Thanatosensitively Designed Technologies for Bereavement Support

by

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Abstract

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Increasingly, technology impacts how we communicate and behave following the death of a loved one. However, little is known about technology use by the bereaved. This thesis contributes to understanding this phenomenon through three linked studies. These studies establish an appreciation of how technology engages with human mortality, and proposes "thanatosensitive design" (TSD) as an approach for developing such systems.

An exploratory study first examines technology use by the bereaved through a survey with follow-up interviews. Findings show that systems for inheriting data and devices are lacking, despite widespread use of technology for remembrance and communication. Using digital assets in social support is selected as a domain for further inquiry.

The second study consists of focus groups with bereaved parents at two community organizations complemented by the perspectives of professional bereavement workers. Based on this fieldwork, 6 considerations concerning interpersonal communication, new ways of being, and materiality are presented. These considerations suggest that systems should permit connections with peers, support storytelling activities, and avoid tendencies to "fix" grief, among others.

In the final study, I present Besupp - a website that permits bereaved users to engage in online peer-support groups. Besupp applied these design considerations and was deployed in a 10-week study. Nineteen bereaved individuals met in 3 support groups for bereaved parents, partners/spouses, and young adults. Based on system logs/data,

questionnaires, and interviews, the study identified barriers to using digital mementos, preferences for online support systems, and issues concerning timing of use.

In the discussion, I reflect on the three studies through four thematic lenses: temporality, materiality, identity, and research ethics/methods. I remark on how systems should consider the varying emotional needs of the bereaved over time. In the conclusion, I summarize and reflect on the status of TSD and identify areas for future work concerning social support for the bereaved, and computing's role at the end of life more broadly.

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Chapter 1

Introduction

The rise of personal computing, mobile phones, and the Internet has changed a variety of practices across the human lifespan. As more and more people communicate, work, and play on personal devices, we are witnessing for the first time situations where such devices are involved at the end of a human life. Death, like many other parts of our lives, is becoming increasingly digital. Human-computer interaction (HCI) has traditionally studied the evolving needs associated with the human lifespan according to a developmental perspective borrowed from psychology that is largely segmented by the age of the individual [73]. Communities of researchers have examined HCI issues by working with children, teenagers, normally-aging adults, and older adults. This approach has been productive and has highlighted the shifting priorities and abilities of user groups. Ultimately, the goal of such work is to make interactive systems useful, usable, and supportive throughout the human lifespan.

At the same time, as an individual ages and shifts among these various stakeholder groups, defining events such as births, graduations, marriages, and deaths occur. These defining events are not so tightly knit to psychological or physiological development; they can occur at a range of ages or stages. These events are profound and warrant the same sort of attention given over to stakeholder groups derived from a developmental

perspective. Each of these events brings about great change in an individual's social, professional, and personal life.

Among these life events, HCI researchers are now beginning to address the unique needs of the bereaved. This thesis considers the bereaved as a stakeholder group comprised of family members and friends of a deceased individual that are coping with the loss in all of its forms. In other words, bereavement is not simply the experiencing of grief (although this is a key part of it). Bereavement can include many different activities: taking on new roles, learning how to engage with outsiders, managing the deceased's assets, creating and organizing mementos, finding support, and so on. This thesis argues that these needs, among others that the bereaved encounter, are viable and valuable sites for technological intervention and support.

As a first step towards exploring this space, the overarching goal of this thesis is to understand how to develop systems that address bereavement in a sensitive manner. Such concerns are rarely considered in traditional user-centred design approaches, and the exploratory studies in this thesis fall under a design approach I term "thanatosensitive design" (TSD)[1]. TSD is relevant to design and research projects where end of life issues are significant.

1.1 Research Questions and Contributions

The overarching research question in this thesis asks "How do we design technologies that meet the unique needs of the bereaved?" I begin to address this question in three phases. Each phase, beginning from conceptual design and following through to software design and deployment, asks these questions in service of the above:

- Phase 1 (Chapter 3): What are possible design spaces where technology could meet

[1] *Thanatos* is the ancient Greek god of death, and thanatology - the study of death - also bears this moniker.

the needs of the bereaved?

- Phase 2 (Chapter 4): What considerations might be important when designing interactive systems for the bereaved?

- Phase 3 (Chapter 5): What are the challenges and outcomes associated with applying these considerations in a user-centred design process?

To embark upon this exploration, a survey and interview study was first conducted (Phase 1/Chapter 3). The purpose of this study was to identify quite broadly the various ways that the bereaved encounter technology following a death. The study examined technology's role along three themes: remembrance, data inheritance, and attitudes towards one's own death. In these categories, I found that technology suffused many of the practices associated with bereavement, including arranging the funeral, communicating the news, expressing grief, and creating an environment of support. Appropriation of existing technologies was common, but at the same time, technology routinely complicated the "doing" of bereavement. Based on the results of the 41 survey responses and 10 follow-up interviews, I identified 10 areas for technology research and design. These issues address the technical and social difficulties associated with inheriting data from digital devices, and how growing adoption of technology intensifies these situations as computers are involved in remembrance and communication activities. Each of these 10 areas represents an opportunity for future work, and together they begin to map some of the ways that designers could potentially support the bereaved. In this study, I find that the bereaved appropriate existing technologies to create mementos and exchange social support based on these mementos. Given the availability of technology to address this area, and past successes of HCI research in online social support, I choose this topic to explore further.

Receiving and providing social support is a prominent concern following a death. To obtain a better understanding of this problem and to generate sensible design options,

deeper user research concerning technology use and social support was conducted in order to complement existing psychological and sociological findings (Phase 2/Chapter 4). To this end, fieldwork with 24 bereaved parents was carried out in a series of 3 focus groups and observational site visits. Informal interviews with professionals from a variety of disciplines were also performed in the context of a five-day workshop on death, dying, and bereavement. Based on analysis of the interview transcripts and reflection on data collected during this fieldwork, a set of design considerations are developed. These design considerations address interpersonal communication during bereavement, how the bereaved adjust to their loss, and the role of mementos in this process. These considerations seek to create a bridge from fieldwork to design by drawing attention to key aspects of bereavement as they relate to technology.

In the final stage of the thesis, these considerations were applied in the user-centred design of a prototype website called Besupp (Phase 3/Chapter 5). Developed in conjunction with a community group called Bereaved Families of Ontario (BFO), Besupp provides a setting for bereaved individuals to conduct online support groups and store mementos associated with the loss. They can then share these with other members of a support group and engage in conversation with one another. Three support groups were formed with 19 participants from BFO's registry: bereaved parents, bereaved partners/spouses, and young adults who have lost a parent or sibling. All 3 groups employed Besupp for a period of 10 weeks in a deployment study. The goal of this study is to identify the challenges and outcomes associated with implementing the design considerations presented in Phase 2. The results of this study are used to refine and elaborate upon the design considerations, and offer additional insights into designing for the bereaved.

In sum, the thesis is constituted of a set of three exploratory studies, which are among the earliest work addressing this topic in HCI. The study from Phase 1 contributes one of the first characterizations of how the bereaved encounter technologies such as personal computers, social networking sites, and mobile phones, and suggests opportunities for

the HCI community to understand and address emerging needs. The second study in Phase 2 then provides technology designers and researchers with a set of resources for inspiration and consideration in working with the bereaved. This study brings together the perspectives of both professionals and the bereaved themselves, and in so doing, provides an introduction to sensitively engaging with this stakeholder group. The final study in Phase 3 contributes a grounded account of applying design considerations to meet the bereaved's social support needs, and identifies the challenges and benefits of technology when applied in this domain. Taken together, this thesis contributes to HCI and computer science by establishing and exploring the process of designing technologies that sensitively engage with bereavement and the end of life more generally.

1.2 Thesis Organization

This thesis is organized as follows. Chapter 2 provides the relevant literature for all studies in the thesis, and identifies a lack of existing knowledge regarding the use of personal technologies by the bereaved, particularly from a technology design perspective. Chapter 3 (Phase 1) presents a web survey and interview study which addresses this issue, and concludes with a set design opportunities for technologists interested in supporting the bereaved. Chapter 4 (Phase 2) describes focus groups, professional education, and fieldwork activities that yield a set of design considerations. In Chapter 5 (Phase 3), I describe how these considerations played a role in the user-centred design of a prototype website called Besupp. Besupp is deployed in an exploratory study to trace the design choices and how they impacted usage patterns and user reactions. Chapter 6 reflects on the three studies as a whole along four themes: materiality, temporality, identity, and research ethics. This discussion raises emergent issues around key concepts in technology design and use around the end of life. Finally, Chapter 7 concludes with a reflection on thanatosensitive design before identifying plausible future work and major lessons

learned.

1.2.1 Publications and Prior Work

Portions of this thesis have been published previously at academic conferences.

- Initial conceptualizations of "thanatosensitivity" and "thanatosensitive design" were presented in an alt.chi paper co-authored with Andrea Charise at CHI 2009 [71].
- Phase 1, described in Chapter 3, was published at CHI 2010, where it received a best paper nomination (top 5% of submissions) [67].
- Phase 2, described in Chapter 4, was published at CHI 2011 [68]. Portions of the fieldwork described in Chapter 4 are discussed as a part of a paper co-authored with Jill Dimond and Christopher Le Dantec that will be published at CSCW 2012 [72].
- The discussion presented in Chapter 6 follows a framing presented in a paper co-authored with William Odom, David Kirk, and Richard Banks and presented at CHI 2011 [73], and based on discussions from a workshop we organized at CHI 2010 [74].

Chapter 2

Related Work

To design and evaluate new technologies for the bereaved, a wide range of insights can be gathered from several different fields. Thanatology, the multidisciplinary study of dying and death, is heavily informed by the humanities, social sciences, biology and medicine, and many other disciplines [7]. In this chapter, I first present some historical and contemporary perspectives on bereavement, beginning with sociological characterizations of Western society's handling of death, and then move to prominent topics in the psychology of bereavement. With this context in place, I review the construct of social support in abstract terms before focusing on how it affects grief and bereavement specifically.

Following this review, I provide an overview of technology's current and potential role during bereavement. I first focus on the use of the Internet for social support, and relate recent efforts in HCI that have engaged with various topics concerning death. I note how there is a relative paucity of research on how the bereaved appropriate or adopt personal technologies, and use this to motivate the exploratory research presented in Chapter 3. Similarly, the lack of resources available for designers seeking to engage with the bereaved as a stakeholder group motivates my fieldwork presented in Chapter 4. Current HCI efforts investigating remembrance and online support are presented as they relate to the deployment study presented in Chapter 5.

