erode the words of the original text that I had either forgotten or replaced with

new words (fig. 13). In later cycles, the text became less and less distorted and assumes its new but altered state. The book was designed and bound in an accordion-style fold along with a stiff board so that it could stand up and be set as a continuous circle, a symbolic shape representing the cyclical nature of life and death (fig. 14).

This project further reiterated the importance of crafting in relation to meaning-making after loss. The act of recalling and forgetting the text was a topical exercise in learning how certain acts can be therapeutic for the bereaved. Another area of importance was studying the effect that digital media has on the bereaved. I have covered in depth how internet culture has transformed the way we live, die, and mourn. The fact that a simple post on an obscure internet forum from a stranger could help thousands of people demonstrates the internet's impact on the bereaved. The book was also a way for me to explore the act of

using digital media (the Reddit post) and physical media (the book) the create a new layered artifact of remembrance.

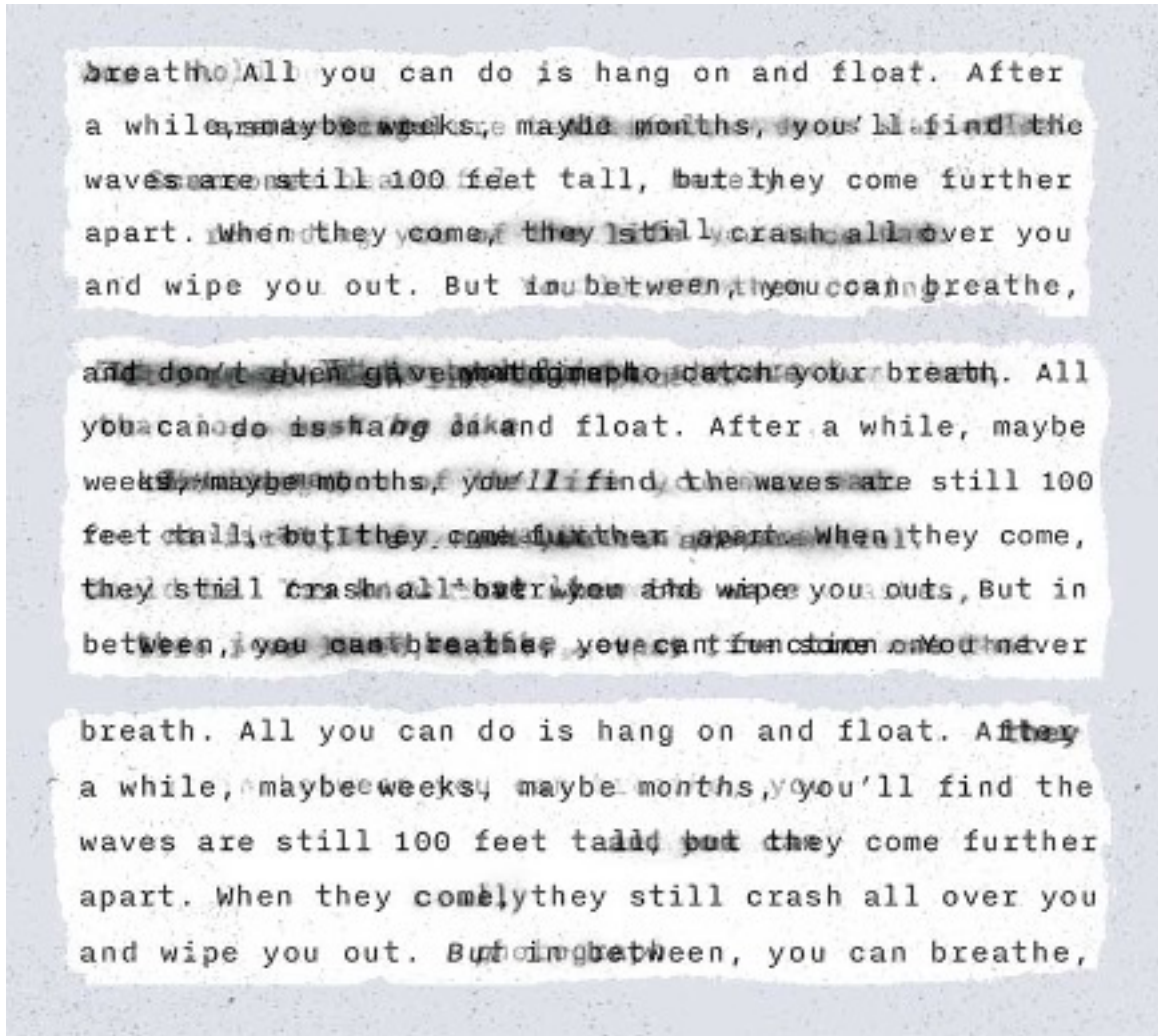


Figure 13. Di Sarli, Gabriela, *Example of Eroded Text from the Shipwreck Project* (Austin, TX, 2019). This experimental book project examines the effects that memory has on grief.

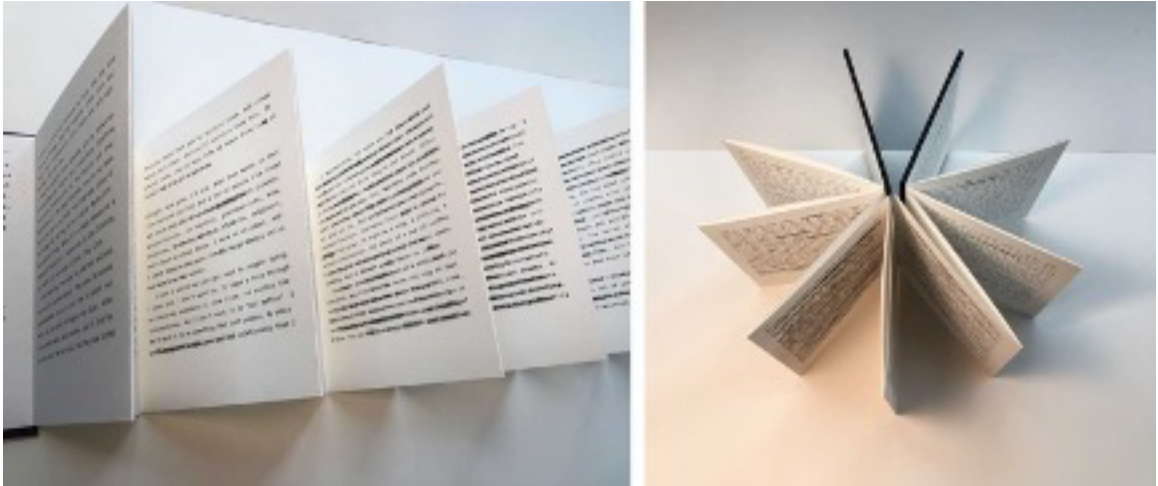


Figure 14. Di Sarli, Gabriela, *Shipwreck*, (Austin, TX, 2019). The book is designed in an accordion style binding to represent the cyclical nature of life and death.

Discovery: Fieldwork

The Effects of Online Experiences on Grief Survey

At the start of my fieldwork, I centered my research plan around my thesis statement. At that time, my initial draw to this area of study was due to my own poor experiences online as a bereaved user. The thesis statement then, understandably, revolved around the investigation of online environments for the bereaved. It read: *digital design shapes the grief experience online; therefore, there is a need to investigate and envision more compassionate ways for designers to make space for grief in digital environments.* I chose a survey because it was an effective way to quantify how many of the bereaved were affected by poor online experiences. I also wanted to know where these interactions were likely to take place. In addition to my initial interest in how the design of SNSs was affecting

the bereaved, my theoretical research on TSD pushed me to investigate how people were continuing their relationships with the deceased through digital media. The survey was also a tool to recruit participants for future interviews. Because of the sensitive nature of the research, I wanted to allow participants to understand the nature of my research through the survey before they reached out and expressed interest in an interview. In my experience, you never know truly what might be triggering until it happens, and I wanted to leave the decision of being vulnerable up to each participant.

The survey contained 13 questions centered on the following two topics: Loss and Mental Health, and Loss, Social Media, and Remembrance. In the Loss and Mental Health section, questions asked participants the type of death loss they experienced, what, if any mental health disorders they suffered from, and how recent their loss was. In the final question of the survey, participants were asked to leave their emails if they were interested in participating in future studies for this project. Following previous study design in this field, I chose to ask how recent their loss was so that I could filter out those participants from further study. This is because when a person is in the acute stages of grief (between 0–3 months post-loss) they can be more susceptible to unnecessary

harm as a research subject (Labott et al. 2013). A list of the survey questions can be seen in the Appendix of this thesis.

Twenty-nine participants took the survey. Of the participants, six self-identified as suffering from anxiety disorders, one self-identified as suffering from Post-Traumatic Stress Disorder (PTSD), and one from Major Depressive Disorder (MDD). Five of the participants self-identified as suffering from a combination of MDD, PTSD, Anxiety Disorder, and PGD. On how recent their loss was, a majority (18) had their loss occur more than one year ago while three respondents had their loss occur between zero and six months. Of the respondents that had used social media in the past, most of them used Facebook and Instagram. On whether they had experienced something on social media or another app that triggered or worsened their grief symptoms 74% responded yes or maybe. Interestingly, many of these poor experiences occurred on Instagram, with Facebook and Twitter tying for second place. Respondents were then asked to provide context to the poor user experience. The responses ranged from being angered when other users spoke lightly about a topic related to the death of their loved one, to being reminded of their loss after seeing others interacting with someone who shared the same role as the deceased. One participant expressed frustration about receiving notifications from their lost loved one's account from games or apps tied to the account. Another was angered after being notified by

Facebook to look back on a memory with that loved one. When asked whether they continued to visit their loved one's profile after the loss, 45.45% responded Yes or Maybe, while 54.55% responded No. In response to the question: *In what ways do you remember your loved one?* Most respondents (18.99%) said they looked at photos, 15.19% said they told stories about them, and 12.66% said they held an object that was important to them.

The Effects of Online Experiences on Grief Interviews

On the final question of the survey, 10 respondents chose to leave their emails to be contacted again for future research. Of those 10, one was disqualified from the study for not meeting the selection criteria (loss occurring at three months or less). Of those contacted to set up an interview, seven participants completed the interview in the form of asynchronously written responses (Participant (P) 1, P2, P3, P4, P5, P6, P7). The interview design was semi-structured to propose questions that prompted discussion about remembrance practices instead of obtaining specific answers. Because of the sensitive nature of this topic, and the hesitancy to talk to a stranger about something as intimate as grief, I designed a digital interview questionnaire as an alternative to a video interview. The questionnaire contained questions I would have asked synchronously, with text field answer boxes for respondents to

express themselves through writing. The questions were grouped into four themes: Retrospection; Personal Reflection After Loss; Grief and User Experience; and Using Digital Media to Connect with Lost Loved Ones.

The first group of questions was meant to put the respondent in the mode of being present in their grief, for example: *How often do you think about him or her? Do you still feel as if they are with you? What did they leave you?* All the participants had their loss occur between one and a half and six years. They thought about their loved ones often, from once a week to all the time. A theme that emerged amongst the participants was the feeling of the deceased being present could be ambiguous and clash with their spiritual beliefs. There was also sadness if they could feel their presence, and then other times not: *"Sometimes more than others: Sometimes WAY more than others. The saddest times are when I feel I can't reach her."* When asked about what their loved one left behind, responses varied from material objects like photos, jewelry, postcards, memorabilia (P1, P3, P4, P6) to financial assets from the estate i.e., stocks, life insurance, retirement, down payments (P4, P6). Other responses reflected more on familial relationships, lessons, and genes (P2, P4, P5, P7).

The second group of questions prompted them to think about how their own legacy might live on and what digital or physical things they think would represent them when they are gone. For example: *Do you think about how your own*

legacy will live on? What digital or physical things do you think will come to represent you after you are gone? What kind of stories will these digital or physical things evoke?

All the participants thought about their legacy and these thoughts were particularly influenced by their grief experience. Participants worried or were paranoid about their own future families or how their children would go on without them (P1, P4). A behavior that was consistently observed was that of starting their own lifelogging practices to leave behind as their legacy after they were gone: “[...] I think of how I want my son (and future second baby—I’m pregnant) to remember me and I make photo books each year for [them] because after losing my dad I am paranoid about dying and leaving my kids without a mother [...]” When thinking about what might represent them when they’re gone responses ranged from physical items like photos, artwork, journals, photo albums, kitchen tools, clothes (P1, P2, P4, P5, P6) to digital things like social media profiles, text messages, emails, blogs, videos, digital journal files (P1, P3, P6, P7).