2.1 Perspectives on Bereavement

Mortality is a concept that suffuses all parts of human behaviour, from cultural practices to individual reactions. Witnessing the death of a member of one's community is a universal experience. As such, there are countless ways in which human beings conceptualize and make sense of death throughout the world. Cultural and religious norms govern many activities and norms at the highest social levels, and provide a starting frame of reference for design work in this space. At the same time, the embodied experience of grief varies widely from person to person. Subjectively, the experience of one individual embedded in a given religious/cultural context will differ from the experience of other individuals, even if both are in similar contexts. To achieve a more complete sense of the experience of bereavement – and its implications for technology design – we must examine the phenomenon from both sociological and psychological perspectives.

The perspectives described in this thesis are rooted in Western, Judeo-Christian cultures. Study participants were from North America in Phase 1, and from Ontario, Canada in Phases 2 and 3. Non-Western cultures are likely to demonstrate different attitudes and behaviours concerning death, bereavement, social support, and technology; the results of this thesis should not be interpreted to represent these cultures as well. Reasons for working in a Western Judeo-Christian culture included the familiarity of the researcher with these cultural perspectives, and the ability to collect data from participants in the English language. To this end, this Related Work chapter only addresses Western perspectives.

2.1.1 Sociological Perspectives

Sociologists interested in this topic concern themselves with how groups of people - from the family unit to entire cultures - organize themselves in their orientations towards death. While every death has its own unique circumstances and rituals, Walter [114]

	Traditional	**Modern**	**Post-modern**
Authority	Tradition	Professional expertise	Personal choice
Authority figure	Priest	Doctor	The self
Dominant discourse	Theology	Medicine	Psychology
Coping	Prayer	Silence	Expressing feelings
The Traveller	The Soul	Body	Personality
Bodily context	Living with death	Death-controlled	Living with dying
Social context	Community	Hospital	Family

Table 2.1: Evolving paradigms of death in Western culture (reproduced from Walter, 2004) [115].

compares three dominant ways in which death is handled in broad social terms (Table 2.1). He suggests that in "simpler" traditional societies (e.g., small, pre-industrial agrarian) the church governed the death of individuals through theologically-grounded ritual. Because these homogenous communities shared a common theology and group identity, each individual death was a highly visible and disruptive perturbation to the daily community routine [46]. Following industrialization and urbanization, oversight of dying and death shifted from the church to medicine. The body, and its pathologies, were seen to be active components in determinations of death, with medicine actively "fighting off" death. This stands in contrast to a religious characterization where death is a solemn but meaningful part of life because it functions as a passageway to an afterlife or salvation.

In the modern schema, dying became "medicalized" and took place predominantly in hospitals, "sequestered" away from the routines of daily living. Even within the hospital, staff may actively hide the death of one patient from other patients to avoid panic [107]. Further, the rise of the city brought together heterogeneous ethnic and religious groups, with varying rituals and attitudes towards death. Because of this urban

diversity, a singular community reaction to the death of one of its members was no longer possible; instead, subgroups maintained their own customs but enacted them in the new urban context. Respect for diverse customs and the movement of dying people to the hospital marked an era during which death was considered an unspeakable topic. Indeed, computing as a discipline was developed at a time, historically, when the death taboo was quite strong. While in more recent years the Western attitude system towards death has become more open to exploration and meaning-making, the death-denying culture in which early computer system designers operated may be partially culpable for the lack of current mechanisms for handling human death in many computing environments. This tradition remains strong in the design of personal devices today, which rarely include use cases for elegantly handling the death of the user.

Some of the earliest and most influential work in the area of dying and death has come from qualitative studies occurring in hospitals. Glaser and Strauss first published their work regarding awareness of death in hospitals, and explored more specifically how the news of a terminal illness or impending death was expressed by the hospital staff and family with respect to the patient [40]. They essentially argue that families and medical personnel should not withhold this kind of information from patients, and classify varying levels of awareness expressed by patients with regards to their own status. Sudnow provides a somewhat similar ethnography which not only provides substantial insight into the hospital-based practices surrounding death, but actually follows family members home from the hospital in order to understand the social repercussions of the death [107]. He bases his findings and analysis on ethnographic observations conducted in a low-income charity hospital in the Western United States and a high-income private hospital in the Midwest. While most of his work is devoted to issues local to the hospital (such as how workers manage the occurrence of death, break news to one another, and integrate the family into the medical environment), he also takes advantage of opportunities to follow families home after the death of a loved one to understand how the bereaved

break the news.

Sudnow discusses how news of the death is spread, and characterizes the social structure of the family and community as a series of concentric circles [107]. The immediate family occupies the center, and members must be informed personally and rapidly, with notification in person the most appropriate method, or failing that, the telephone. He notes that it is inappropriate to use impersonal or slow forms of communication (such as postal mail or telegraph wire) when breaking the news to the immediate family, but that these are perfectly suitable forms of communication for extended family and friends. Of particular note is the need for sensitive timing for discussion of the death. Further, he notes how individuals further away from the centre of the circle must time their condolences so as not to impose upon a "family affair," and that news spreads through intermediate "organizers" who notify those further away from the family of the proper timing for offering condolences. Family members further organize plans for disseminating the news, with multiple members calling family and friends in a particular and coordinated order. This organization occurs along lines of perceived closeness to the deceased (e.g., notifying the deceased's spouse first, then parents, children, and siblings later, with cousins or uncles and aunts being notified afterwards). He describes how people close to the deceased will claim "quasibereavement" status by making statements such as "he was like a brother to me." These statements seek to incur upon the individual the right to receive sympathy or condolences, while obligating them in some way to participate in funerary activities.

While the familial structure has certainly changed since this work occurred in the 1960s, social distance remains pertinent for communicating surrounding a death. Exactly who constitutes a bereaved person following a death is not well-defined. Rather, a death results in a set of people with varying levels of bereavement. As Sudnow notes, "[m]erely 'finding out' is not sufficient, for in not being specifically informed by the right party, or in finding out only incidentally, persons have...a way of seeing that what they took

to be their own ranking in the unit is obviously not so regarded" [107]. A death in the family results in, he argues, the re-expression and organization of the familial and social structure. This conceptualization raises questions about contemporary methods of notifying the deceased's social network. Broadcasting the news on Facebook, for example, can flatten this distinction and result in an individual learning about a death in impersonal way. Indeed, this concept of personhood and personality becomes quite important.

Although computing came about at a time when death denial was strong, contemporary thanatologists remain optimistic and suggest that "psychoanalysis and science...might succeed in making the immortal 'personality' more intelligible and restore the balance between death denial and death acceptance in the West" [103]. To return to Walter, Western culture is seeing a shift to a post-modern handling of death [114]. Depictions of death, and reactions to it, are increasingly mediated by mass communication (e.g., television, the Internet) and serving to create generic narratives of how individuals die, and how people should react to these deaths. These modern media make images of death much more common - from news headlines to televised entertainment. Rejecting this commoditization along with religious and medical authority, members of post-modern cultures seek to ensure their deaths reflect their personalities and individuality, with communication and expression between family members serving as the primary mechanism for comfort and making meaning. Of particular importance here is the family as the dominant social unit, and the newfound emphasis on communication about the death as a coping mechanism.

Bartalos argues that for the Western world, and in particular the United States, the events of September 11, 2001, have brought mortality and speaking of death to the foreground of the cultural consciousness [9]. This comes after a long period where talking about mortality, dying, and death has been considered taboo or inappropriate. Staudt notes that "concealment and disregard, forms of implicit denial, were the prevailing

attitudes to death in Western societies for most of the twentieth century, reaching a culmination in mid-century" [103]. As a result, each death is received as a surprise because "the inability to overcome death is seen as a failure, making repression, isolation, and denial normative responses" [ibid.]. Bartalos suggests that in the early 21st century, the dominant discourse will acknowledge death as a valuable topic for discussion and elaboration. This reversal of the death taboo mirrors a historical period where computing is more pervasive than ever, and it stands to reason that people will apply these technologies to end of life issues in unprecedented ways. Under this new schema, technology-enabled media has been posited by some to even act as a replacement for religion in making sense of death [115]. These cultural and societal trends motivate the need for a stronger consideration of mortality, dying, and death in the creation and application of technology in the years to come.

Materiality, Objects and Meaning

Sociologists are primarily concerned with the interpersonal phenomena surrounding death, and have described these phenomena through embedded observation of groups of people. Another way of understanding these phenomena which has direct bearing on the design of digital devices is through a critical analysis of the physical artifacts employed before, during, and after a death. Tombstones, personal possessions, relics, gifts, and other objects persist far beyond the death of the individual. Hallam and Hockey describe how cultures create special spaces for acknowledging death (e.g., graveyards), and use the body of the deceased as the most meaningful type of object through which to remember the individual [42]. They describe how in some parts of the world, locks of hair would be carried by mourners as a token of the individual. Even artifacts held close to the body (such as jewelry) were considered to be more important than artifacts held at length. Further, they describe the privileging of the visual over the other senses, and argue that we understand that a person has died primarily through how they look and feel. Even

in more recent times, bereavement is expressed through items such as sympathy cards, condolence letters, or candles [79]. These types of objects allow for the living to connect to the dead and to other bereaved people by allowing for some action to be taken. These items can be held, read, written, or lit - these types of actions are ways of communicating an individual's mental or emotional state to others without words. In this vein of research it stands to reason that digital assets and mementos may become similarly important, and valuable tools during bereavement for accepting the death and reminiscing about the deceased.

2.1.2 Psychological Perspectives

Psychological understandings of death strongly inform the work presented here through their conceptual elaborations and methodological traditions. Much of the work presented here examines an individual's reaction to a death, rather than prevailing cultural attitudes. Additionally, clinical psychology becomes relevant in characterizing grief reactions. Psychology also offers some perspectives on interventions for coping with grief, such as support groups or therapy.

An item of importance when discussing psychological findings is that of terminology. While there remains considerable confusion in the literature regarding the interchangeability of terms, it is useful to present a working definition for each in this document. The term "bereaved" generally applies to individuals who experience the death of a loved one, although as described above, there are varying intensities and forms of bereavement based on the relationship between the deceased and the living. One working definition put forth by Stroebe, Hansson, Schut, and Stroebe states:

> "*Bereavement* is the term used to denote the objective situation of having lost someone significant through death. This naturally leads to the question of how to define *someone significant*. The category is generally taken to include personal losses experienced across the life span: the deaths of parents, siblings,

> partners, friends, and – against the expectations of parents – one's own child. Bereavement is associated with intense distress for most people. This is one of the main reasons for the burgeoning body of research on the topics; a major concern is to understand and try to relieve the suffering of bereaved people" (italics in original, [106], p. 5).