The third group asked them to remember a time when an experience online affected them while grieving. They were asked to recount this experience in detail. There were tensions between the embodiment of digital profiles and personal devices and betrayal and shock when those were reanimated (P1, P2, P5). One respondent recounted: “A few days before my aunt passed. She had me help her set up an Instagram account so she could see images my cousin was putting up of his

children. Then as I was on Instagram after she passed, she came up as a suggested friend." Sometimes this reanimation was due to a family member accidentally interacting with the family through the deceased's phone or online profiles, other times it was the actual digital devices and companies themselves doing the reanimating: *"My iPhone kept trying to suggest that I tag photos of my dad... maybe because I was looking at photos of him so much."*

The fourth group asked participants about their current usage of digital media when practicing remembering: *Are there any other digital or physical items that you interact with that belonged to your loved one or remind you of them? How do you store or manage these items for future remembrance?* Like previous research has shown, participants did visit the profiles of their deceased loved ones (P3, P4, P5, P6) and often did so on anniversaries, birthdays, and other meaningful days. One notable theme was the emergence of practices around collecting, editing, and disseminating materials in the immediate year after a loss. Some participants spent time digitizing physical materials to preserve them for future remembrance. Digital materials were also of immense importance and participants took great care in making sure precious digital artifacts like voicemails, photos, and texts were backed up and "in the cloud." Each participant had their own method for digital archiving. Some used a combination of things like word processors and their hard drives or cloud storage services like

Google Drive. This practice of archiving and preserving material histories made participants feel better and even motivated them to document their own lives for their descendants:

“I SPECIFICALLY documented my pregnancy in case my future child/ren want to know what it was like. I had no real records of my mom’s pregnancy and my dad’s memory wasn’t great. It’s all in my personal OneNote and I’m writing it with the hope/intent that my children will have access to it if they want it. Since my mom died, my dad and I have started scanning all the pics my mom took of our family from the time we were babies, and My hope is that technology will allow these scans to be a permanent family record. I’ve always written, and I’ve slowly started the process of typing up handwritten journals. I want those to be discoverable when I’m gone. I think what remains after you’re gone is stories and feelings, however those get translated while you’re alive.” (P7).

Both physical and digital objects were noted in the items that belonged to their loved ones, but digital items varied in their endurance. Participants had to do the work to remove digital items off soon-to-be discarded devices or inactivated accounts and put them somewhere safe. Some participants also expressed that once they were in the cloud, they did not revisit the items often. This might be due to the “out-of-sight” nature of digital storage.

Fieldwork Observations

Fieldwork with bereaved users revealed common practices around the handling of digital material after a loved one passes away. While Massimi and Rosner’s 2013 study showed the importance of crafting for the bereaved, my research has shown that in addition to traditional physical crafting, *digital crafting*

has become increasingly common due to many conversations and interactions being digitally mediated. Digital crafting in the context of bereavement can be described as the act of gathering, editing, curating, and archiving of a variety of digital materials for the purpose of record-keeping, remembering, sharing, and future bequeathing. Digital crafting helps the bereaved reconnect with the deceased through digital media and provides them a sense of comfort knowing that these normally ephemeral materials are kept safe. Digital crafting can include creating a family slideshow for a funeral or transferring photos off a personal device into a collaborative cloud storage service for future remembering, for example.

Currently, users are left with everyday computing tools to enact digital crafting. What would future tools and systems look like that support the digital crafting needs of the bereaved? Lacking in current systems is the ability to collect, edit, store, and interact with digital materials in meaningful ways for the bereaved. The generic interfaces of the smartphone and computer are hardly an ideal place to interact with these belongings. When you lose someone important, what remains is the relationship, the memories, and the material items that represent the deceased or an aspect of the relationship. Postmortem, digital materials like chats, photos, videos, writings, audio recordings, and interactions become elevated beyond their everyday object status and become precious *things*

with new value. But current systems do not honor this new value. A voicemail from the deceased might stay for years in the bereaved's phone alongside a generic voicemail from the pharmacy. Photos and videos stay on a hard drive, mixed in amongst insignificant files and documents. Chat conversations stay contained within their platforms with the risk that one day the profile will get deleted, or the company will close. Digital legacies need systems that recognize this shifting status and support easy removal from generic interfaces into new spaces of importance. New systems will also need to use elements of slow technology to support the remembrance and reflection practices of the bereaved.

V. DESIGN AND IMPLEMENTATION

The Design Concept

Speculative Digital Design

In addition to highlighting the vital role that designers play in the experiences of the bereaved, another goal of this thesis is to challenge designers to consider new ways to facilitate connections between the bereaved and the deceased. The bereaved are already using SNSs and digital media to continue their bonds with the deceased, but there is a need to re-envision current systems to support this practice more purposefully. This is where *speculative design* can come into play. Speculative design uses design to propose alternative futures not as they should be, but how they could be. It is used as a lens to view wicked problems and imagine new futures by asking questions about the status quo. The act of imagining alternatives without the weight of getting it right helps free the mind of judgment. Critical designers and educators Anthony Dunne and Fiona Raby present three categories of futures with an illustrative diagram in their book *Speculative Everything: Design, Fiction, and Social Dreaming* (2013). In the diagram, several cones are fanning out from the present to various future states, the possible, the plausible, and the probable (see fig. 15). The probable cone is the area where most traditional design objectives take place. It is the future that will happen if we stay on our trajectory without any extreme change to our social,

political, or ecological environment. The next cone represents what could plausibly happen in the future. Plausible futures are not predictions but alternative outcomes that could happen depending on certain shifts. Beyond the probable and plausible cones lies the possible. This area contains all physically possible things that could happen in our future, but it is difficult to imagine how we would get from our present state to this potential future. Speculative design aims to give material expression to outcomes that can fall between the probable and plausible cones of the diagram. This sweet spot Dunne and Raby refer to as the preferable future. Speculative designers use this framework to open discussions for groups of people to think critically about their current realities “and provide platforms for future collaborative speculation (Dunne and Raby 2013, 6).” Using this lens, we can use speculative digital design to describe design projects that seek to propose alternative possibilities to current digital systems in place. So often digital design projects live in the world of the practical and the probable. This speculative thesis project seeks to give material expression to a preferable future in which designers have created new systems that can support digital crafting practices of the bereaved.

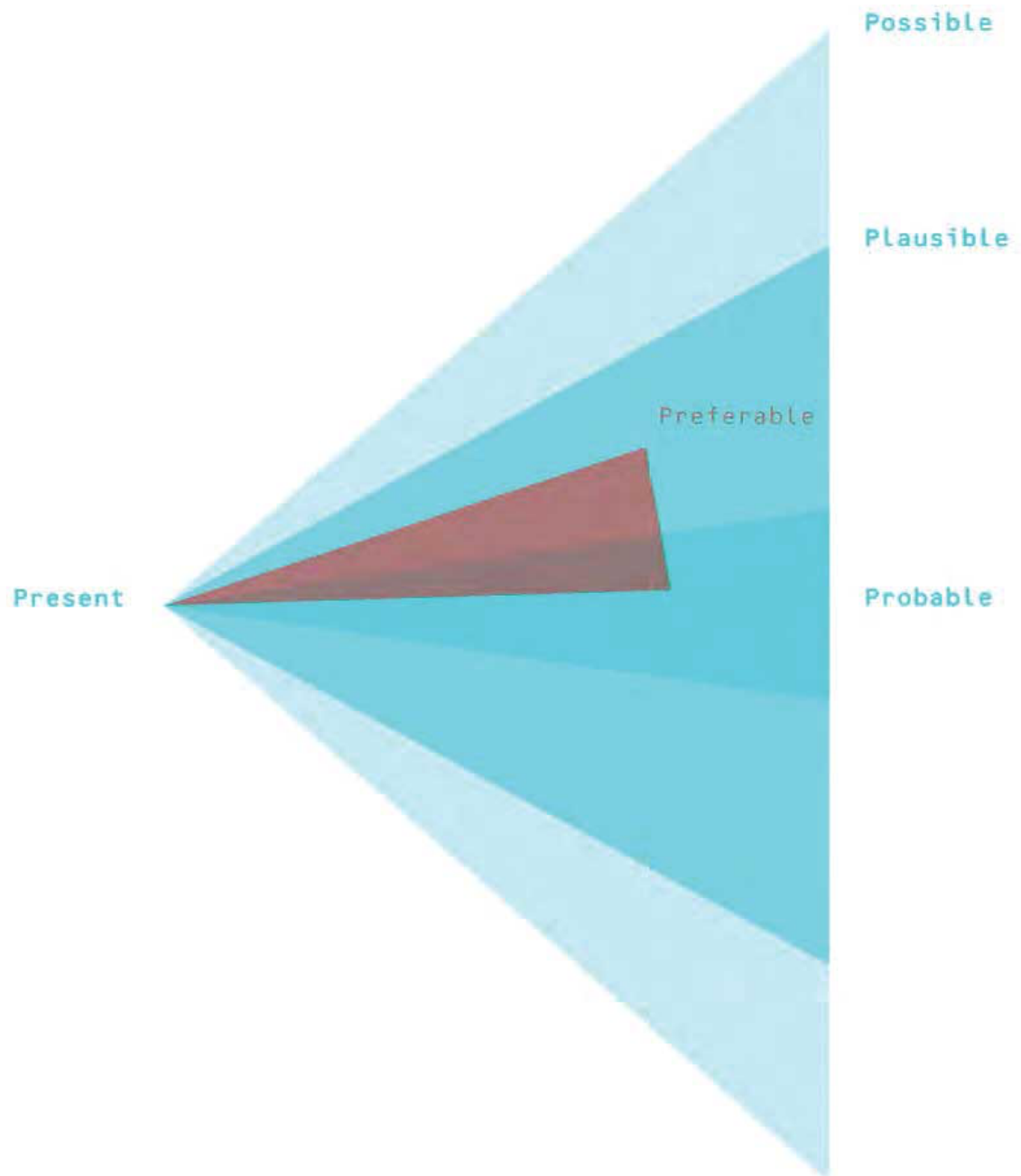


Figure 15. *Dune & Raby, PPPP Illustration (Cambridge, MA: MIT Press, 2013).*

Project Guiding Principles

Guiding principles were created based on the quantitative, qualitative, and analytical research conducted to narrow the scope of the thesis project to what I felt were the most salient user needs. These guiding principles are:

1. Make room for digital crafting as a form of therapy. Participants often expressed how the acts of making something out of digital materials were therapeutic and meaningful for them.
2. Support archiving as a form of grief work. Part of the process of honoring the relationship and legacy of the deceased revolved around gathering, editing, disseminating, and archiving digital materials.
3. Consider that users are not just their grief. Bereaved users might only want to revisit archived collections on significant days like anniversaries and birthdays. Designers should avoid making assumptions about users when creating features meant to “connect” or remind users of relationships and memories with other users and instead focus on ventures that support autonomous rituals for the bereaved.
4. Know that this is not a one-size-fits-all solution. The grief experience is highly individual, and what works for someone will not necessarily

work for everyone.

Framing the Challenge

The *Frame Your Design Challenge* is a method offered by IDEO, a nonprofit design studio that practices human-centered and participatory design practices (“Design Kit” n.d.). I used this method to properly frame my design challenge and narrow the project scope. This thesis has unveiled several user experience issues faced by the bereaved, but it is not possible to solve all these problems. I started the challenge with many *How Might We* statements (HMW) (see fig. 16) to capture the many problems I was trying to solve and consolidate them into single sentences. A lot of these HMWs revolved around systems that allowed for deep storage and rich contextualization of data for bereaved users. Others were about the social media problems that the bereaved were currently experiencing.

It was helpful to revisit the objectives of the thesis at this moment of design and implementation. The improvements that I wanted to make were: 1) That bereaved would have less traumatic user experiences, and 2) To push designers to help bereaved users connect and remember their lost loved ones in ways that were meaningful for them. The next step of the challenge was to really think about the target audience and what constraints and influences existed in their lives. I considered that my users were the bereaved, but I also wanted to

consider the needs of a person at the end of life (PEOL) who might be anxious about bequeathing their possessions. An ecosystem map was created for these two user groups to illustrate the social, service, and institutional forces that affect them (see fig. 17). The goal of this step is to produce shifts in behavior for your main audience (see fig. 18). For PEOL these changes revolved around ideas like automatic and intelligent backup services for data creation and transforming systems to incorporate semantic data into the practice of lifelong data logging. For the bereaved, the main behavior shift I was drawn to was: *From feeling like the traces of their loved one is slipping away, to feeling like they have everything that would have to remember them after death.* This shift felt much closer to how participants were already using digital crafting and archiving in their rituals. After this exercise, it was evident that I was looking to shift too many behaviors and that the challenge needed to be narrowed in scope to offer a strong solution. I decided at this time that although I had considered a PEOL as a prominent user, the shifts that needed to happen were unique to those of the bereaved.



Figure 16. *Di Sarli, Gabriela, How Might We Statements Generated as Part of the Frame Your Design Challenge (Austin, TX, 2021).*

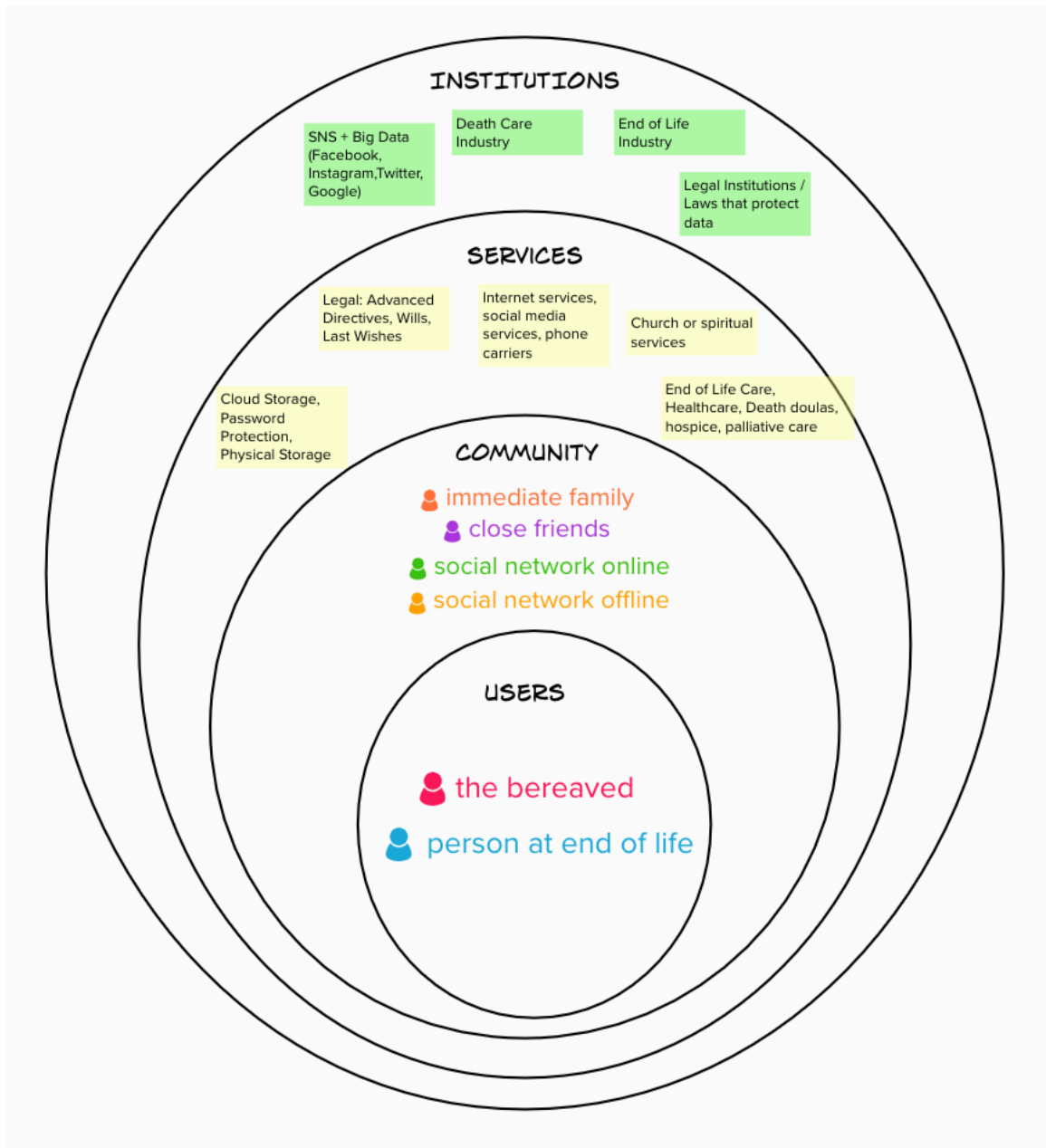


Figure 17. Di Sarli, Gabriela, *Main Audience Ecosystem Map* (Austin, TX, 2021). This map shows the community, services, and institutions that exist in the target users' lives.

<h2>THE BEREAVED</h2> <p>From feeling burdened by too much inherited digital data to feeling grateful for having cherished mementos/connections to loved one</p> <p>From feeling like the traces of their loved one is slipping away, to feeling like they have everything they could have to remember the them after death</p> <p>From being confused as to a object's significance to the deceased to understanding fully the context of that object in their loved one's lives</p> <p>From being anxious of losing disparate data stored in different devices to feeling confident that precious materials/data are conserved</p> <hr/> <h3> immediate family</h3> <p>The bereaved may need feel like the burden of managing digital inheritances falls on them for the rest of the family because of being the most tech-savvy or being the primary recipient of the items</p> <p>Other family members are likely to be contending with their own inherited items and their own grief work</p> <hr/> <h3> close friends</h3> <p>Close friends are important support to the bereaved, but they may be skeptics of rituals of remembrance. It is common that misguided advice encouraging the bereaved to move on and let go might make the bereaved feel embarrassed or ashamed.</p> <hr/> <h3> social network online</h3> <p>Larger social network online and offline may be skeptics of the bereaved's mourning rituals and give misguided advice.</p> <hr/> <h3> Internet Services, Social Media Services, Phone Carriers</h3> <p>Social media will have to be dealt with promptly as some providers terminate absent accounts after a certain time. Often phone provider will need to be disconnected so memories/ data on devices will need to be archived quickly. This all occurs during acute loss stage so it is hugely taxing on individual</p> <p>SHIFT = need automatic backup service for peace of mind when the time is appropriate to sift thru data.</p> <h3> Cloud Storage, Password Protection, Physical Storage</h3> <p>Challenge = if no password received, fear of data lost, no access. Subscription based data storage will need to be transferred or dealt with.</p> <p>SHIFT= way to easily pass on passwords ie LastPass</p>	<h2>PERSON AT END OF LIFE</h2> <p>From feeling overwhelmed with digital data at end of life planning to feeling at ease knowing loved ones will received precious items</p> <p>From wondering what will happen to their data/online presence once they die to knowing that there are systems in place for relinquishment of data beyond life</p> <p>From worrying that your heirs will not understand their inherited mementos significance to you to knowing they will understand the story behind the object</p> <hr/> <h3> immediate family</h3> <p>Person at End of Life (PEOL) may be pressured by family to not worry or focus on curating digital inheritance.</p> <p>Family may push for access to personal data that PEOL does not want to give</p> <p>Family may want to know what will be given to them and pressure PEOL</p> <p>PEOL loses autonomy and control to family usually</p> <hr/> <h3> close friends</h3> <p>Depending on family dynamic close friends may lose touch with PEOL as family takes over their care</p> <hr/> <h3> social network online</h3> <p>social network online/offline may check with others in the network for status updates on PEOL.</p> <hr/> <h3> Internet Services, Social Media Services, Phone Carriers</h3> <p>The user at end of life is worrying about more important things like pain management, spiritual and emotional concerns, tying up loose ends</p> <p>SHIFT = need automatic backup service for peace of mind so user does not feel need to take care of those items right away</p> <h3> Cloud Storage, Password Protection, Physical Storage</h3> <p>Again, similar challenges as the bereaved. Other more pressing concerns at end of life.</p> <p>Is there a need to incorporate systems for lifelong data logging? Is this a burden? What systems could be changed to make this process a lifelong process so that the end is just as easy as passing on a password.</p> <p>SHIFT= Shifting systems to lifelong datalogging</p>
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Figure 18. Di Sarli, Gabriela, Audience Ecosystem Notes (Austin, TX, 2021). These notes detail the considerations and shifts for each part of the ecosystem.

The *Memory Keepsake* System

Concept Narrative

Memory Keepsake is a system made up of a web-based service and collection of interactive devices that offer a way for the bereaved to digitally craft a unique object of remembrance. On the *Memory Keepsake* website, a user can learn how to download data from prominent SNSs or other personal sources, upload it to the service, and select and customize a keepsake to house a collection of digital materials for future interaction and remembrance. The keepsakes vary in shape, size, and appearance but consist of a physical object with a digital interface, operating system, speakers, and buttons for navigating and viewing content (fig. 19). The keepsake devices offered are a semi-circular handheld keychain, a desktop or nightstand clock, a hand-held pocket mirror, and a digital frame. The *Memory Keepsake* objects are designed to look like everyday objects that might be carried on your person or displayed at home.

The goal behind this speculative project is to stimulate the imagination of designers to consider the possibilities of designing for the unique needs of the bereaved. In this preferable future, the bereaved would experience less second loss-related anxiety and distress at the thought of losing precious digital materials related to their loved one. In this future, the previously mentioned

friend of Debra Bassett would be able to transfer the last recording of her daughter's voice off the cell phone and into a place where it will be preserved and accessible. The keepsakes are a way for users to author open-ended items of remembrance through the ability to edit, curate, and interact with meaningful data collections. *Memory Keepsake* is not intended to be a testable product subject to the realities of current market forces but meant to offer a potential reality to stimulate change and deepen awareness for designers.

The idea behind the system's design was influenced by artifacts of the Enabling Ongoingness Project and Zapptales service. However, this system of objects differs in some key ways. First, *Ivvor*, *ReFind*, and *Trails* seek to offer richer contextualization of data belonging to the deceased for the consumption and interaction of bereaved users. Their goals were to contextualize substantial amounts of inherited data especially by those who have had cognitive decline like dementia. *Memory Keepsake* would be a technology designed for the personal archiving of many different forms of media collected by the bereaved in the digital crafting phase of grief. This is significant because although there is a need for systems that contextualize inherited data, there is an equally important need for the creation of a specialized space and container for users' own personal collections. As shown in this study, mundane digital materials like voicemails, texts, and chats, between two people become transformed into an immensely

special collection that can act as a proxy for the relationship when one of those people dies. The *Memory Keepsake* system is a way to honor this collection by offering education on downloading data from hard-to-reach sources and providing software for editing, curating, and archiving that data into a special location that is separate from the computer or smartphone. *Memory Keepsake* seeks to build off Zapptales chat history archiving by offering a way for users to store these chats on a digital device. One benefit to this is that the user can interact by scrolling through the conversation, mimicking the process by which we chatted with the deceased on our smart devices in the past. Another is that these devices offer a location where many diverse types of media can be viewed, listened to, or read in one place. Additionally, the device has the functionality to be updated, backed up, and maintained via an online user dashboard. The physical design of the keepsake objects was intentionally designed for privacy for the user. It is common to see a desktop smart clock or digital frame in a house. Similarly, a person could be carrying a pocket mirror or keychain without getting any unwanted attention. This design decision is another departure from previous projects, like *Ivvor*, *ReFind*, and *Trails*, whose abstract designs might stand out in the bereaved's possession and represent a noticeable grief symbol.

The user journey would look like this: the user would enter the *Memory Keepsake* website and start by clicking a button to start building their keepsake.

Many large platforms like Facebook and WhatsApp do not let other websites crawl their data so the website first guides the user along a step-by-step process for downloading and then uploading various data types to the service. This is a key step in the process of digital crafting as the *Memory Keepsake* service would serve as an important guide for bereaved users who lack the technical literacy to pull precious data off various sources. After the data is uploaded to the service, the user enters the Keepsake Customizer where they can select a keepsake object design, customize the keepsake to their liking, and craft the arrangements of photos, videos, texts, chats, and audio files they want to be loaded on their keepsake. In the Keepsake Customizer, the user has a live view of their keepsake as well as areas for editing the content and shuffling through how the content will look on the keepsake's screen. Items uploaded to the keepsakes can include, for example, social media chats, comments, photos, videos, texts, and voicemails. After customizing their keepsake, the user would purchase it, and wait for it to ship to their home. In the storyboard and designs below, the user has purchased the keepsake in the design of the desktop clock. The user can then place their keepsake on their nightstand, for example, and interact with the items whenever they want to. Another key departure from other design projects is that the device does not make decisions for the user on when and how they engage with the collection in the keepsake. From speaking with the bereaved, it was indicated

that they feel uncomfortable when devices and companies make assumptions on when and how they would like to interact with the memories of their loved ones. *Memory Keepsake* devices do not make autonomous decisions for the user for this reason. The desktop clock when not in use would display the time on its digital screen so that the object can have a function other than a remembrance object and so that others who view the keepsake will not recognize it as a grief-related device. The user can also use a security passcode to further control who sees the personal contents of the device. A storyboard illustration shows visually how this user story unfolds (see Fig 20).

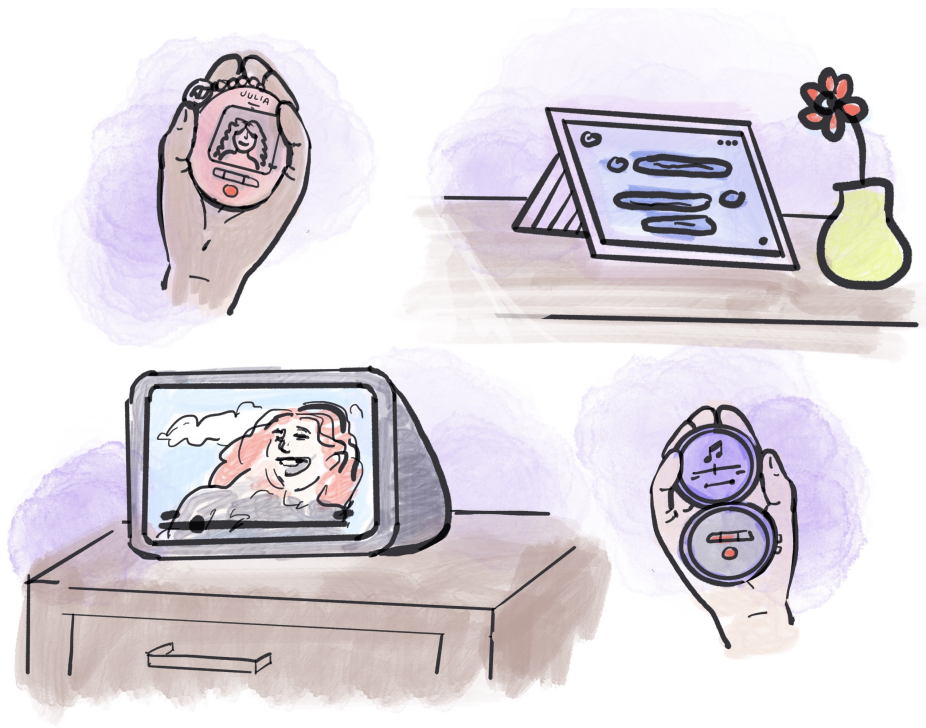


Figure 19. *Di Sarli, Gabriela, Concept Drawings of Memory Keepsake Objects Displaying Different Types of User Media (Austin, TX, 2021).*