They go on to define grief primarily as the "primarily emotional (affective) reaction to the loss of a loved one through death" ([106], p. 5). As Parkes describes it, "[w]hen a love tie is severed, a reaction, emotional and behavioural, is set in train which we call grief" [89]. Of note here between these two definitions is that in the latter, grief may occur due to death, but it may also occur due to other types of profound loss (e.g., divorce, loss of child custody). In this work, we refer to grief as it relates primarily to death and bereavement.

Mourning, on the other hand, refers to "the public display of grief, the social expressions or acts expressive of grief that are shaped by the (often religious) beliefs and practices of a given society or cultural group" ([106], p. 5). In other words, mourning requires the presence or influence of other people, and may also refer to the outward ways that an individual adapts his or her life to the loss [36]. The studies described herein examine both how technology impacts grief, and how it impacts aspects of mourning.

Another benefit of turning to psychology is how it informs us of the wide range of ways in which people experience grief. While an exhaustive examination of the ways in which grief manifests is beyond the scope of this document, a summary of recent research directions collected by Worden illustrates the complexity of this topic [119]. One relatively new area of research is that of disenfranchised grief: a reaction experienced when an individual loses a loved one that they are not culturally sanctioned to love, such as a mistress [27]. Another important emergent area is the examination, treatment, and conceptualization of trauma as it relates to grief, as may occur in violent deaths [33]. While this heterogeneity in grieving styles may initially appear to complicate or invalidate

any proposed technological interventions, the underlying experience of loss remains a rich site for exploration. Further, the difference in usage of new technologies by individuals experiencing different kinds of grief is not well understood (e.g., the differential use of the Internet for traumatic losses versus non-traumatic). The focus of this research remains on the bereaved as individuals who may be experiencing various severities and kinds of grief, and mourning in their own unique ways.

Finally, psychology provides perspectives on aspects of inquiry into this space. Kastenbaum, in an elaborate review of the state of psychology concerning death, notes that self-reports can be difficult to elicit, and traces this perspective back to Freud's initial assertion that human mortality cannot be adequately measured [48]. Despite this difficulty, Kastenbaum also reviews the developmental psychology of death from infancy to adulthood, and highlights numerous areas for further exploration from this perspective.

Grief and Time

Freud described "cathexsis" as the libidic life-energy possessed by all people [36]. He argued that over time, an individual invested this cathexis in relationships with others. Following a death, however, Freud saw that his patients found a need to withdraw this energy from the lost relationship - an idea he termed "anticathexsis." Only after reclaiming this energy from the relationship with the deceased could the patient reinvest that energy in new life-affirming relationships or activities.

While Freud's interpretation does not represent current psychological understandings of grief, this idea of the individual "working" to overcome the grief persists. We hear about people "working through their grief" as if the grieving process is simply a matter of moving through stages or completing a checklist of tasks. However, this "grief work" hypothesis has been found to be equivocal at best; that is, individuals do not need to perform specific activities or mental exercises in order to move through their grief [105]. Even so some people may find performing certain activities to be meaningful ways of

expressing their grief or memorializing their loved ones, and there is likely an opportunity for technology to contribute to such activities.

While grief is a natural reaction to a loss, there does not appear to be an associated natural recovery process. Rather, grief is an ongoing phenomenon that generally subsides over time. The exact timing of grief, however, has been the topic of much discussion. So-called "stage theories" of grief can be traced to the book *On Death and Dying* by Elizabeth Kübler-Ross [55]. A psychiatrist and educator with an interest in better understanding the psychological process of dying, Kübler-Ross famously suggested the five stages of coming to terms with one's impending death: denial, anger, bargaining, depression, and acceptance. Since this time, these stages have been applied to the grieving process as well and are commonly referred to in self-help books and articles on coping with grief.

This model has been the subject of considerable critique. One study claims to empirically validate this stage theory via a longitudinal study wherein questionnaires were repeatedly administered to grieving individuals in order to measure their responses along five dimensions of disbelief, yearning, anger, depression, and acceptance that were based on Kübler-Ross's model [65]. However, Bonnano and Boerner argue against these findings on the basis of methodological insufficiences and misinterpretations of the scales given to subjects [14], and cite other work which contradicts the notion of a "normative" or "healthy" grief response [121]. The primary danger, Wortman et al. argue, is that by putting forth such a definitive idea of what grief should be, individuals who find themselves responding differently from the model may think of themselves as handling their grief in an unhealthy or incorrect way [121]. They review a stronger body of research that suggests that individuals may be in multiple states at any given time, and in any order – if there are "stages" to grief at all. Despite the controversy surrounding these stages, the rich analysis given to this data has been seminal in the understanding of grief, and provides some context for individuals who are seeking support during their grief.

Bonnano and Kaltman, in a review of empirical longitudinal studies of grief progression, suggest that "chronic" grief is present in approximately 15% of cases after a year [15]. More commonly, after the first year of bereavement, most individuals revert to a baseline state which they term "minimal grief." They further note that no empirical studies to date have successfully identified a state of "delayed grief," although the notion of a delayed period before grief symptoms occur continues to persist. These concepts concerning progression become important in considering when and how a technology could play a role in the grieving process.

Some psychologists argue that believing the dead continue to have a presence and look after the family can be a comforting thought for some people [79]. This notion of "continuing bonds" suggests that it is normal for the living to continue to have thoughts and feelings about the deceased, and that responding to these thoughts and feelings is a healthy part of the grieving process [52]. A continuing bonds model promotes the idea that the relationship is renegotiated and continues in some form, and that this relationship with the deceased is an adaptive and comforting way to react to the loss (rather than distressful). In continuing bonds, the emotions felt may also be less intense or frequent. This model provides an interesting starting point for the design of technology that is meant to represent and honour the relationship beyond death, and has been used as a method for examining data collected from social networking sites [39].

2.2 Social Support

In both sociological and psychological perspectives on bereavement, there remains a common emphasis on how an individual responds to the loss as part of a social unit. In such a life-changing event, an individual may be able to draw upon their relationships with others in order to alleviate aspects of the hardship. The benefit that an individual receives from other people in his or her social network is often referred to as social support.

While social support can take many forms, Jacobson delineates three overarching types of support as follows [47]:

> "*Emotional support* refers to behavior that fosters feelings of comfort and leads an individual to believe that he or she is admired, respected, and loved, and that others are available to provide caring and security.
>
> *Cognitive support* refers to information, knowledge, and/or advice that helps the individual to understand his or her world and to adjust to changes within it.
>
> *Material support* refers to goods and services that help to solve practical problems.
>
> Most other typologies of social support appear to be derivatives of this tripartite classification..."
>
> (italics in original, [47])

This definition provides a helpful way to think through the ways in which technology might provide different kinds of support, and helps to disentangle this multifaceted concept from the more limited usage that refers solely to emotional support.

The health benefits of having social support are well-documented (e.g., see [20]). It has been identified as a mediating factor that protects against deleterious health effects of stress by creating a "buffer" of sorts [21]. Social support has also been correlated with longer lifespans in longitudinal studies [13].

2.2.1 Social Support in Bereavement

As with health conditions, social support is commonly considered to have a protective or shielding effect from the grief associated with a death [92]. Social support can be obtained from a variety of sources [49, 86]. Common sources include face-to-face support

groups at community or religious centers, family and friends, therapists, and Internet discussion forums. However, each of these sources of support has tradeoffs. Family and friends are often supportive at first, but may become "burned out" in the long term; similarly, the bereaved worry about straining these relationships. One-on-one support from a counselor may be another option for some bereaved individuals. However, this method of support can be costly and difficult to access without a clinical diagnosis.

In a survey of bereaved respondents, Lehman et al. found that contact with "similar others," opportunities to "ventilate," and "expressions of concern" were rated the three most helpful gestures during grief [57]. Support groups may offer such options, but are often only available for a limited number of weekly meetings, and may be insufficient for providing long-term support. Even then, support groups as a form of intervention are not necessarily effective for all bereaved people. In a systematic review of the literature on bereavement treatments, Forte et al. found that interpersonal support groups were not effective at a highly rigorous level of evaluation that included randomized control trials [35]. For example, in one trial, Levy et al. [60] found that levels of depression, anger, and stress for support group participants were not significantly different 18 months following the loss of a spouse from those who did not attend a group.

In most of these studies, grieving individuals were assigned to a group at a given point in time and compared against others who were not assigned to a group. A more realistic scenario is one where a bereaved individual elects to join a group at a point in time of their own choosing. There is evidence to support the notion that those who seek support groups are different in ways from those who do not. For example, Levy and Derby found that those who join such support groups report higher levels of depression, anger, anxiety, and stress, but are not significantly different from non-joiners in terms of perceived social support [59]. Picton et al. suggest that such groups are most effective for those with poor family support and within three months of the loss, but that the perceived need for support persists regardless of time elapsed since the death [91].

A reading of the literature would suggest that while grief interventions may not be beneficial for everyone, they provide value and benefit to those who desire them. In a meta-review of the literature concerning grief therapy more generally, Allumbaugh and Hoyt find "a small number of studies involving self-selected clients produced relatively large effect sizes, whereas the majority of studies involving clients recruited by the investigators produced effect sizes in the small to moderate range" [3]. With this in mind, technologies designed for the bereaved are likely to be most effectively applied to individuals who are seeking support.

2.3 Technology and Bereavement

In HCI, there has been relatively little attention paid to the role of technology in end of life issues. One of the earliest reports comes from Sofka in 1997, who reported on how the Internet could provide numerous opportunities for the bereaved for social and functional support [102]. She identifies the use of online forums, mailing lists, websites, and chat rooms as places where individuals can share stories about the dead. Sofka describes the Internet as a type of "thanatechnology" – a system which permits thanatological topics to be made available to a wider group of people. She focuses exclusively on webpages as sites for reflection, commemoration, and social support, and discusses implications of the Internet on counselling, research, and education. Since that time, additional psychological research has focused on the Internet as a site for memorialization, self-expression, and crafting of identities for the deceased [94]. Most scholarly research in this space examines existing, well-understood Internet technologies recast as interventions or treatment plans (e.g., studying a forum or bulletin board system for the bereaved). These studies frequently collect standardized, goal-directed outcome measures in order to understand the effects of the pre-existing systems and communities they study.