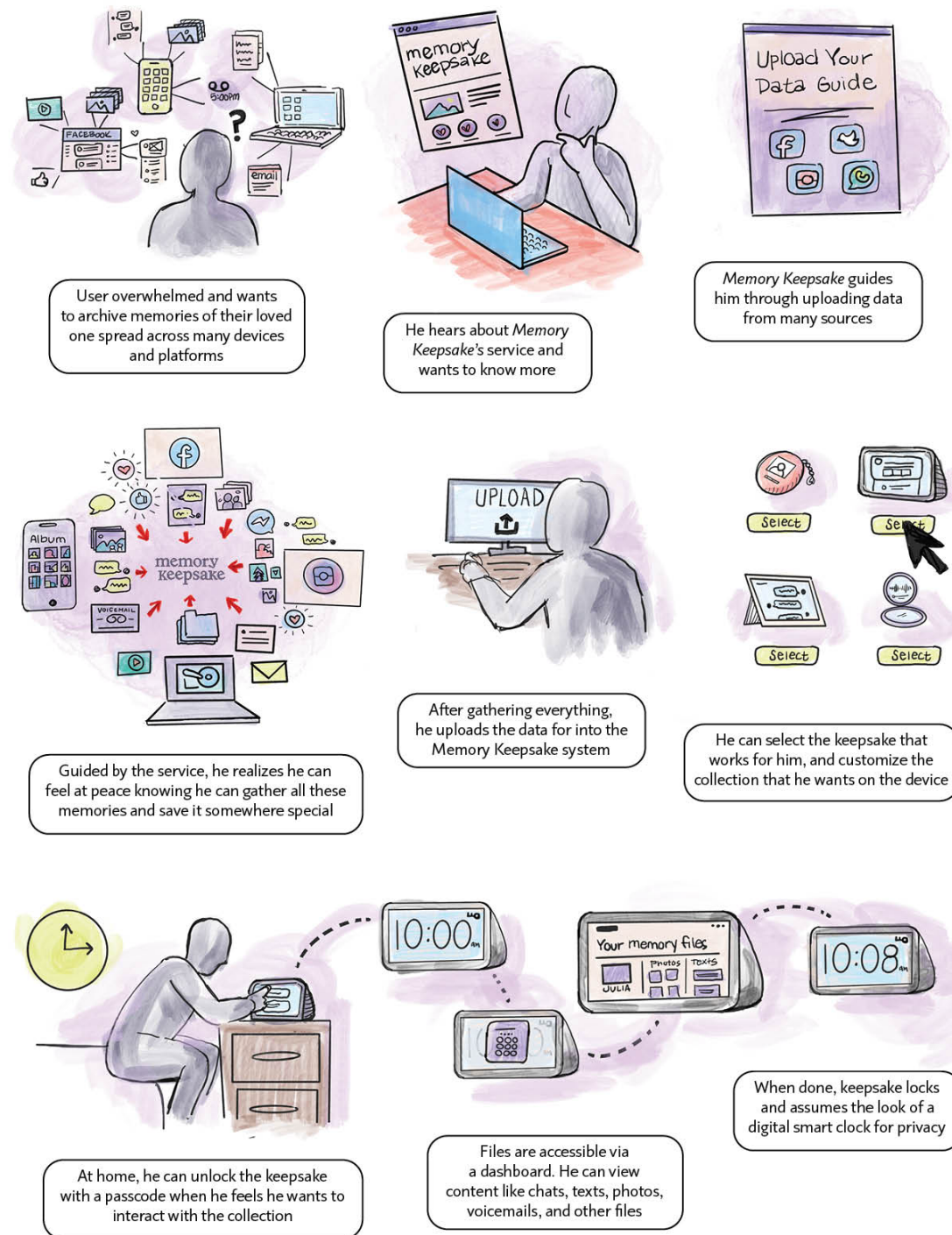


Figure 20. Di Sarli, Gabriela, Storyboard Showing How the Memory Keepsake System Works (Austin, TX, 2021). The user uploads their data to the keepsake, customizes their collection, and interacts with the collection at home through the desktop/nightstand clock keepsake.

Design Elements

The *Memory Keepsake* System was visualized through low and high-fidelity prototypes and preliminary feedback was sought from potential users. The user feedback notes are in Appendix C. The design elements of the *Memory Keepsake* system include a landing page (fig. 21), data upload user flow (fig. 24), and the Keepsake Customizer page (fig. 25). The brand color palette is made up of a soft gradient of purple, blue, cream, and white hues. These colors were purposefully chosen as they typically evoke feelings of calm, serenity, and spirituality (Schauss 1979). The background of each page has a multi-color gradient with soft changes of color and texture to maintain an organic and sensitive feeling. To emulate the digital spaces that these collections of data occupy, sections of the web page containing key information reference the design of user interface modals found in Apple's internal operating system. Since Apple's user interface patterns are familiar to many users adhering to these patterns ensures understandability for a large user base. By placing copy and the user's digital data within this visual space, it offers a familiar visual language while also elevating the data in its importance. The juxtaposition of the data within the keepsake, housed inside the Apple OS-style modal forms a subconscious connection between the everydayness of computer user interfaces and the specialness of the keepsake. An illustration showing the various digital media

that we produce daily was added as an illustrative visual (fig. 22). At the top of the landing page is a video that would show footage of a user interacting with an example keepsake. Below the fold of the website there is copy stating the problem statement and further down the user could learn more about each keepsake object offered by the service. The renderings of the keepsake on the landing page show that these objects can handle many diverse types of data, from photos to chats to voicemails. The user can also click on each photo to learn more about that keepsake's specifications. (fig. 23).

The data upload flow includes several page designs that walk the user through selecting their data source(s), how to download their data from each source, and then prompts them to re-upload those files into the system (fig. 24). After the data is uploaded, the user would be brought into the Keepsake Customizer screen.

The Keepsake Customizer contains areas four distinct areas. The first and largest area is the live preview where they can view how the keepsake they are building will look like (fig. 25). The live preview is responsive to the actions that happen in the other three areas of the customizer. On the left side, users can read specifications, like the object's size and screen, and toggle various states, as well as automatic media cropping and shuffled content. The bottom editor features tabs to switch between photo, video, audio, chat, and text content (fig. 26). The

user can work within the editor to edit or remove whatever items they do not want to go into the keepsake. On the right side, there are toggles so that users can view different media types in the live preview, cycle through content, or rotate the view of the keepsake. The top area contains buttons to switch between keepsake models so the user can decide if they want a smaller, hand-held object (the keychain or pocket mirror) or something larger that they can place on a surface at home (the clock or frame) (fig. 27).

To visualize how the keepsake user interface would function, designs were created modeled on the desktop clock keepsake (fig. 28). The desktop clock prototype is modeled after an Amazon Echo Show as it resembles current desktop smart clocks on the market. The desktop clock contains an 8-inch screen and a rounded backside. On onboarding, the user would be guided through creating a passcode so that they could keep the contents of the keepsake private and discreet. The default screen displayed is a clock when it is not in Keepsake Mode. The desktop clock screens were also designed using a modified version of the textural gradient from the website as the background for the clock's user interface. To unlock the keepsake and enter the digitally crafted collection the user would press the small key icon at the bottom right of the screen and enter their passcode. After the passcode is entered, the user gains access to the collection and sees the dashboard. On the dashboard, there is a card featuring a

photo of the deceased along with their name and a customized memorial message that has been added to the card. Next to it are three columns with various categories of content: Photos, Videos, Chats, Texts, Voicemails, and Other. In the hypothetical flow below (fig. 29) the user clicks a button that says “shuffle content” so they can view their collection in a slideshow. In the slideshow, we see a video auto-play, a photo, a Facebook chat conversation, and a voicemail (fig. 29). There is a back button so the user could return to the dashboard and the key icon remains on the screen in case they quickly want to return to the clock interface for privacy.

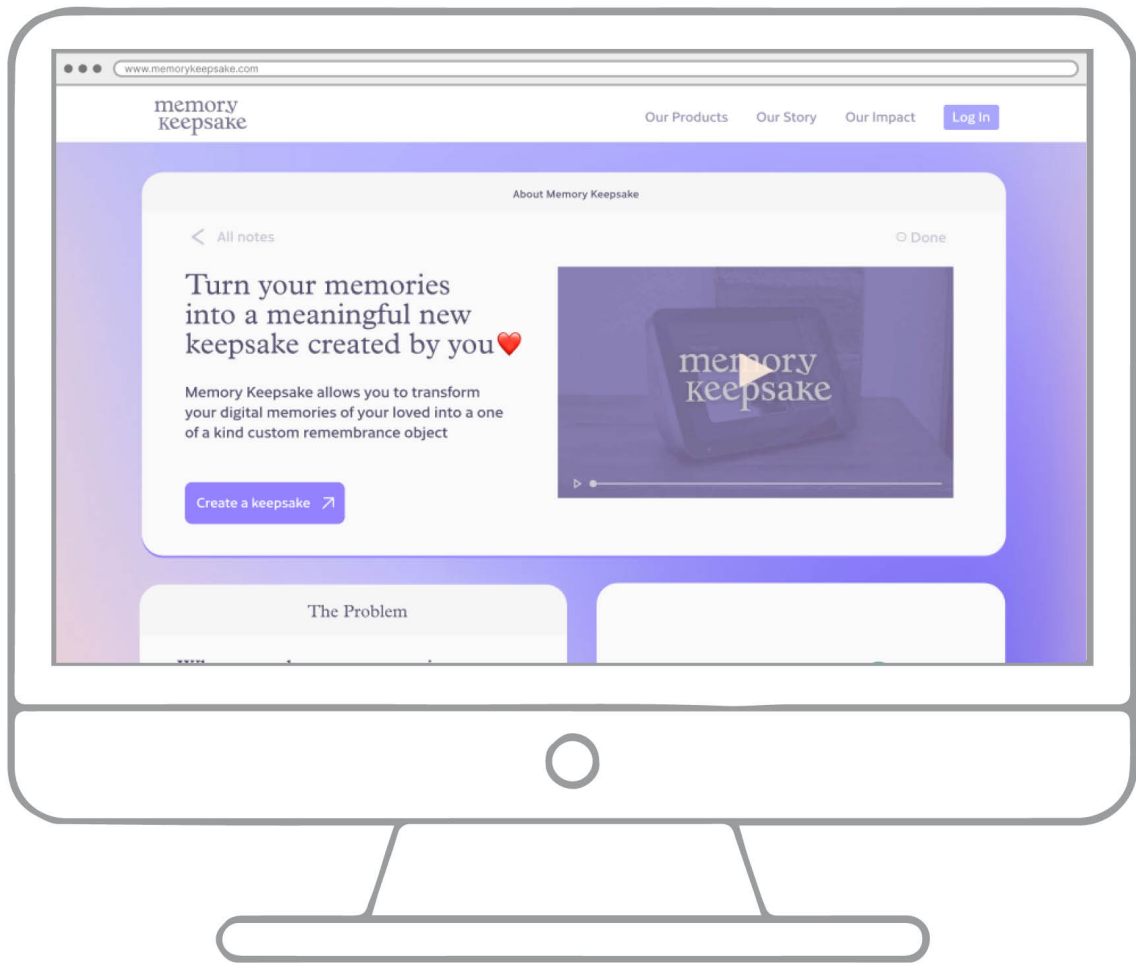


Figure 21. *Di Sarli, Gabriela, Memory Keepsake Landing Page Mockup (Austin, TX, 2021).*

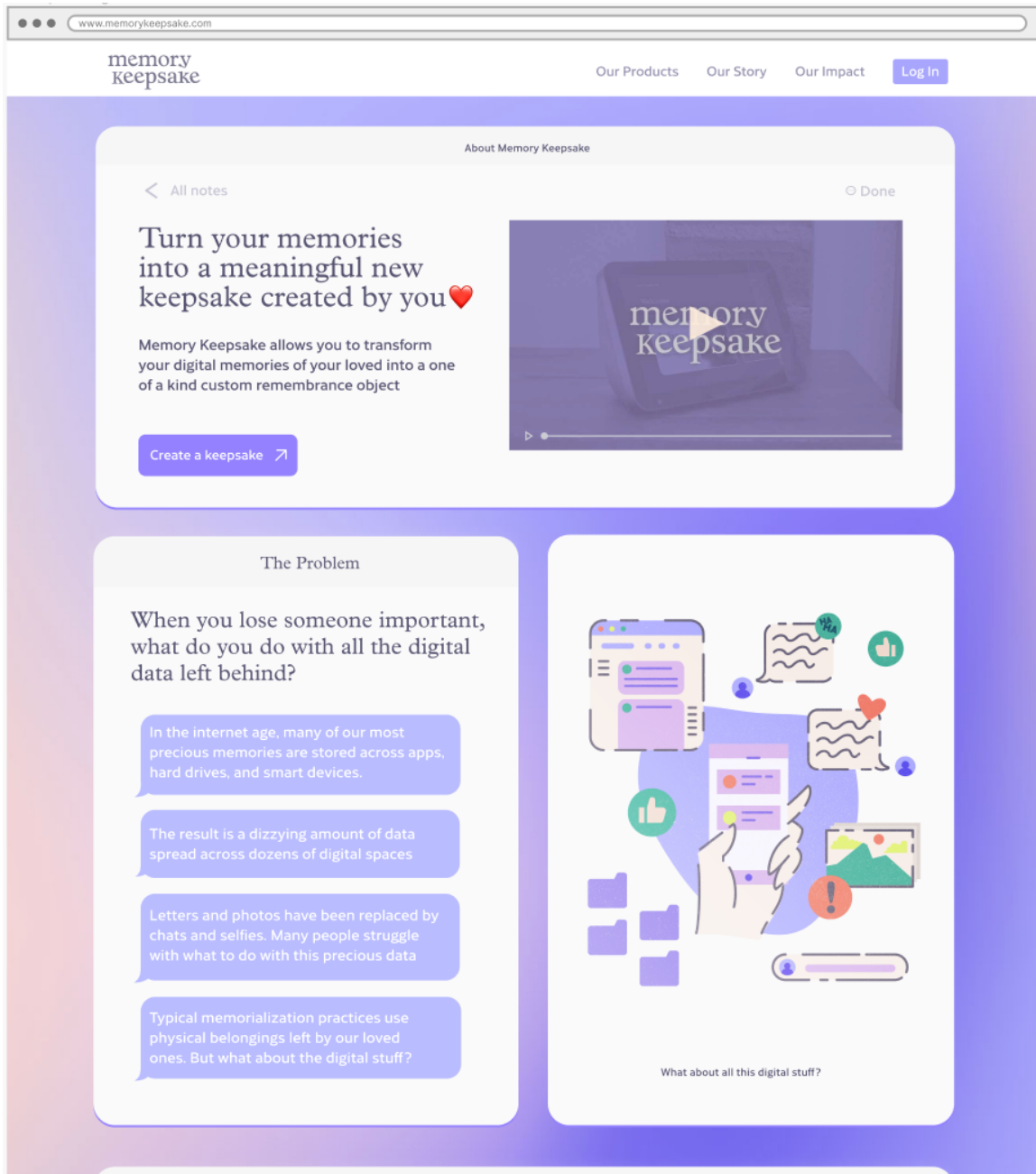


Figure 22. Di Sarli, Gabriela, *Landing Page Mockup Expanded* (Austin, TX, 2021). Copy and illustrations on the Memory Keepsake landing page show the variety of digital media that we produce and how that data might be of interest to other parties after death.

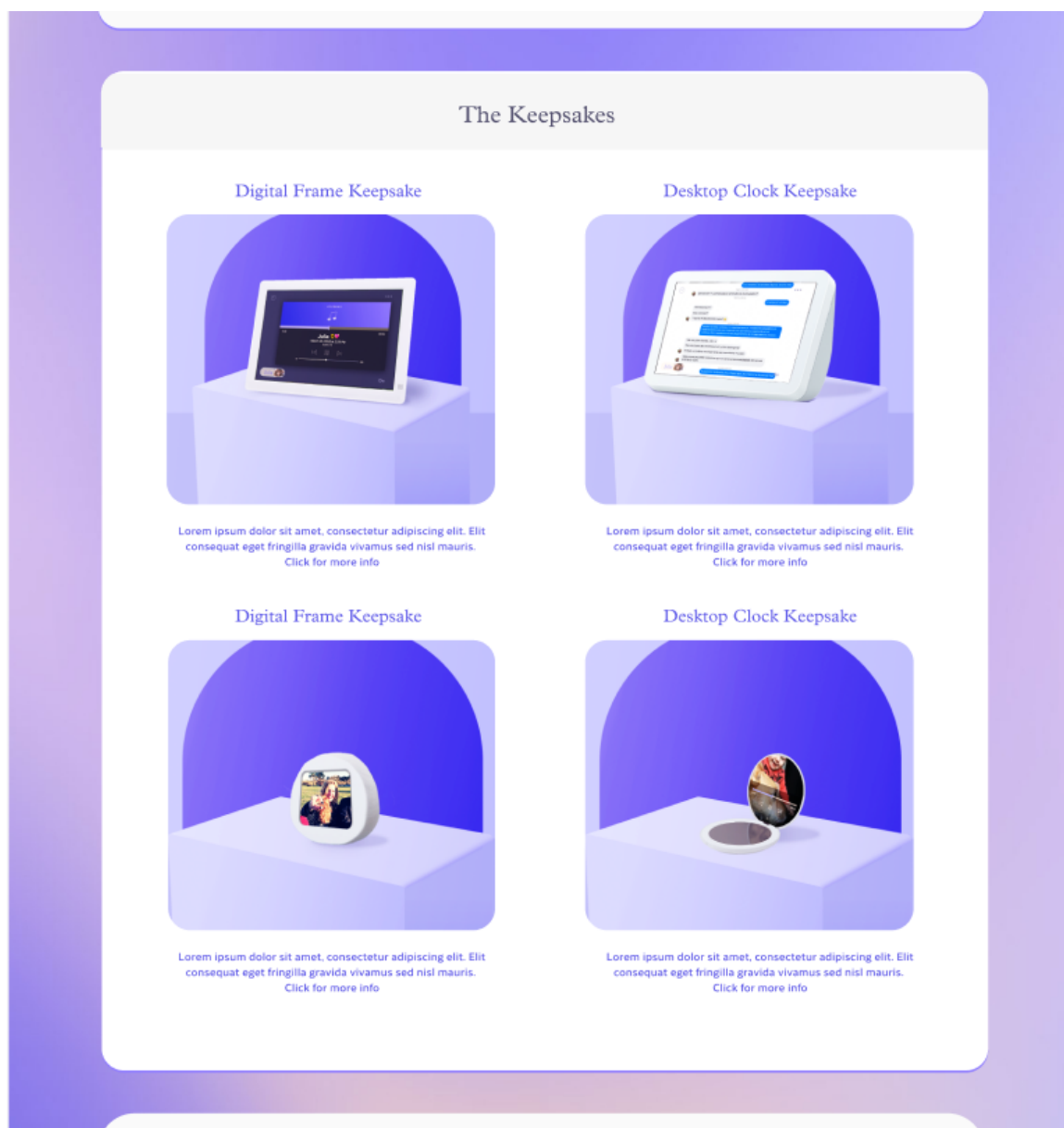


Figure 23. *Di Sarli, Gabriela, Landing Page (detail) Showing Keepsake Models Offered Through the Memory Keepsake Service (Austin, TX, 2021).*



Figure 24. Di Sarli, Gabriela, *Memory Keepsake Data Upload Guide* (Austin, TX, 2021). This series of pages guides the user through selecting their data source(s), downloading their data from each source, and uploading the data into the system.

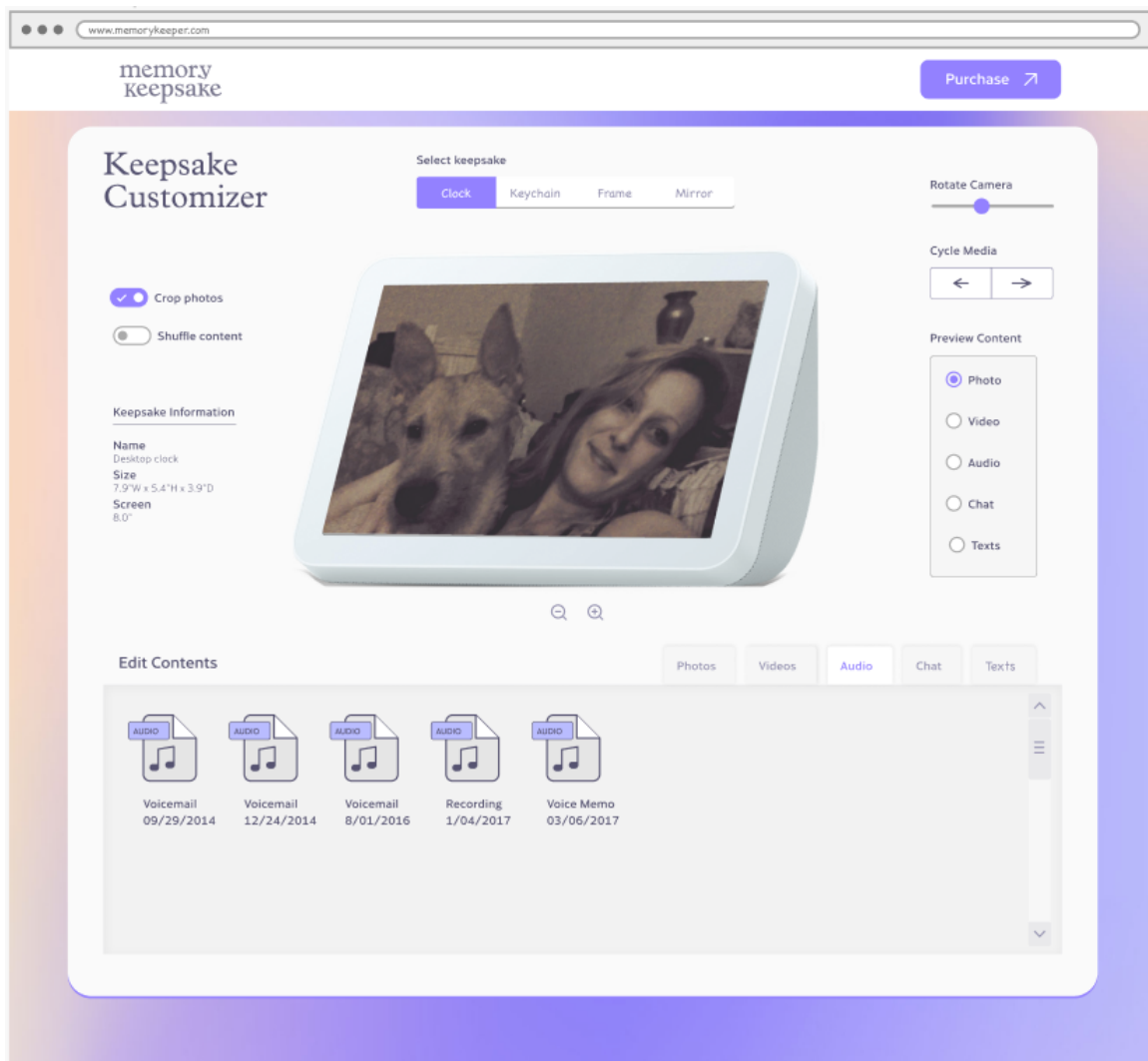


Figure 25. *Di Sarli, Gabriela, Keepsake Customizer Page Mockup (Austin, TX, 2021). On this page the user can customize their keepsake and digitally craft their data collection.*

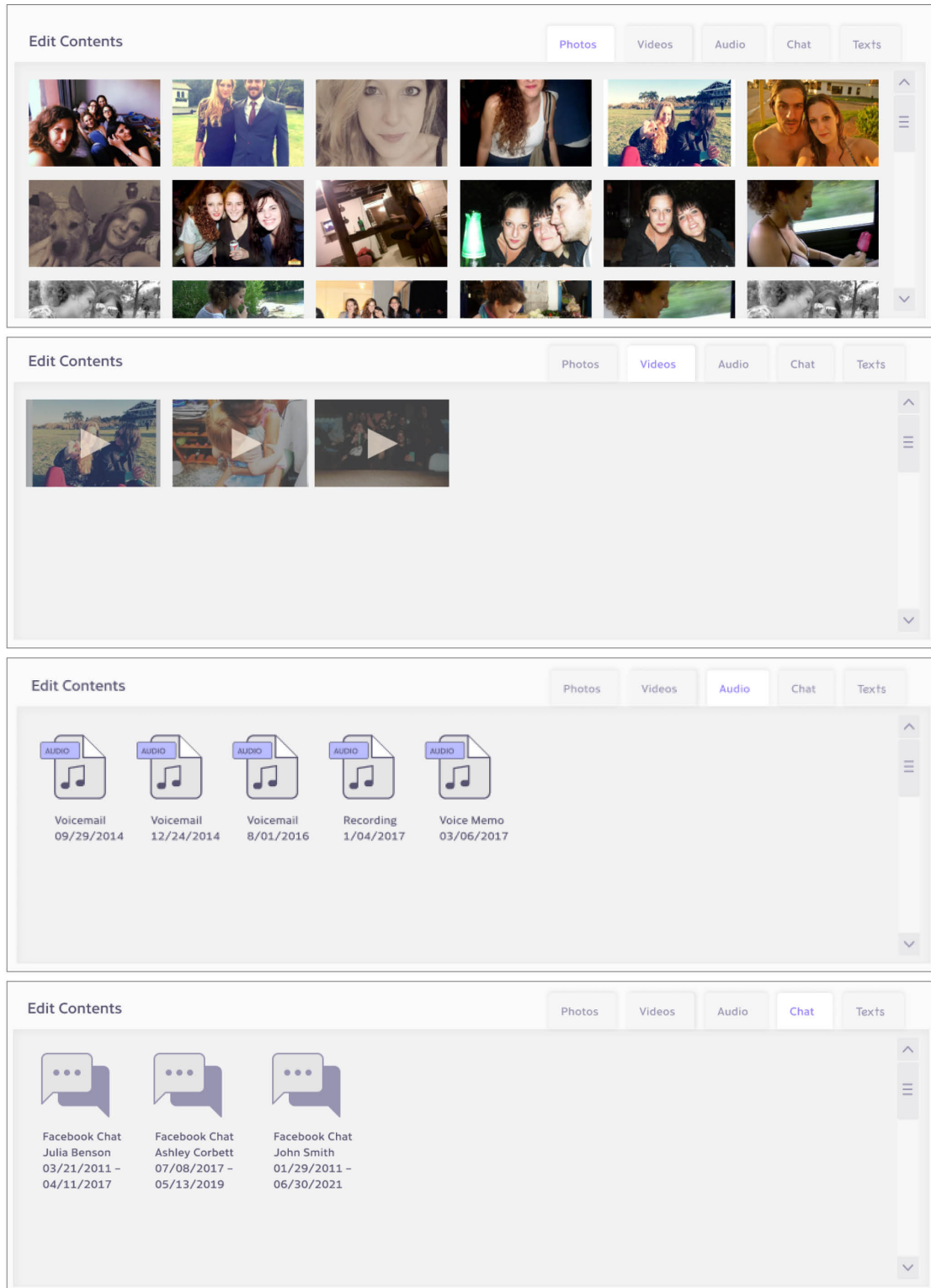


Figure 26. Di Sarli, Gabriela, *Keepsake Customizer Editing Area* (Austin, TX, 2021). At the bottom of the Keepsake Customizer is an area where users can cycle through media types, add, or remove media from the keepsake, and edit specific files for their collection.