While websites remain the dominant technology in this domain, recent efforts in

HCI and ubiquitous computing have also emerged in recent years (several of which I review below) [74, 109, 8, 44]. These efforts have begun to explore new "off the desktop" technologies and interaction paradigms as applied to the end of life, and are often custom-tailored prototypes. These differ from earlier work undertaken by social scientists in key ways. These prototypes are often used to suggest how technologies might be designed in the future, and may be used to study aspects of bereavement (rather than provide a service, as with the websites described in Section 2.3.2). These studies also trace the ways that decisions regarding the technology's form or function impacts the experience of users, and treats the technology as a method of inquiry. This type of approach to studying bereavement differs from traditional studies because it permit the researcher to trace particular design aspects and study these carefully in a small number of cases (and is the approach in this thesis). This stands in contrast to studies that take an existing website "as is" and perform an evaluation of its impact on psychological constructs or patterns of usage.

In reviewing the literature on technology and bereavement, I organize related work along three of the most prominent needs of the bereaved: remembrance, support, and estate planning/inheritance.

2.3.1 Remembrance

Remembering and honouring the dead is a practice that exists throughout the world. As personal technologies and the Internet become more widely available, this practice is taking on new technologically-mediated forms. The Internet, in particular, has changed the ways that numerous aspects of dying and remembrance are performed. In this section, I briefly review some of the relevant work. A more thorough introduction to the space can be found in [116], which addresses remembrance among a set of other issues including the bereaved's information-seeking behaviours, digital inheritance, online support, and equitable access (especially for older adults). They further remark on the distinction be-

tween physical death and the "social death," which refers to the "withering and eventual extinction of social identity and social interaction" (p. 15). This social death is often what is being addressed with Internet-based remembrance technologies, which seek to preserve and create social interaction around the memory of the deceased.

Virtual Memorials

One of the most frequent and oldest uses of the Internet by the bereaved is to produce, view, or contribute to a virtual memorial. There are numerous websites that help the bereaved design, host, and/or share a memorial for a loved one. Some memorial websites are independent entities that are designed for general usage [e.g., memory-of.com, remembered-forever.org, muchloved.com]. Others memorial websites are affiliated with a religion [christianmemorials.com], non-profit organization such as Mothers Against Drunk Driving [madd.ca/tributes], or the cause of death such as breast cancer [remembered.com/pink]. Funeral homes may provide online guestbooks that function in conjunction with a pen-and-paper guestbook at the memorial service [e.g., see oshawa-funeralservices.com]. The content and purposes of these memorials can often be tailored to the individual (e.g., Figure 2.1 shows a memorial created on a general-purpose website that raises funds for a Motor Neurone Disease Association).

In coming years, the number of virtual memorials will continue to grow. In a 2006 study of 276 Internet entries on memorial websites, Roberts and Vidal found that memorials were predominantly created for young male individuals within one year of the death, with cancer and accidents listed as the most frequent causes of death [95]. Most memorials were classified as a site for "storytelling" (as opposed to other classifications such as "obituary" or "grief"), and represented an "opportunity for personalizing death, where the bereaved are drawn to a common space...in the simple need to share about their loved one and their loss." In one study performed in 2004, it was found that those who created such memorials tended to have higher levels of grief and used the Internet as a way to

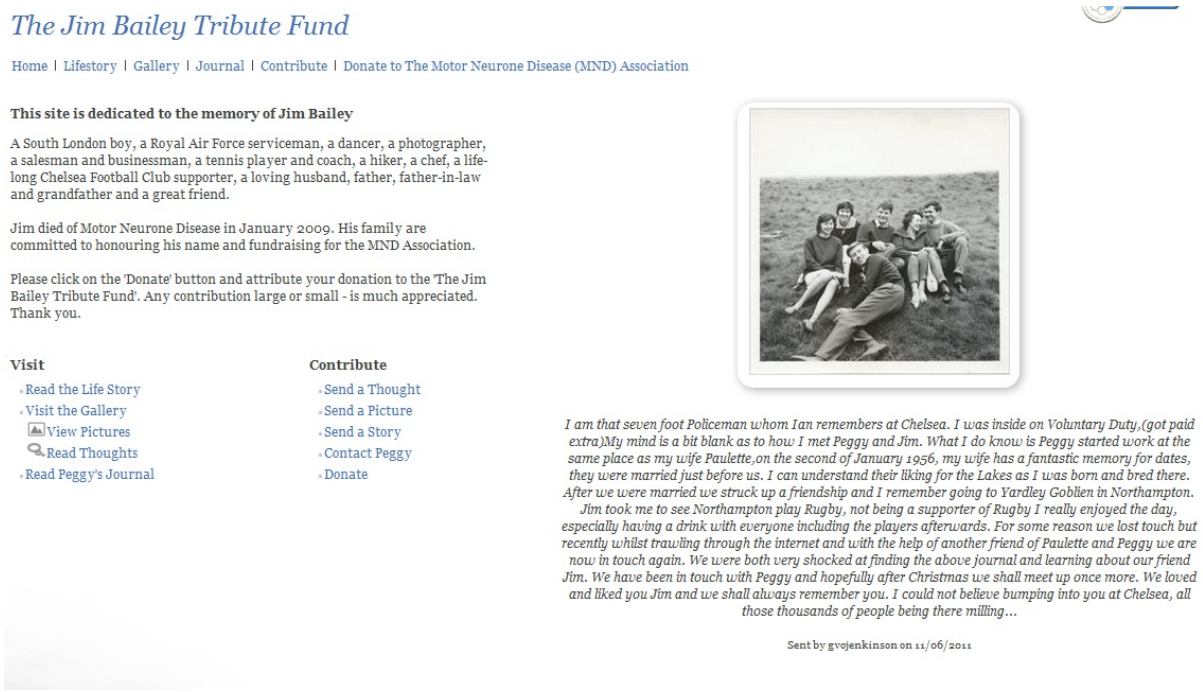


Figure 2.1: An example of a public web memorial developed on muchloved.com. The memorial includes photos, a biography, thoughts and wishes from the bereaved, and opportunities to donate to the Motor Neurone Disease Association in the deceased's memory [jim.bailey.muchloved.com].

express this emotion [78].

Virtual memorials are not limited to web browsers, however. Mobile technology can be interwoven into physical locations dedicated to remembering the deceased. For example, one project augmented the experience of visiting a cemetery through "spatial narratives" wherein actors, posing as historical characters interred at a cemetery in Atlanta, provided spoken information about local history in a mobile tour guide application similar to those found in museums [29]. Another project, Spomenik, seeks to use location-aware mobile devices in order to create a "pervasive monument" that provides history and context for those visiting sites where Stalinist purges occurred in Slovenia [53]. Other work in this vein has also employed mobile devices to help commemorate the deaths of individuals who died in brushfires in Victoria, Australia [76]. In the commercial arena, one vendor now sells headstones embedded with a QR code. Visitors can scan the code with their mobile phone in order to access a virtual memorial webpage offering additional information about the deceased [monuments.com/livingheadstone].

Social Networking Sites

In the 10 years since Roberts and Vidal published their analysis of virtual "cemeteries," the rise in popularity of social networking sites (SNSs) has changed the sites and forms of memorialization [95]. Rather than creating an entry on a special memorial website, the deceased are now listed alongside the living in SNSs such as Facebook [facebook.com] or MySpace [myspace.com]. Individual companies set their own policies for handling personal data following the death of one of their users, with significant variation in the documentation required to inherit the account [22, 64]. Facebook, for instance, requires the completion of a form in order to request that a profile page be "memorialized" - essentially preserved but with a limited subset of functionality.

More and more studies are emerging that examine Facebook memorials as a way to understand mourning behaviour. Early evidence indicates that families use Facebook as

a unique communication tool. For instance, the bereaved may appreciate the ability to "speak" to the deceased by writing on their profile wall or creating a group dedicated to remembering the deceased - a way of continuing their relationship with the deceased (Figure 2.2). Further, they may appreciate witnessing the outpouring of support from other Facebook users (including people that the bereaved did not themselves know, and people from around the world) [82]. Facebook also permits a unique response mechanism in the event of mass deaths or catastrophes, providing a forum for simultaneous information-seeking, commiseration, and commemoration [88].

Recent work in HCI has analyzed the postings made to SNSs in order to identify patterns of behaviour and increase our understanding of how mourning is performed online. Brubaker and Hayes analyzed 1,369 profiles of deceased users on the SNS MySpace [16]. They raise interesting issues concerning how mourners repurpose MySpace in the aftermath of the death. They find that comments posted to the profile still address the deceased as the target audience, rather than a community of other mourners. They also note how postings frequently occur at particular points in time: following the funeral, on the birthday/death anniversary of the deceased, and around special occasions such as the holidays. They find that these posts decreased in number over time, and suggest the number of posts may decreased because the bereaved spend less time on memorializing and remembering the deceased online (a finding that is consistent with the deployment study described in Phase 3). In another study, Getty et al. report on how Facebook users write on profiles of the deceased to keep their relationship alive and visibly perform activities associated with mourning such as remembering, sharing, and consoling [39]. Using linguistic analysis of postings made to these sites and drawing upon Goffman's [41] theatrical conception of front-stage and back-stage activities in social life, they suggest that SNSs permit for expressions usually conducted in private to find a more public audience. Based on these studies and the rapid adoption rates of Facebook and other social media, SNSs may become a more prevalent site for remembrance and memoralization

Figure 2.2: A Facebook group used as a memorial to a young man who was murdered [http://www.facebook.com/group.php?gid=22639421199].

as opposed to special-purpose memorial sites.

Digital Mementos

Much of the work in HCI concerning inheritance draws upon how digital assets support practices surrounding human memory. Modern forms of personal technologies such as mobile phones and social networking sites permit new forms of digital memorabilia to be collected more easily than in the past.

Digital photography, for example, has prompted new forms of photo-based reminiscence, and new practices surrounding photo production, sharing, and archival [38]. One practice enabled by digital photography is the ability for end users to create multimedia biographies that include photos, music, video, and so on [38, 24]. Photos often form the basis of storytelling activities where they prompt discussion and reflection between multiple people [6, 56]. Photos taken on mobile phones can document a special family event, such as the visit to a theme park [30]. The home has been a key site for novel photo display devices that makes viewing these digital assets more accessible and frequent (e.g., [8, 69]). Indeed, photos - as one type of digital memento - have been explored in many design and research efforts and continue to play a prominent role in many projects concerning digitally-mediated memory [61].

Other types of digital mementos may include sound recordings, music, and videos. Petrelli et al. explored the acquisition and playback of "sonic mementos" by creating a device resembling an old FM radio which stores and plays sound files collected from a family vacation [90]. Popular music has also been explored as a cue for remembrance. Baur et al. describe a visualization of an individual's music listening history to support reminiscence in lifelogging systems [10], while Shimizu et al. present a tabletop system that plays music from past decades as a way to prompt reminiscence [98]. The multimedia biographies described above also include music and sound in support of reminiscence [24, 69]. Other exploratory work has examined the types of sounds that people

might wish to capture for purposes of reminiscence, with identified categories such as natural/ambient sounds, voices, special music, the sounds of pets, "everyday" domestic noises, and recordings from special events such as weddings [85].

During bereavement, these forms of digital memories can take on new meaning. These mementos can help the bereaved to call to mind memories about their deceased loved one and reminisce about their time spent together. In work with bereaved parents, Riches and Dawson describe how photographs attest to the life of the deceased child, help parents come to terms with the reality of the loss, and capture details that may fade from memory over time [93].

Domestic Remembrance

As work emerges regarding the intersection of technology and death, the home is clearly an important site of technology use. More people receiving hospice palliative care are choosing to die at home, rather than in a hospital [5]. The home is also a primary site for remembering, mourning, and enshrining the dead [58], and plays a key role in religious observation (e.g., the Jewish tradition of "sitting shiva"). Based on the home's centrality in the processes of dying and death, it stands to reason that domestic technologies could sensitively support the bereavement process. Domestic ubiquitous computing interventions have supported other family activities in the past, including scheduling [80], health management [81], and religious observation [118]. These studies demonstrate the power of technology to affect domestic practices, and provide implications for the design of technologies which are used in this most private and heterogeneous of spaces [2].

With an understanding that families honor their collective pasts through the acquisition and display of personal materials, ubicomp designers have proposed unique conceptual prototypes which layer interactivity, multimedia, and communication capabilities atop more traditional forms of representation (such as photos). These exploratory efforts, on some level, seek to draw attention to the enshrined individual while simultaneously

offering users the opportunity to engage with that person's life history in new ways. One illustrative example is that of PersonCards (Figure 2.3), a design concept which supports lightweight messaging between older adults in the home and younger family members outside of the home: "a PersonCard is dedicated to one person only. It thus honours them in the same way that a picture frame might, and is indicative of a direct connection between, say, a son and his parents" [62]. The photograph of an individual is thus enshrined and augmented, and situated in a family context.

In a similar vein, ThanatoFenestra is a system designed for the domestic space that creates a digital representation of an individual [109] (Figure 2.4). As a design project, ThanatoFenestra draws upon common themes concerning remembrance in the home, such as the usage of photographs and the dedication of a place in the home to a memorial. Unlike PersonCards, ThanatoFenestra was designed specifically for remembering the deceased. This ambient display cycles through photographs of the deceased individual and contains a virtual candle that flickers in the wind. While ThanatoFenestra has not been deployed, it remains an example of a device embedded in the home – a site closely associated with remembering the family, and with remembering the deceased [58].

Other specific design projects which embody these principles have included "tilting frames" and "mourning stones" which communicate family commemoration across time and distance [111, 34]. Many of these ubicomp design projects are inspired by material items - such as clothing, jewelry, relics, and grave markers - which mediate the ways in which members of Western cultures remember the dead [42]. While these innovative projects continue to emerge and challenge our conceptualizations of death, much less is known about the reality and practicality of using technology when a person in the family has died.

Figure 2.3: A PersonCard, an ambient display dedicated to a member of a household [62].

Figure 2.4: Thanatofenestra, a domestic shrine to the deceased [109].

2.3.2 Finding Support Online

Beyond remembrance, the bereaved find themselves dealing with a new set of emotions and challenges that can be difficult to handle. The Internet provides a means for the bereaved to find information and connection with others that may help them to acclimate to their new circumstances. The Internet's effectiveness for providing social support has been well-documented in a number of stressful, life-changing events. Internet support is widely available, and can connect people who have suffered a particular kind of loss in ways that local groups cannot; however, it is difficult to ensure these environments are trustworthy and credible. At the same time, using the Internet for social support is a well-established practice. There are examples of online social support systems in HCI that have focused on cancer [11, 100], caring for high-risk infants [63], and improving physical fitness [23]. Bender provides a more complete picture of online health communities with respect to social support, with an emphasis on cancer [12].

Properties of Support Groups

Online support groups for grief provide opportunities for the bereaved to contact one another in a number of different ways (Tables 2.2, 2.3). Some sites offer open registration where users can create accounts and begin participating without first obtaining moderator approval, while others eschew accounts altogether and only ask users to choose a username before chatting. Some sites make their content public to the entire Internet, and allow visitors to read messages or view photos posted by support group members without first logging in, while others maintain privacy and only allow authorized users to access this content. While statistics regarding the size and activity of these sites are not available, many groups do not place a cap on the number of people that can participate in a group at a given time (at least according to their websites, although this may be different in practice). Sites frequently offer their services free of charge, but some may charge for participations or rely on advertising/commercial partnerships to sustain their services.

Site property	**GriefNet**	**Compassionate Friends**	**Online Grief Support**	**Besupp**
Open registration	No	Yes	Yes	No
Messages readble without login	No	No	Yes	No
Message format	Email	Realtime chat (ephemeral)	Threaded discussion board	Unthreaded persistent chat
Like-loss groups	Yes	Yes	Yes	Yes
User-created groups	No	No	No	No
Moderated	Yes	Yes	Yes	Yes
Group size	Unlimited	Unlimited	Unlimited	Capped (12)
General discussion forums	No	No	Yes	No
Dedicated loss type	No	Yes (loss of child)	No	No
Photo sharing	No	No	Yes (public)	Yes (private to group)
Memorials	Yes	No	No	No (Memory Box)
Corresponding real-life community	No	Yes	No	Yes
User profiles	No	No	Yes	Yes
Always available	Yes	No (scheduled chats)	Yes	Yes
Financial cost	$10/month donation	Free	Free	Free
URL	griefnet.org	compassionatefriends.org	onlinegriefsupport.com	besupp.com

Table 2.2: Comparison of a sampling of dedicated online grief support websites obtained from a Google search for "online grief support" performed on January 2, 2012, along with Besupp (described in Chapter 5).

Site property	**Grief Recovery Online**	**Grieving.com**	**Besupp**
Open registration	Yes	Yes	No
Messages readble without login	Yes	Yes	No
Message format	Realtime chat (ephemeral)	Threaded discussion board	Unthreaded persistent chat
Like-loss groups	Yes	Yes	Yes
User-created groups	No	No	No
Moderated	Yes	Yes	Yes
Group size	Unlimited	Unlimited	Capped (12)
General discussion forums	No	Yes	No
Dedicated loss type	Yes	No	No
Photo sharing	No	Yes (public)	Yes (private to group)
Memorials	Yes	No	No (Memory Box)
Corresponding real-life community	No	No	Yes
User profiles	No	Yes	Yes
Always available	No (scheduled chats)	Yes	Yes
Financial cost	Free	Free	Free
URL	groww.org	grieving.com	besupp.com

Table 2.3: Comparison of a sampling of dedicated online grief support websites obtained from a Google search for "online grief support" performed on January 2, 2012, along with Besupp (described in Chapter 5).

Many sites offer like-loss groups where a user can join one (or more) groups that are dedicated to a particular kind of loss. For example, GriefNet [griefnet.org] has 40 email lists organized by type of loss. These groups can become quite specific; GriefNet offers groups for the accidental death of a child, death of an adult child, death of a child by suicide, death of a child due to substance abuse, death of an only child, and so on. Others are less specific, and may offer discussion groups for "Bereaved Parents" and then allow users to create their own subgroups within this heading. Some websites address particular kinds of loss. Compassionate Friends [compassionatefriends.org] is dedicated to the death of a child, and group chats may be organized according to the relationship (e.g., parent, grandparent, sibling of the child), by the time since loss (under or over two years), or by the circumstances of the death (suicide, only child, infant loss).

Almost all groups include moderators, but the responsibilities and activities associated with moderating can vary widely. In some groups, moderators may actively guide discussion, while in others, moderators may primarily exist to remove undesirable posts (e.g., spamming or inappropriate behaviour). Other sites are led by the founders of the site, or prominent therapists. Online Grief Support [onlinegriefsupport.com], for example, is led by "Coach Louise" who maintains the site and writes newsletters to members. Indeed, some sites are created as extensions of existing "real-life" communities (such as Compassionate Friends). When a group relies on strong moderator presence, online chat meetings may be scheduled instead of offering constant availability. For example, online groups run by Compassionate Friends and Grief Recovery Online [groww.org] take place in a Java Chat client at pre-determined weekly times. If a user does not join at the pre-determined time, they may find that the chat room is empty of both messages and users.

While all peer-support sites allow users to chat with one another, some sites also offer remembrance activities. For example, GriefNet allows members of its community to create web memorials for their deceased loved ones in addition to offering support

groups. Similarly, Online Grief Support allows users to upload photos to a shared member gallery. Users may also be able to create their own profile page where they can provide more background information about themselves and recount the story of their loss. The memorials, photos, and profiles may be publicly accessible or limited to authorized members, depending on the site.

The above review serves as a thumbnail sketch of the ways that sites differ from one another. It should also be noted that social networking sites may begin to fill in for these dedicated communities. For example, according to a message posted on September 6, 2011 on the website for the Center for the Grief Journey [griefjourney.com], their dedicated groups have been removed and migrated to Facebook due to the number of spammers posting messages in their grief support forums.

Efficacy of Online Support Groups

There is often a perception that online support groups are less helpful than face-to-face groups, but are still better than no support at all for those who desire it. However, a growing body of research suggests that online support is qualitatively different, and not necessarily better or worse. For many grieving people, online support groups offer convenient alternatives to face-to-face groups that require less formal time commitment, but still offer the ability to talk with people besides friends and family [86]. Concerns over security certainly exist, but online communities have begun to institute policies that require registration and authorization. For example, WidowNet [www.widownet.org] (Figure 2.5) requires participants to register for their discussion lists, providing forum users a modicum of accountability, oversight, moderation, and protection [99]. In a 2008 study, Feigelman et al. compared bereaved individuals who participated in an online community for parents whose children committed suicide against those who sought face-to-face support [32]. This study found that the constant availability of Internet support encouraged participants to invest more heavily into the group experience, as compared

to face-to-face groups that might end after a set number of weeks. They also find that the Internet provides a less stigmatizing environment, and that contrary to expectations, usage of the Internet-based support group was consistent across both rural and urban centres with varying levels of access to face-to-face resources.