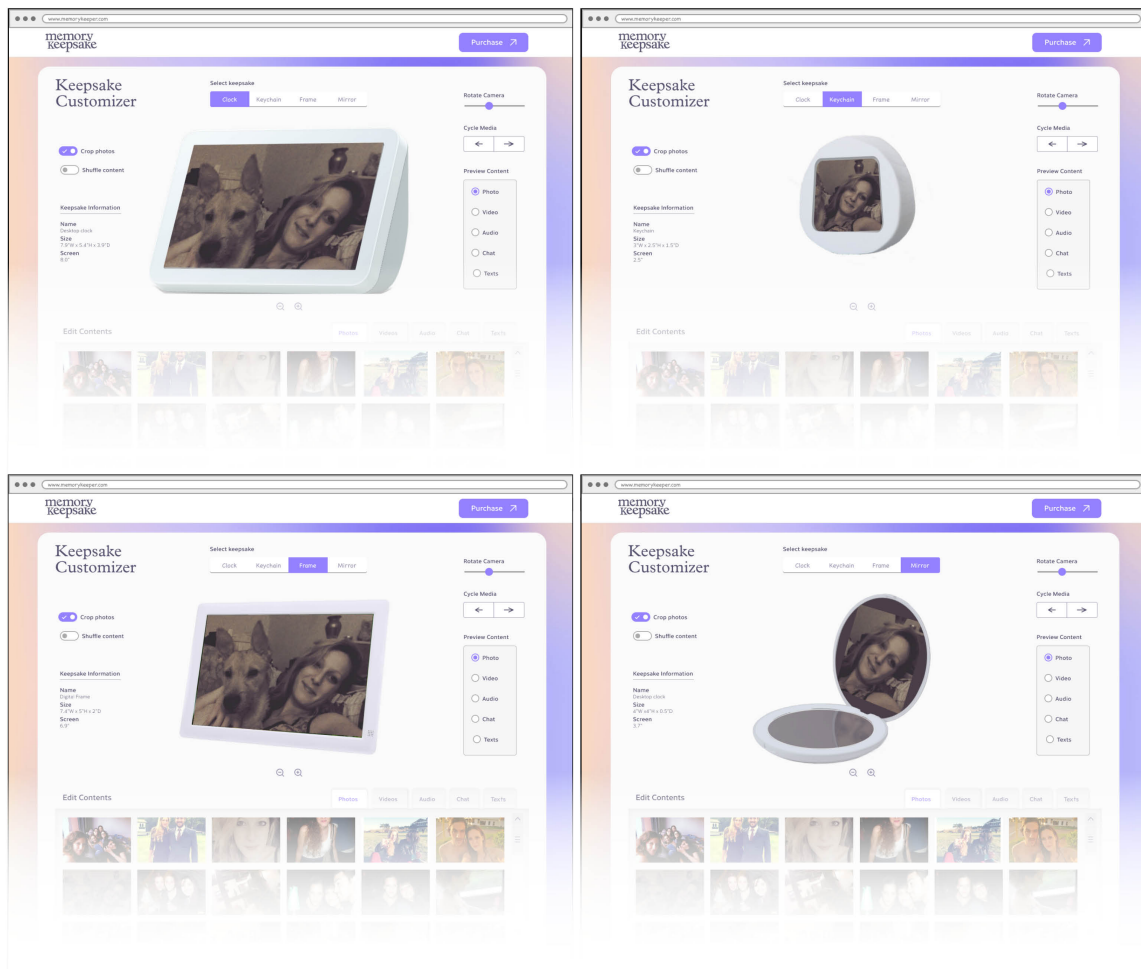


Figure 27. Di Sarli, Gabriela, Keepsake Models Previewed in the Keepsake Customizer (Austin, TX, 2021). Users can switch between keepsake models and preview what their collections look like in each one.



Figure 28. *Di Sarli, Gabriela, Keepsake Desktop or Nightstand Clock Mockup (Austin, TX, 2021). A mockup showing what the clock keepsake model might look like with the dashboard screen displayed.*

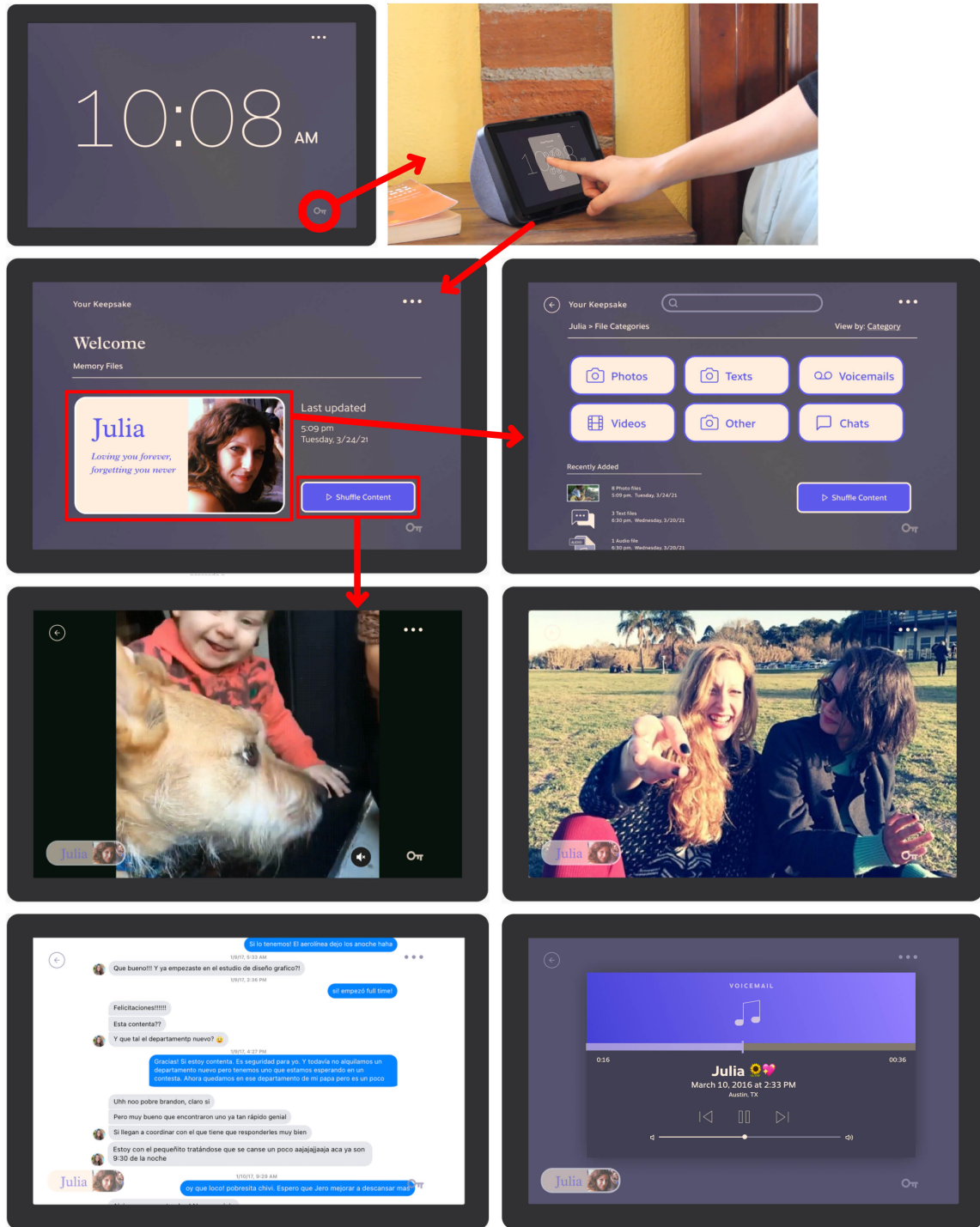


Figure 29. Di Sarli, Gabriela, *An Example User Flow for a Memory Keepsake Device* (Austin, TX, 2021). The user unlocks the keepsake, enters the dashboard, and clicks shuffle content to view various media items in the collection.

VI. CONCLUSION

Designers play a significant role in the design of digital spaces and experiences that affect the bereaved. As shown in this study, while there are cases where poor design decisions have led to harmful experiences for the bereaved, these spaces and experiences can also be used in therapeutic ways. Designers can use the critical tool of TSD to imagine new ways to facilitate connections between the bereaved and the deceased if they educate themselves on these users' unique needs. Surely, the creators of SNSs could have never anticipated that these spaces would hold the relationships of both the living and the dead, but SNSs have been transformed through their usage in society. Practices amongst the bereaved are highly varied online, some like to visit the profiles of their lost loved ones, and for some, it brings only pain. The bereaved will use SNSs and digital media differently depending on the type of loss, their attachment style, and the nature of their relationship with the deceased. The truth is that these spaces and experiences have grown larger than their original purpose of creating a space for the living—they are now a place where the living and the dead live side by side.

Future systems need to support users in saving some data for future remembrance and allowing some data to decay gracefully. When the next of kin had to go through the belongings of their loved one in the past, decisions of what

to keep and what to throw away had to be made quickly because of the lack of storage space. With growing infinite digital storage, how will this pairing down, an essential task of grieving, be handled?

As SNSs platforms wane and grow in popularity, the bereaved will have to contend with the possibility that this last online place where they could “reach” their loved ones might be gone forever. This means the bereaved will have to pull data off these sources and archive them for safe and private future remembrance. The proverbial shoebox of letters and photographs will need to evolve to hold the needs of a generation that lives on the web. Designers wanting to be more death-sensitive in their designs must educate themselves on the needs of these users because they are not unique, and grief eventually touches everyone young and old. Additionally, some users are dealing with extraordinarily complex grief and trauma and so stress cases need to be worked into UX research practices. Making decisions for users on what they would like to see and when they would like to see it makes assumptions that the user wants to be reminded of something when that something might be re-traumatizing for a person who is grieving. Designers in established SNSs like Facebook, Instagram, and Twitter need to consider how these spaces can be activated in new ways to facilitate connections between the bereaved and the deceased. It is

my hope that awareness has been brought to the responsibility that designers hold in the experience of the bereaved.

Postmortem, there is a marked shift of data from trivial to valuable for those who are left behind. These material and immaterial things can become a proxy for a new shifting relationship between the bereaved and the deceased. Slow technology can be used to create innovative solutions that help the bereaved practice digital crafting after losing a loved one. In this speculative project, I have proposed one way for users to archive, craft, and interact with collections of data. While computers and smartphones allow us to store infinite amounts of data, many people struggle with the task of collecting data from many diverse sources and how to archive this data. User interaction has made the systematic organization of files easy, and these same principles can be used to create new experiences that support the shift in the status of data after death. New spaces for collection, interaction, and viewing of this data need to be differentiated and given more respect in their design than the generic interfaces of the smartphone and computer. In addition to shedding light on the need for more TSD, I challenge designers to re-think current systems in place for archiving meaningful collections of data as well as consider new paradigms for viewing and interacting with these collections.

Recommendations for Designers Who Wish to Be More Death-Sensitive

A goal of this thesis was to highlight the responsibility designers play in the sociomaterial ecosystem of the bereaved and the deceased through a digitally mediated world. Throughout this thesis, I have offered several recommendations for designers who want to be more death-sensitive in their practice. These recommendations are gathered from several prominent researchers at the intersection of HCI, design, and death studies. In my research journey, I have also presented my findings that led to my final speculative outcome. In this section, I will summarize these recommendations in the following guide for designers to use in their practice.

1. When designing digital experiences meant to support crafting, consider open-ended ways for users to author highly personalized artifacts of remembrance (Massimi and Rosner 2013).
2. Apply the critical tool of TSD in your daily practice. When designing systems and discussing the needs and role of the user, consider what will happen after the death of the user. If intelligent agents like AI and smart assistants are involved, can they be allowed to operate on behalf of a user after their biological death? When doing design research and gathering user data postmortem, consider the ethical rights of the user. Privacy is a big concern for those in the field of TSD since the

boundaries of what is private or not can change after death. When designing data-creating tools, think of how these processes need to shift to allow the user to decide what will remain private posthumously (Massimi and Charise 2009).

3. Many current systems and products revolve around a lifelong practice of data creating that do not make for easy relinquishment or bequeathal after death. Designers should reconsider these behaviors and think of ways to incorporate a more nuanced approach that considers the eventual death of the user. In addition, how can data be ascribed with more meaningful context beyond current metadata design?
4. Allow users to choose when they want to engage with technology designed for grief. Do not force users to advertise their grief status and allow for the control of mourning symbols. Learn about the role of meaning-making as an essential task of grief work and use it as a tool for designing experiences that support crafting. Grief is a highly diverse experience so never impose on users the “right” way to grieve. Designs for the bereaved should not be created to “solve” grief but to avoid pain due to insensitive systems. Since grief is one of the most deeply human experiences, human-centered design frameworks that

place users at the center of the design process should be used to avoid stressful or harmful experiences for the bereaved. Acknowledge that your own values, beliefs, and taboos regarding death will influence how you design systems for people with values and beliefs different than your own (Maciel and Pereira 2012).

5. When creating user personas, consider how each persona's experience will differ in different contexts, like if they are in a crisis. Understand that often, a user will be simultaneously juggling a dozen other things while using your product. Since time is the most valuable resource, do not waste the user's time. Consider how copy, imagery, and illustration can make assumptions about the user's story that can be harmful to someone experiencing a crisis (Bawcombe 2016).
6. Design for experiences that support digital crafting as a form of therapy and the essential archiving task of the bereaved. Be careful of features intended to remind or connect users to memories or people that could, in a different context, be harmful to the bereaved. Allow users to control when they want to visit their grief using technology.