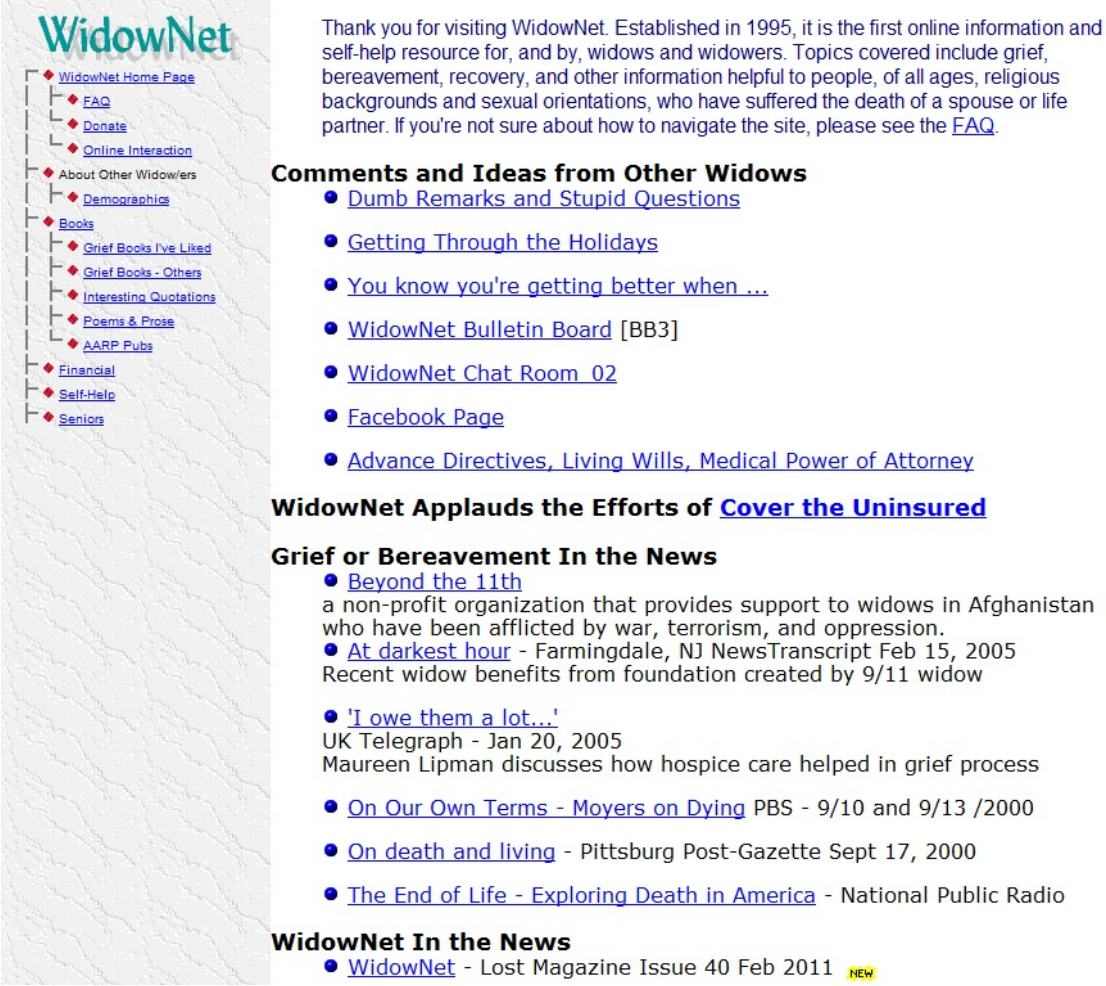


Figure 2.5: WidowNet.org, the "first online information and self-help resource for, and by, widows and widowers." [www.widownet.org]

While online support groups can provide emotional support and suggest resources that may be helpful to the bereaved, there are a variety of resources online that can support the bereaved in other ways. The Internet can be used by bereaved individuals to access interactive materials or texts which can help them normalize, understand, and reflect

on the progression of their grief. Bereavement professionals can also offer counseling services online in a one-on-one environment. In one 2007 study, Wagner and Maercker developed an Internet-based cognitive-behavioural therapy program for individuals who were identified as suffering from complicated grief [113]. After 18 months, participants receiving the treatment maintained reductions in their grief symptoms. Most recently, such Internet-based resources for self-help have been evaluated in normally grieving adults and found to provide significant gains in attitude, self-efficacy, and reductions in state anxiety [28]. This study included materials for both self-tracking and monitoring of improvement, and the provision of texts or links to other resources related to coping with grief. The Internet can provide increased informational support through the provision and curation of these resources, in addition to forms of social support as expressed through online messaging systems.

Teenagers and young adults have been identified as one of the most likely groups to benefit from online support systems. Recent studies have examined how young adults employ social networking sites such as MySpace and Facebook following a loss in order to publicly mourn or express hitherto private emotions [19, 39]. Williams and Merten analyzed the comments left on the social networking profiles of 20 deceased users between the ages of 15 and 19, and concluded that this form of mourning permits teenagers to maintain their attachment to the deceased while offering new opportunities to reflect and cope [117]. In addition to social networking sites, Sofka has discussed the various ways that teenagers handle grief reactions via information and communication technologies more broadly, including the use of search engines, blogs, and text messaging [101]. She identifies potential areas of concern associated with these practices, including the potential for cyber-bullying or using the Internet as an avoidance mechanism. As today's teenagers grow older and encounter death again throughout their lives, their patterns and behaviours concerning technologically-mediated forms of support will become an interesting area for exploration.

2.3.3 Digital Inheritance

Another way in which the bereaved may encounter technology is when trying to sort through the digital assets of the deceased. When a person passes away, the objects they leave behind become more important to preserve across time and distance. Drawing on a number of theoretical frameworks, Odom, Pierce, Stolerman, and Blevis suggest that this is due to their function, symbolism, and material qualities [84]. Before applying these concepts to a number of personal inventories, they further suggest that the reason that items are so important is because they are present in the here-and-now and provide a symbolic link to a person (who may no longer be present). In a subsequent series of home tours with 11 bereaved individuals, Odom et al. present a rich description of how inherited physical and digital items help supplement or confuse the relationship between the living and deceased [83]. They describe how the items that we inherit can be cherished reminders of our deceased loved ones, or confusing burdens that leave us wondering as to the intentions of the bequeather. Similarly, Kirk and Banks describe how technology designers might begin to create familial intergenerational heirlooms [50]. They raise critical issues concerning how families bequeath content and how one's digital estate accumulates. These heirlooms are crafted to respect and invoke social relationships and memories across generations through "deep storage" of data for future generations [51]. Ongoing design work (Figure 2.6) has explored additional formats for storing and retrieving various types of personal data [www.richardbanks.com/?p=2043].

A number of start-up companies have also emerged that seek to deal with issues of data inheritance and security. Websites such as Entrustet [entrustet.com, Figure 2.7] and Legacy Locker [legacylocker.com] allow customers to purchase an online "vault" for safekeeping of digital valuables. Users can upload copies of important documents, account passwords for services like Facebook, Flickr, or Gmail, and designate individuals to whom these items should be made available upon the death of the customer. At the same time, these services face considerable challenges. For example, customers may not trust that

Figure 2.6: Three examples of technology heirlooms developed by Richard Banks, Abigail Sellen, and colleagues at Microsoft Research Cambridge. Left: Timecard, a display that depicts the events of an individual's life. Center: Backup Box, a device that archives copies of a user's Twitter feed to allow for later exploration. Right: Digital Slide Viewer, a device which permits a user to browse collections of digital photos in a familiar format [www.richardbanks.com/?p=2043].

these services will still be operational at the time of their death, especially given the rapid pace of technological change. Other legal and technical issues present themselves as these tools move into territory that is commonly governed by local laws or software terms of service. Security concerns also present themselves, as current encryption and credentialing techniques may be potentially difficult to enforce or inherit (e.g., passing along a biometric security marker) [71, 64].

2.3.4 Towards a Broader Understanding of Technology Use by the Bereaved

HCI researchers have also addressed issues which speak to end of life issues more tangentially. Friedman and Nathan describe multi-lifespan information system design as a unique type of design which addresses issues of profound human importance that are unlikely to be solved within a single generation [37]. Wyche, Magnus, and Grinter, in their account of Charismatic Pentecostals in Brazil, address religious understandings of the

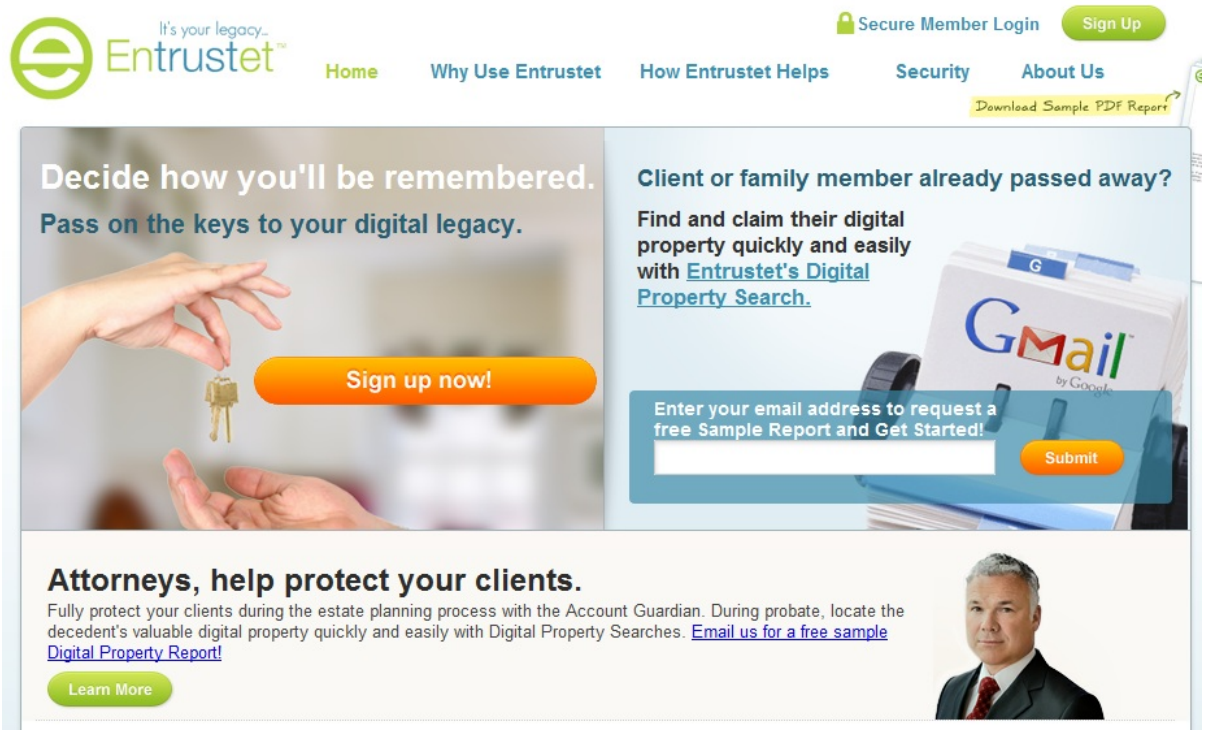


Figure 2.7: Entrustet.com is a web service that allows users to store and bequeath digital assets.

afterlife in their fieldwork and suggest that ICTs be designed to account for spirituality as well as the physical body as part of a supportive health paradigm [122]. These studies raise questions concerning how technology is designed to address profound human issues that are not easily answered.

Death has also been identified as a concern in dealing with issues of domestic computing. Dimond, Poole, and Yardi describe how death, among other forms of life disruption, impacts the ability for families to maintain home networks [26]. For example, if the person who maintains a home network passes away, arrangements must be made to handle the home's technical infrastructure. Massimi, Dimond, and Le Dantec reflect on death, homelessness, and intimate partner violence to identify common issues surrounding "life disruptions," and how technology plays a role in achieving a new normal [72]. The rippling effects of a death demonstrate the importance of studying the bereaved and the end of life from a technology-focused perspective.

This leads to the first study in the thesis, which seeks to identify and categorize how the bereaved employed technology in the five years following a death in the family. While the studies described above have identified important needs areas, and evaluations of existing systems are beginning to emerge, this first study provides an end-user perspective on how technologies are appropriated in various ways in the aftermath of a death. This exploratory approach sets the stage for deeper exploration of technology-mediated social support and remembrance in the remainder of the thesis.

Chapter 3

Opportunities for Technology in Bereavement

The previous chapter demonstrated how the end of life is a relatively new space for exploration and design in human-computer interaction. For computer scientists working in this area, drawing upon resources from psychology, sociology, and other fields of study can help cultivate empathy and understanding of bereaved individuals. At the conceptual level, these results could potentially help system designers identify opportunities for meeting the needs of the bereaved. At the same time, and despite the richness provided by these resources, most research in the social sciences examines bereavement in settings that do not directly address the role of technology; those that do often focus on existing websites or communities.

A more complete picture of contemporary bereavement would require due attention to the role of personal technologies, and how they interact with existing or emerging bereavement practices. Personal computers, mobile phones, consumer entertainment systems, and many other forms of personal technology have been commercially available for decades. It would seem plausible that end users of existing general purpose technologies appropriate these devices to perform the tasks associated with bereavement. However,

very little is known about how individuals encounter such devices in the context of a loss, and the circumstances associated with this appropriation have not been thoroughly examined. This comes despite the powerful role that technology can potentially play in assisting the bereaved to work through the range of experiences that follow the death of a loved one.

This thesis begins to address this area by starting with an exploratory study that examines how bereaved people currently inherit, use, and reflect on digital assets. Digital assets were selected as a starting point for study because they help to ground technology redesign efforts in discrete forms of data. This study offers one of the first explorations into this emerging phenomenon, and presents evidence from an empirical survey and interview study. This study presents findings along three strands of inquiry that can shed light on technology's role in bereavement more broadly, and underpin a preliminary mapping of potential opportunities for design work. Results in this study are reported primarily based on responses to a web survey, with insights from interviews and open-ended survey responses informing these findings. This study concludes with a series of design opportunities based on these results, and motivates further exploration into social support during bereavement in subsequent parts of this thesis.

3.1 Method

The study included a web survey (complete questionnaire in Appendix A) and a follow-up semi-structured interview (Appendix B). Instruments were organized into three categories: inheriting technology, using technology to remember, and anticipating one's own death. Each of the three categories are listed below, with representative items from the web survey listed beneath a set of more general research questions. Interview items focused primarily on the technologies/assets left behind, and follow-up questions addressed all three categories below.

3.1.1 Inheriting Technology

Like other possessions, digital artifacts and the data associated with them can carry significant sentimental value for bereaved family members. With physical items, standard legal and cultural practices for repossession exist. However, for digital assets, practices surrounding the inheritance of data are nascent and diverse. What devices and types of data are being inherited? How do they reconcile the dual digital/physical nature of electronic assets such as computers? What data stored on these devices should be made visible to friends, family, or the world at large? What practical problems are encountered when inheriting digital assets?

Survey items in this category included:

- What technologies did the deceased own? [Possible responses include: personal computer, mobile phone, email account, online banking account, social networking account, iPod/music player, digital camera, blog, online photo sharing account, instant messaging account, video game system, personal TV device, other (specify)]
- What happened to each of these items? [For each technology above, one of: unknown, thrown away, inherited by a family or friend, donated to charity, other (describe)]
- When the person died, did you digitize any physical items? [yes/no]
- If yes, what did you digitize? [text, open ended]
- Is there anything else you could share about how the deceased's technologies were distributed following their death? [text, open ended]

3.1.2 Using Technology to Remember

Remembering and honoring the dead is a custom that exists in almost all cultures. The ways in which we do so have always been tied to symbolic materials which often (but

not always) represent the corporeality of the deceased [42]. Examples of such symbols include grave markers, photographs, personal possessions such as jewelry and clothing, and gifts symbolizing an exchange between the deceased and the living. Increasingly, these symbolic markers may be digital, and intersect with physical mementos in important ways. How do people appropriate technologies following a death to help them remember, commemorate, and reminisce about the deceased? What types of data do they find meaningful when commemorating the dead? Can digital artifacts support or replace more material ways of remembering?

Survey items in this category included:

- Did you ever use technology to help you remember the deceased? [Yes/No]
- Which of the following have you used to help you remember the deceased? [Checkbox for each item: photos, music, sound files (e.g. voices), journal or documents written by the deceased, videos of the deceased, other (specify)]
- Please rate how strongly you agree with each of the following statements. [Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree]
  - I treasure mementos of loved ones who pass away.
  - Having reminders of my deceased loved ones is important to me.
  - Bringing up memories of deceased loved ones is unpleasant for me.
  - I prefer having physical mementos to remember deceased loved ones rather than intangible ones.
  - Using a computer to remember a loved one can be just as meaningful as using physical items.
  - I feel like I should think about my dead loved ones more frequently than I do.
  - I resent it when other people bring up dead loved ones in conversation.

  - It's hard to find time to reminisce.
  - I would welcome more opportunities to think about deceased loved ones.

- In what other ways do you use technology to help you remember your loved one? [open ended]

3.1.3 Anticipating One's Own Death

The death of a family member can prompt reflection on one's own mortality. While technology is commonly silent on such existential issues, the bereavement process may cause individuals to consider their own digital estate and how it might be handled after their own death. Are people aware of their digital estate after the death of a loved one? What data would this individual want their family and friends to inherit when they die? Do people take action to prepare their digital estates for distribution?

Survey items in this category included:

- Prior to this questionnaire, have you ever considered what would happen to your digital assets once you pass away? [Yes/no] If yes, how frequently? [Very infrequently, infrequently, sometimes, frequently, very frequently]

- Please rate how strongly you agree with the following statements [Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree]

  - I am concerned about how my possessions will be handled when I die.
  - I have documents on my computer I would not want my family to see when I die.
  - I have documents on my computer which I would not want my friends or acquaintances to see when I die.

- What percentage of files on your computer would you not want released upon your death? [number, open ended]

- What percentage of files on your computer would you want released, but only to very specific individuals? [number, open ended]
- What percentage of files on your computer would you want released to family only? [number, open ended]
- What percentage of files on your computer would you want released to friends? [number, open ended]
- What, if any, preparations have you made to handle your digital possessions after you die? [text, open ended]
- What other thoughts do you have with regards to your digital estate and what will happen to it after you die? [text, open ended]

3.1.4 Recruitment

Both instruments investigated the research questions in the three categories above, and also provided opportunities for open-ended responses. Participants were recruited through convenience and snowball sampling, and via postings to Toronto Craigslist and local newspapers. To be included in the study, participants must have been over the age of 18 and have experienced the death of a family member within the past 5 years. Five years was chosen as a maximum because beyond this point participants' memory becomes increasingly unreliable, but at the same time, allows enough time for dealing with inheritance and early grief reactions. Determination of who constituted a "family member" was left to the participant's discretion. Participants who completed the survey were entered in a raffle to win a $100 gift card.

The survey received 41 complete responses (17 incomplete responses were omitted from analysis, but participant numbers in this chapter retain their original numbering from the survey). From these respondents, 10 participated in follow-up interviews in per-

son, by telephone, or by instant message depending on the preference of the respondent. Interview transcripts were analyzed according to the three aforementioned themes.

3.2 Survey Results

3.2.1 Respondent Demographics

Of the respondents who completed the survey (n = 41), most were middle aged ($\mu = 35.1$, $\sigma = 11.9$, min =18, max = 65), female (n = 28), and lived in North America at the time of the survey (n = 40) (Table 3.1). Occupations of respondents varied widely, with students being the most common response (n = 16). Respondents were adept with email, the Internet, and mobile phones; between 90% (email) and 73% (mobile phone texting) of respondents rated themselves familiar or very familiar with these technologies.