Future Investigations

The design project uses a speculative approach that offers an alternative and preferable future. While technology and market forces may not be quite

there today to handle something as robust as the *Memory Keepsake* system, there is a path that can be followed from now to the not-so-distant future. For many, the process of organizing, editing, and archiving important digital memories and interactions after the death of a loved one can be a daunting task. To help people with this process, and introduce them to the *Memory Keepsake* system, a series of workshops could be organized. For some, digital crafting could be second nature, but for others, a guiding hand could be helpful. As I have shown, users are often grappling with many diverse types of data from a variety of sources and devices. There is also usually a desire to digitize important material items so they can be preserved in a more enduring way. The workshop series could offer a guided experience on gathering all this material into a manageable collection. People would be invited to bring their computers, smartphones, thumb drives, and any physical materials they want to document digitally. Since much of this data between the person and the deceased exists on the servers of Facebook, Google, Instagram, Twitter, and WhatsApp, facilitators would walk the attendees through the process of downloading their data from each platform. Once that data is removed from the SNSs and onto their hard drives, other data types can be gathered like pulling voicemails off phones or scanning and storing physical photos. After all the data the person would like to use at that time is gathered, they can upload their data to the *Memory Keepsake* service to start

crafting their collection. The *Memory Keepsake* software would provide a manageable way for participants to curate their collection in a way that is most meaningful to them. Additionally, the workshop could have prototype keepsake models available so users could interact with the physical object to see what form they would like to have their keepsake in. As for where these workshops could take place, partnerships would be formed with local grief support organizations so that they could take place at their facilities. These partnerships would be mutually beneficial for the organizations as digital crafting could be therapeutic for some bereaved individuals. These workshops would be appropriate for all levels of technical literacy and groups would be made according to level. Because of the variety of media types, sources, and roadblocks to downloading data, these workshops would benefit even the savviest tech user.

While preliminary feedback on this speculative project was positive and hopeful, more user testing needs to be done with prototypes of all the keepsake models. More customizability will need to be added into the Keepsake Customizer and testing will need to be done on how the user edits and interacts with various data types on the Keepsake Customizer page. Users will be uploading many varied sizes, resolutions, and file types so the system will need to have some guidance on what can be handled by the system well and what might not work. For example, what happens if a user uploads a photo with poor

resolution? Is the user given an error code and directed to upload a higher resolution image or does the system respect that the user will want this meaningful item in their collection whether it is blurry or not? In a physical analogy, if a photograph is damaged or torn, we might still hold on to it for its value as an object that represents the person we lost. The Keepsake Customizer will have to have extra functionality when cropping images, editing chats, and trimming audio and video. Obviously, there will be limits to what the system can handle, but at the very least users will expect to be able to adjust their items slightly for archiving in the keepsake. The *Memory Keepsake* system will also need to allow for more customization of the keepsakes themselves. For example, users may want to choose distinct colors, apply custom patterns, or inscribe their keepsake with a custom phrase. The number of participants in this study was also limited. It would be interesting to see what a larger sample size would reveal about the practices of the bereaved using digital media.

This thesis presents a growing body of literature and research that calls upon designers to practice TSD. Designers can view practical examples of designs that are not death sensitive as well as innovative TSD solutions that imagine new ways for bereaved users to interact with digital and physical materials. Additionally, the *Memory Keepsake* Project offers a speculative look into what future designs could look like that consider the important practice of digital

crafting for the bereaved. The recommendations for designers listed in the previous section will also help designers in the future to create innovative technologies that offer practical ways for users to practice this type of grief work and remembering.

APPENDIX SECTION

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Appendix A: Grieving in an Online World Survey Questions

Loss and Mental Health

Q1 What type of (death) loss have you experienced? (Check all that apply)

- Loss due to illness or disease
- Loss due to old age
- Pregnancy loss
- Loss due to crime
- Loss due to an accident
- Loss due to a disaster
- Loss due to suicide
- Loss due to overdose
- Other sudden or violent loss
- Other (Please identify loss)

Q2 Have you ever suffered, or do you currently suffer from any of the following disorders? (Choose all that apply)

- Major depressive disorder (MDD)
- Post-traumatic stress disorder (PTSD)
- Prolonged grief disorder (PGD)
- Complicated grief disorder (CGD)
- Anxiety disorders
- I do not suffer from any of the above disorders

Q3 How recent was your loss?

- 0 – 3 months
- 3 – 6 months
- 6 months – 1 year
- More than 1 year ago

Loss, Social Media, and Remembrance

Q1 Do you use or have you used social media in the past?

- Yes
- No

Display This Question:

If Do you use or have you used social media in the past? = Yes

Q2 What social media platforms do you use, or have you used in the past? (Select all that apply)

- Facebook
- Instagram
- Twitter
- LinkedIn
- Snapchat
- Pinterest
- Reddit
- Tumblr
- TikTok

Display This Question:

If Do you use or have you used social media in the past? = Yes

Q3 Have you ever experienced something on social media or another app that triggered or worsened your grief symptoms?

- Yes
- Maybe
- No

Display This Question:

If Have you ever experienced something on social media or another app that triggered or worsened you... = Yes or Maybe

Q4 What social media platform or app did you experience this on? (Check all that apply)

- Facebook
- Instagram
- Twitter
- LinkedIn
- Snapchat
- Pinterest
- Reddit
- Tumblr
- TikTok
- Other app or platform (please identify)

Display This Question:

If Have you ever experienced something on social media or another app that triggered or worsened you... = Yes or Maybe

Q5 If you answered yes to experiencing negative grief symptoms on social media or another app, you may provide more context here. (optional)

Q6 Regarding your loss, did your loved one use social media?

- Yes
- Not Sure
- No

Display This Question:

If Regarding your loss, did your loved one use social media? = Yes or Not Sure

Q13 Did you continue to visit your loved one's profile after the loss?

- Yes
- Maybe
- No

Q14 In what ways do you remember your loved one? (Select all that apply)

- Look at photos
- Listen to music
- Listen to audio recordings (including voicemail)
- Read letters or cards
- Visit their resting place
- Hold an object that was important to them
- Smell their perfume/cologne
- Visit their social media profile
- Go through previous interactions with them on social media
- Hold linens or clothing owned by them
- Write to them
- Journal
- Visit locations sentimental to them or both of you
- Tell stories about them
- Watch movies
- Read texts, emails, or other digital conversations
- Go to church or place of worship
- Other (please enter any other ways you practice remembering)

Future Research

Q9 If you are interested in being contacted by the principal investigator for future research, please type your email in the field below. By leaving your email, you are not consenting to take part in any future studies, you are simply expressing interest in being contacted for another study.

Appendix B: Grieving in an Online World Interview Questions

Retrospective

Q1 How long has it been since you lost your loved one?

Q2 How often do you think about him or her?

Q3 Do you feel as if they are with you?

Q4 What did they leave you?

Personal Reflection

The questions in this section cover how your own self-reflection has changed after your loss. The following three questions are open ended and are for you to answer however you want. There are no right answers.

Q1 Do you think about how your own legacy will live on?

Q2 What digital or physical things you think will come to represent you after your gone?

Q3 What kind of stories will these digital or physical things evoke?

Grief and User Experience

The questions in this section cover how social network sites and digital media affected your grief experience. The following three questions are open ended and are for you to answer however you want. There are no right answers.

Q1 After your loss, do you remember anything on social media that affected you while you were grieving? Think back to the instance where you saw this. Describe how it happened and any other details you feel are relevant.

Q2 Did this happen anywhere else online? How about while using your computer or smartphone?

Q3 After losing your loved one, did you ever see their name pop up on social media, as if they were still alive?

Using Digital Media to Connect with Lost Loved Ones

The questions in this section cover how social network sites and digital media affected your grief experience. The following seven questions are open ended and are for you to answer however you want. There are no right answers.

Q1 Describe your relationship with your loved one on social media. How about off of social media?

Q2 If your loved one's profile is on Facebook, is the profile now a legacy profile? How did the process of changing it go?

Q3 Are there other spaces your loved one occupied online that don't allow a "legacy" status that you wish did?

Q4 Do you still visit the profile(s) of your loved one after their death?

- Definitely yes
- Probably yes
- Might or might not
- Probably not
- Definitely not

Q5 How regularly do you visit your loved one's profile online? Are there times or days you do more often? The last time you visited their profile, what did you do?

Q6 Are there any other digital or physical items that you interact with that belonged to your loved one or remind you of them? How do you store or

manage these items for future remembrance? What devices do you use to interact with these items?

Q7 Do you practice keeping your loved one's story alive? If so, how?

Appendix C: Preliminary User Feedback

Table 1. Low Fidelity User Feedback

Key	Feedback Comment
	LANDING PAGE
1	The user is unsure of what the service offers. Would like to see a video or photo illustrating the keepsake.
2	Parts of these sentences feel too academic
3	User confused as to what the testimonial section is.
	DATA UPLOAD FLOW
4	User unclear that the ability to select multiple data sources is present
	KEEPSAKE CUSTOMIZER
5	Customizer screen is overwhelming at first glance. User expresses that they would like to have a “one-click button” that populates keepsake with their collection and then allows the user to add or remove the content contained in the keepsake.
6	User expresses it would be nice to view the keepsake and editor at the same time.
7	User expresses confusion about their being two different headers on side bar and modal. Not sure what each section does.
	CLOCK KEEPSAKE
8	Users felt confused whether this was a password with letters or numbers and did not understand how the keyboard icon at the bottom of the screen worked.

9	On entering the dashboard felt a bit overwhelmed at the amount of data on the screen. They expressed that there were too many things showing up at once and they did not understand if they could click on these items to view them larger.
10	On viewing the example Facebook chat, they did not know how to go back to the dashboard, or how to scroll through the content.
11	Much like the Keepsake Customizer, the users expressed that they would like a “one-click button” that they could press to view all the data they had in the keepsake like a slideshow.

Table 2. High Fidelity User Feedback

Key	Feedback Comment
	LANDING PAGE
1	User needs context for how large these objects are in relation to each other.
	DATA UPLOAD
1	User likes the security and privacy focus of the sensitive data
2	User asks what happens if you don't have access to the data? Asks if there is a way to just send in a profile instead of requesting data.
	KEEPSAKE CUSTOMIZER
2	User asks what happens if they upload a vertical photo?
3	User wants to know the size of the object in real life. Would like some information about size of keepsake.
4	User would like to see all keepsake options upfront instead of having to find them in the dropdown.
5	User would like to see less of the edit contents module and wants the object to automatically populate with content.
6	User expresses that they wish that the design was visually more sensitive. The adding of certain photos and media could be triggering.
	CLOCK KEEPSAKE
1	Generally, user wonders if this system would expand to include even more keepsakes.

REFERENCES

- American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- Apart, An Event. 2015. *Designing for Crisis by Eric Meyer — An Event Apart Video*. <https://vimeo.com/148927676>.
- Bassett, Debra. 2018. "Digital Afterlives: From Social Media Platforms to Thanabots and Beyond. (Forthcoming)." In.
- Bridge, Donna J., and Ken A. Paller. 2012. "Neural Correlates of Reactivation and Retrieval-Induced Distortion." *Journal of Neuroscience* 32 (35): 12144–51. <https://doi.org/10.1523/JNEUROSCI.1378-12.2012>.
- Bonanno, George A. 2004. "Loss, Trauma, and Human Resilience: Have We Underestimated the Human Capacity to Thrive After Extremely Aversive Events?" *American Psychologist* 59 (1): 20–28. <https://doi.org/10.1037/0003-066X.59.1.20>.
- Bowlby, John. 1961. "Separation Anxiety: A Critical Review of the Literature." *Child Psychology and Psychiatry*, 1. pp. 251-269
- Brubaker, Jed R, and Gillian R Hayes. n.d. "'We Will Never Forget You [Online]': An Empirical Investigation of Post-Mortem Myspace Comments," 10.
- Clark, David. 1993. *The Sociology of Death: Theory, Culture, Practice*. Blackwell Publishers/The Sociological Review. <http://libproxy.txstate.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cat00022a&AN=txi.b1365813&site=eds-live&scope=site>.
- Carroll, Evan, and John Romano. 2011. *Your Digital Afterlife: When Facebook, Flickr and Twitter Are Your Estate, What's Your Legacy?* New Riders. <http://libproxy.txstate.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cat00022a&AN=txi.b5118427&site=eds-live&scope=site>.

- Corr, Charles A. 2019. "Should We Incorporate the Work of Elisabeth Kübler-Ross in Our Current Teaching and Practice and, If So, How?" *OMEGA—Journal of Death and Dying*, July. <https://doi.org/10.1177/0030222819865397>.
- Cumiskey, Kathleen M., and Larissa Hjorth. 2019. "'I Wish They Could Have Answered Their Phones': Mobile Communication in Mass Shootings." *Death Studies* 43 (7): 414–25. <https://doi.org/10.1080/07481187.2018.1541940>.
- Czech, Elaine, Mina Shibasaki, and Keitaro Tsuchiya. 2019. "Haptic Remembrance Book Series." In *Extended Abstracts of the 2019 CHI Conference on Human Factors in Computing Systems*, 1–6. Glasgow Scotland UK: ACM. <https://doi.org/10.1145/3290607.3309685>.
- "Death and Taxes." 2019. Adam Smith Institute. Published November 13, 2019. <https://www.adamsmith.org/blog/death-and-taxes>.
- "Design Kit." n.d. Accessed May 25, 2021. <https://www.designkit.org/methods/frame-your-design-challenge>.
- "Dialogical Self." 2021. In *Wikipedia*. https://en.wikipedia.org/w/index.php?title=Dialogical_self&oldid=1022125644.
- Dunne, Anthony, and Fiona Raby. 2013. "Beyond Radical Design" in *Speculative Everything: Design, Fiction, and Social Dreaming*, 1–9. MIT Press, 2013. ProQuest eBook Central, <http://ebookcentral.proquest.com/lib/txstate/detail.action?docID=3339745>.
- Duschinsky, Robbie, Marinus Van Ijzendoorn, Sarah Foster, Sophie Reijman, and Francesca Lionetti. 2020. "Attachment Histories and Futures: Reply to Vicedo's 'Putting Attachment in Its Place.'" *European Journal of Developmental Psychology* 17 (1): 138–46. <https://doi.org/10.1080/17405629.2018.1502916>.
- Den Elzen, Katrin. 2021. "Therapeutic Writing through the Lens of the Grief Memoir and Dialogical Self Theory." *Journal of Constructivist Psychology* 34 (2): 218–30. <https://doi.org/10.1080/10720537.2020.1717136>.

- Field, Nigel P., Beryl Gao, and Lisa Paderna. 2005. "Continuing Bonds in Bereavement: An Attachment Theory Based Perspective." *Death Studies* 29 (4): 277–99. <https://doi.org/10.1080/07481180590923689>.
- Gibson, M. 2018. *Memorialization and Immortality: Religion, Community and the Internet. Popular Spiritualities: The Politics of Contemporary Enchantment*. Taylor and Francis.
<http://libproxy.txstate.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=edselc&AN=edselc.2-52.0-85083915458&site=eds-live&scope=site>.
- Giddens, Anthony. 1999. "Modernity and Self-Identity: Tribulations of the Self." In *The Discourse Reader*, edited by Adam Jaworski and Nikolas Coupland, 415–27. London, England: Routledge.
<http://libproxy.txstate.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=mlf&AN=1999077698&site=eds-live&scope=site>.
- Gilbert, Sandra M. 2006. *Death's Door: Modern Dying and the Ways We Grieve*. First edition. W.W. Norton & Co.
<http://libproxy.txstate.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cat00022a&AN=txi.b1641491&site=eds-live&scope=site>.
- Gray, Selina Ellis, and Paul Coulton. 2013. Living with the Dead: Emergent Post-mortem Digital Curation and Creation Practices. In Maciel, Cristiano, and Vinícius Carvalho Pereira (Eds.), *Digital Legacy and Interaction: Post-Mortem Issues*. Human–Computer Interaction Series. (pp. 31–48). Cham: Springer International Publishing. <https://doi.org/10.1007/978-3-319-01631-3>.
- Granek, Leeat. 2010. "Grief as Pathology: The Evolution of Grief Theory in Psychology from Freud to the Present." *History of Psychology* 13 (1): 46–73. <https://doi.org/10.1037/a0016991>.
- Grau, Oliver, Janina Hoth and Eveline Wandl-Vogt (Eds.), *Digital Art through the Looking Glass: New strategies for archiving, collecting and preserving in digital humanities*. Austrian National Library.
<https://mediarep.org/handle/doc/14282>

- "HCI at End of Life & Beyond." 2020. Enabling Ongoingness. Accessed June 30, 2020. <https://enablingongoingness.com/CHI2020>.
- Hallnäs, Lars, and Johan Redström. 2001. "Slow Technology – Designing for Reflection." *Personal and Ubiquitous Computing* 5 (3): 201–12. <https://doi.org/10.1007/PL00000019>.
- Hardy, Quentin. 2013. "Technology Workers Are Young (Really Young)." *Bits Blog* (blog). July 5, 2013. <https://bits.blogs.nytimes.com/2013/07/05/technology-workers-are-young-really-young/>.
- Hashim, Syahnaz Mohd, Tan Chai Eng, Noorlaili Tohit, and Suzaily Wahab. 2013. "Bereavement in the Elderly: The Role of Primary Care." *Mental Health in Family Medicine* 10 (3): 159–62.
- "Kanban Board." 2021. In Wikipedia. https://en.wikipedia.org/w/index.php?title=Kanban_board&oldid=1013562770.
- Kasket, Elaine. 2012. "Continuing Bonds in the Age of Social Networking: Facebook as a Modern-Day Medium." *Bereavement Care* 31 (2): 62–69. <https://doi.org/10.1080/02682621.2012.710493>.
- Kimbell, Lucy. 2009. "Beyond Design Thinking: Design-as-Practice and Designs-in-Practice." Paper presented at the *CRESC Conference*, Manchester, September 2009. http://www.lucykimbell.com/stuff/CRESC_Kimbell_v3.pdf
- Kristensen, Pål, Lars Weisæth, and Trond Heir. 2012. "Bereavement and Mental Health after Sudden and Violent Losses: A Review." *Psychiatry: Interpersonal and Biological Processes* 75 (1): 76–97. <https://doi.org/10.1521/psyc.2012.75.1.76>.
- Kübler-Ross, Elisabeth. 1969. *On Death and Dying*. Macmillan.
- Labott, Susan M., Timothy P. Johnson, Michael Fendrich, and Norah C. Feeny. 2013. "Emotional Risks to Respondents in Survey Research: Some Empirical Evidence." *Journal of Empirical Research on Human Research Ethics: JERHRE* 8 (4): 53–66. <https://doi.org/10.1525/jer.2013.8.4.53>.

- Lindemann, Erich. 1944. Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141–148.
- “Medical Definition of Thanatology.” n.d. MedicineNet. Accessed July 3, 2021. <https://www.medicinenet.com/thanatology/definition.htm>.
- Maciel, Cristiano, and Vinícius Carvalho Pereira, eds. 2013. *Digital Legacy and Interaction*. Human–Computer Interaction Series. Cham: Springer International Publishing. <https://doi.org/10.1007/978-3-319-01631-3>.
- Massimi, Michael, and Andrea Charise. 2009. “Dying, Death, and Mortality: Towards Thanatosensitivity in HCI.” In *Proceedings of the 27th International Conference Extended Abstracts on Human Factors in Computing Systems - CHI EA '09*, 2459. Boston, MA, USA: ACM Press. <https://doi.org/10.1145/1520340.1520349>.
- Massimi, Michael, and Daniela K. Rosner. 2013. “Crafting for Major Life Events: Implications for Technology Design and Use.” <https://doi.org/10.14236/ewic/HCI2013.43>.
- “Median Age of the Labor Force, by Sex, Race, and Ethnicity: U.S. Bureau of Labor Statistics.” n.d. Accessed August 25, 2020. <https://www.bls.gov/emp/tables/median-age-labor-force.htm>.
- Meyer, Eric, and Sara Wachter-Boettcher. 2016. *Design for Real Life*. Jeffrey Zeldman.
- Microsoft. 2018. “Kanban basics.” Accessed July 4, 2021. <https://docs.microsoft.com/en-us/azure/devops/boards/boards/kanban-basics>.
- Mitford, Jessica. 1964. *The American Way of Death*. First Fawcett Crest edition. Fawcett Crest.
- Neimeyer, Robert A. 2001. *Meaning Reconstruction & the Experience of Loss*. 1st ed. American Psychological Association. <http://libproxy.txstate.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cat00022a&AN=txi.b5295476&site=eds-live&scope=site>.

- Neimeyer, Robert A., and Barbara Thompson. 2014. "Meaning Making and the Art of Grief Therapy." In Thompson & R. A. Neimeyer (Eds.), *Series in death, dying, and bereavement. Grief and the expressive arts: Practices for creating meaning* (p. 3–13). Routledge/Taylor & Francis Group.
- Norman, Don. n.d. "Why Design Education Must Change." Core77. Accessed February 14, 2021. <https://www.core77.com/posts/17993/Why-Design-Education-Must-Change>.
- Northwestern University. "Your memory is like the telephone game, altered with each retelling." ScienceDaily.
www.sciencedaily.com/releases/2012/09/120919125736.html.
- Guy Oakes. 1977. "The Verstehen Thesis and the Foundations of Max Weber's Methodology." *History and Theory* 16 (1): 11–29.
<https://doi.org/10.2307/2504575>.
- Odom, William, Richard Harper, Abigail Sellen, David Kirk, and Richard Banks. 2010. "Passing on & Putting to Rest: Understanding Bereavement in the Context of Interactive Technologies." In *Proceedings of the 28th International Conference on Human Factors in Computing Systems - CHI '10*, 1831. Atlanta, Georgia, USA: ACM Press. <https://doi.org/10.1145/1753326.1753601>.
- Odom, William, Richard Banks, Abigail Durrant, David Kirk, and James Pierce. 2012. "Slow Technology: Critical Reflection and Future Directions." In *Proceedings of the Designing Interactive Systems Conference on - DIS '12*, 816. Newcastle Upon Tyne, United Kingdom: ACM Press.
<https://doi.org/10.1145/2317956.2318088>.
- Reddit. u/[deleted]. 2011. "My Friend Just Died. I Don't Know What to Do. - r/Assistance."
https://libredd.it/r/Assistance/comments/hax0t/my_friend_just_died_i_do_not_know_what_to_do/.
- "Reddit." n.d. Reddit. Accessed April 24, 2021. <https://www.reddit.com/>.
- Rees, Dewi. 2001. *Death and Bereavement: The Psychological, Religious, and Cultural Interfaces*. Vol. 2nd ed. London: John Wiley and Sons, Inc.
<http://libproxy.txstate.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=nlebk&AN=100220&site=eds-live&scope=site>.

- Rittel, Horst W. J., and Melvin M. Webber. 1973. "Dilemmas in a General Theory of Planning." *Policy Sciences* 4 (2): 155–69.
- Roberts, Pamela, and Lourdes A. Vidal. 2000. "Perpetual Care in Cyberspace: A Portrait of Memorials on the Web." *OMEGA: Journal of Death and Dying* 40 (4): 521–45. <https://doi.org/10.2190/3BPT-UYJR-192R-U969>.
- Rosales, Andrea, and Jakob Svensson. 2021. "Perceptions of Age in Contemporary Tech." *Nordicom Review* 42 (1): 79–91. <https://doi.org/10.2478/nor-2021-0021>.
- Schauss, Alexander G. 1979. "Tranquilizing Effect of Color Reduces Aggressive Behavior and Potential Violence," 14.
- Sidaway, James D., and Avril Maddrell. 2010. *Deathscapes: Spaces for Death, Dying, Mourning and Remembrance*. Farnham, Surrey, England: Routledge.
- Sierra, Kathy. 2015. *Badass: Making Users Awesome*. First edition. O'Reilly Media. <http://libproxy.txstate.edu/login?url=https://search.ebscohost.com/login.aspx?direct=true&db=cat00022a&AN=txi.b5146740&site=eds-live&scope=site>.
- Stroebe, Margaret, and Henk Schut. 1999. "The Dual Process Model of Coping with Bereavement: Rationale and Description." *Death Studies* 23 (3): 197–224. <https://doi.org/10.1080/074811899201046>.
- Pitsillides, Stacey. 2019. "Digital Legacy: Designing with Things." *Death Studies* 43 (7): 426–34. <https://doi.org/10.1080/07481187.2018.1541939>.
- Plummer, Ken. 2021. *A World in the Making: Symbolic Interactionism in the Twentieth Century. A Companion to Social Theory*. 2nd ed. Blackwell.
- Prigerson, Holly G, Mardi J Horowitz, Selby C Jacobs, Colin M Parkes, Mihaela Aslan, Karl Goodkin, Beverley Raphael, et al. 2009. "Prolonged Grief Disorder: Psychometric Validation of Criteria Proposed for DSM-V and ICD-11." *PLoS Medicine* 6 (8): e1000121. <https://doi.org/10.1371/journal.pmed.1000121>.

- Wallace, Jayne, Will Odom, Kyle Montague, Nantia Koulidou, Corina Sas, Kellie Morrissey, and Patrick Olivier. 2020. "HCI at End of Life & Beyond." In *Extended Abstracts of the 2020 CHI Conference on Human Factors in Computing Systems*, 1–8. Honolulu HI USA: ACM.
<https://doi.org/10.1145/3334480.3375143>.
- Walter, Tony. 1999. *On Bereavement: The Culture of Grief*. McGraw-Hill Education (UK).
- Walter, Tony. 2012. "Why Different Countries Manage Death Differently: A Comparative Analysis of Modern Urban Societies." *The British Journal of Sociology* 63 (1): 123–45. <https://doi.org/10.1111/j.1468-4446.2011.01396.x>.
- Walter, Tony, Rachid Hourizi, Wendy Moncur, and Stacey Pitsillides. 2012. "Does the Internet Change How We Die and Mourn? Overview and Analysis." *OMEGA - Journal of Death and Dying* 64 (4): 275–302.
<https://doi.org/10.2190/OM.64.4.a>.
- Wayment, Heidi A., and Jennifer Vierthaler. 2002. "ATTACHMENT STYLE AND BEREAVEMENT REACTIONS." *Journal of Loss and Trauma* 7 (2): 129–49.
<https://doi.org/10.1080/153250202753472291>.
- Willmott, Hugh. 2000. "Death. So What? Sociology, Sequestration and Emancipation." *Mort. Et Après? Sociologie, Séquestration et Émancipation* 48 (4): 649–65.
- Worden, J. William. 2009. *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*. Fourth edition. New York, NY: Springer Pub. Co.
- Telier, A., Thomas Binder, Giorgio De Michelis, Pelle Ehn, Giulio Jacucci, Per Linde, and Ina Wagner. 2011. "Design Things." In *Design Things*, 1–8. The MIT Press.