3.2.2 Deceased Demographics

Each respondent represented a different family and reported on the single most recent death in that family (Table 3.1). The median number of years since that death was between 2 and 3, with the remainder distributed across the span from 0-5 years. The average age of the deceased at the time of death was $\mu = 72.3$ ($\sigma = 17.95$, min = 25, max = 95). The gender of the deceased was roughly split, with 21 female and 18 male responses, and 2 not reporting. The occupations of the deceased varied, with homemaker (n = 11) the most frequent response. The deceased was most frequently the grandparent of the respondent (n = 16), with parents (n = 7) and aunt/uncle (n = 6) also reported frequently. Compared to the respondents, the deceased were reported to be less familiar with technology. Most respondents assessed the deceased's pre-morbid comfort with technology to be "somewhat familiar," (n = 17), with the remainder of assessments distributed roughly equally between familiar (n = 11) and unfamiliar (n = 13).

Measure	**Respondents**	**Deceased**
Age	$\mu = 35.12$ ($\sigma = 11.94$, $min = 18$, $max = 65$)	$\mu = 72.3$ ($\sigma = 18.0$, $min = 25$, $max = 95$)
Gender	Female = 28, Male = 12, N/A = 1	Female = 21, Male = 18, N/A = 2
Occupation	Student = 16 Other academic (professor, researcher, teacher) = 4 Technology professional = 3 Social worker = 2 Consultant = 2 Other (homemaker, accountant, architect, health and safety manager, nurse, mathematician, sales manager., newscast director, photographer, disabled, unemployed, quality assurance analyst, project manager) = 13	Homemaker = 11 Retired (non-specific) = 7 Trade skill worker (farmer, mechanic, carpenter, electrician, factory worker) = 5 Academic (teacher/educator) = 4 Businessperson/entrepreneur = 3 Engineer = 3 Other (film maker, mathematician, nurse, border agent, newscast director, student) = 7
Relationship of deceased to the respondent	Grandparent = 16 Parent = 7 Aunt/uncle = 6 Sibling = 2 Cousin = 1 Other (daughter-in-law, father-in-law, husband's ex-wife, step-parent, fiance, significant other, girlfriend, great niece) = 8 N/A = 1	

Table 3.1: Survey respondent and deceased demographics. N/A = not applicable, participant provided no response.

3.2.3 Inheriting Technology

Before being asked to report on technologies left behind by the deceased, participants reported whether or not the deceased had a will. About half (58%) of respondents reported the deceased had a will, 22% did not, and 20% had no response or were not sure. No respondent indicated that the deceased individual made specific arrangements for their personal technologies in the will.

After death, technologies were handled in a multitude of ways (Table 3.2). Personal computers (PCs), TV/VCR devices, mobile phones, email accounts, and online banking accounts were the most commonly possessed types of technologies. Of these, PCs and TV/VCR devices were more frequently reported to be "inherited," while email and online banking accounts were most likely to have indeterminate outcomes (i.e., the respondent did not know what happened to them). Participants who answered "Other" to this question had a range of responses indicating complications in handling the devices. These are described in more detail in Section 3.3.

3.2.4 Using Technology to Remember

This section asked respondents about their use of technology as a means of commemorating or remembering deceased loved ones. On Likert scales (5-point, level of agreement), respondents indicated that they treasure mementos (78% of respondents), think that reminders of the dead are important (82%), and do not associate reminiscing with negative affect (61%). About 54% believed that digital mementos could be as meaningful as their physical counterparts (e.g., digital photos vs. printed photos). Slightly less than half of respondents (43%) expressed no preference for physical mementos over intangible mementos. Thus, participants were roughly split about the value and utility of digital devices when compared against physical mementos.

After the death of a family member, about half (51%) of respondents digitized posses-

	Total	Inherited	Sold	Gift	Charity	Disposed	Unknown	Other
PC	19	12	0	0	1	3	2	1
TV/VCR devices	19	13	1	1	1	2	0	1
Mobile phone	15	7	0	0	2	3	2	1
Email account	15	2	0	0	0	4	7	2
Online banking	11	2	0	0	0	1	5	3
Digital camera	6	4	0	1	0	0	1	0
Social networking	4	0	0	0	0	2	1	1
IM account	4	0	0	0	0	2	2	0
Music player	4	3	0	1	0	0	0	0
Video games	3	2	0	1	0	0	0	0
Online photos	1	1	0	0	0	0	0	0

Table 3.2: Frequency of ownership and what happened to the technology after its owner's death. An "Unknown" response indicates that the deceased owned the item, but that the respondent did not know what happened to it.

sions of the deceased. When asked what they digitized, almost all respondents indicated photographs (90%). In an open-ended response item, participants identified "digitizing" in some form the following items in addition to photographs: furniture, jewelry, letters, journals, bills, voice mails, videos, obituaries, newspaper clippings, art, and silverware[1].

Of all respondents, the majority (65%) reported using their computer and the Internet to help them remember their deceased family member. Specifically, participants described using their computer and the internet for the following activities:

- searching for genealogical or biographical information about the deceased (2 responses)
- sharing photos (e.g., Facebook, Flickr) (4 responses)
- creating a quilt square to represent the deceased in a memorial quilt for victims of drunk driving (1 response)
- using digital pictures frames in the home (2 responses)
- reminiscing in emails to relatives (3 responses)
- eulogizing the deceased on memorial websites or Facebook (3 responses)
- completing administrative tasks (e.g., comparing funeral homes) (1 response)

When remembering or reminiscing, respondents reported that they most valued photographs (92% of respondents), followed by video of the deceased (41%), journals or written works (39%), music (29%), and non-musical sounds (e.g., voice recordings of the deceased) (29%).

While about half of respondents (53%) reported that they tried to keep a "connection" to their deceased loved one alive, and 95% thought that talking about the deceased was

[1]While the method of digitization was not collected, it seems likely that the digitization process included using document scanners, digital cameras, or asset-tracking software (e.g., a spreadsheet for purposes of handling assets).

socially acceptable, they did not appear to desire significant changes in the way they reminisce. Respondents reported that they had enough time to reminisce (73%), and only about one-third (36%) desired more opportunities to reminisce. Only 14% thought that they should be thinking about their deceased family member more frequently than they currently do.

3.2.5 Anticipating One's Own Death

The final section of the survey asked participants to reflect on the passing of their family member, and answer questions about their *own* attitudes towards their digital estate. Most respondents (65%) had never thought about how they wanted their digital devices to be handled upon their own death. Consistent with this, 80% had not made plans for their technological possessions upon death. Despite this lack of thought and action, a little more than half of respondents (56%) reported that they were concerned about how their personal technologies would be handled after they die.

Respondents varied in their privacy attitudes regarding their own personal files. Slightly less than half (46%) of respondents reported that they have files on their computer which they would not want their family members to see if they were to die. A similar number (51%) indicated that they have files on their computer which they would not want friends to see. Participants were asked to estimate what percentage of files on their personal computer they would want released after their death. In the aggregate, respondents reported that they did not want to share $\mu = 19\%$ ($\sigma = 24\%$) of their files with anyone (i.e., these files should be deleted permanently upon death). Respondents desired that more files ($\mu = 50\%$, $\sigma = 35\%$) be released, but only to specifically designated individuals. A slightly higher percentage of files ($\mu = 61\%$, $\sigma = 33\%$) should be available to family members generally, while a lower percentage ($\mu = 36\%$, $\sigma = 30\%$) should be accessible to friends generally.

3.3 Discussion: Inheriting Technology

In this section we revisit the question of how individuals inherit digital technologies, illustrating with items from the interviews and open-ended survey response items.

3.3.1 Generational Differences in Technology Possession

The average age of respondents was 35 years old, while the average age of the deceased at the time of death was 72 years old. While the sample of deceased individuals did include a range of ages (from 25 to 95), respondents overall rated the deceased as being less "tech savvy" in comparison to themselves, and this was reflected in the interviews and survey regarding technological comfort.

> "No [files or online accounts], she died roughly at the age of 95, so her generation...I'm 33 myself, so I was born into a digital era in a way." - P56

Examining the occupations of the deceased gives insight into the types of possessions that they held. The deceased sample included 5 individuals working in trade skills (farmer, mechanic, carpenter, electrician, and factory worker). These trade skills result in the production of physical items which can be easily inherited by family members, such as furniture. In comparison, respondents in the younger group were more likely to have occupations which do not produce tangible artifacts - for example, as knowledge workers who produce spreadsheets or digital documents.

> "Being the youngest in the household, plus being involved in the IT world, I took possession of any item that ran on current." - P49

Younger respondents saw themselves as having more valuable information stored in digital devices and more familiarity with technology than previous generations of family members. This suggests that handling digital data following a death will become more common as younger generations grow up and pass away.

3.3.2 Physicality in Inheritance

Table 3.2 indicates an interesting trend: respondents reported that physical items such as PCs and televisions were commonly inherited by a family member, but non-physical digital assets such as email or social networking accounts were either destroyed or had an unknown outcome. Why might tangible technologies be inherited so much more frequently than intangible ones?

The first reason is that many online accounts require passwords. Passwords can prevent people from inheriting or distributing assets associated with this account (unless circumvention measures are taken, such as hacking the account or making a request to a service provider).

> "We just left it, I couldn't get into [my brother's] account... his school account was deleted obviously, but I left his personal account." - P58

Second, participants noted two stages of inheriting physical assets. To inherit an item, the bereaved must first become aware of its existence and see value in preserving it. Then, they must determine who will receive the item. For instance, walking through her mother's household, P8 and her siblings claimed her mother's paintings by writing their names on the back of each one they wanted.

> "She was a good artist, and they are just small paintings she did...all of them have been scooped up. Someone's got their name on the back of it." - P8

Becoming aware of valuable digital files was considered more difficult because (a) the bereaved are often unaware of what digital assets the deceased possessed, and (b) they may have trouble ascertaining which files are valuable (see Section 3.3.5).

A final reason why physical items are more likely to be inherited is because they bore personal touches, such as handwriting. These personal touches imbued objects with meaning and made them unique [51]. Participants were more motivated to retrieve these one-of-a-kind assets.

> "This postcard was written by hand, with photos - it's more romantic than nowadays..." - P56

Participants talked about these kinds of physical assets in a different way than they did digital assets. Having outlined some of the properties of physical assets that participants valued, I now turn to how domestic computing played a role in inheritance.

3.3.3 Domestic Data: Inheriting from the Home

We often think of computer files as assets which are owned by a single person or user. In reality, many assets are owned by the household of which an individual is a member. Participants remarked on how assets - both tangible and intangible - belonged to the house and to whomever lived there: usually, the widowed partner.

> "My dad is still living, anything that was in the house goes to him, and all of her investments, all the money, goes back to him." - P8

What does it mean to inherit a digital device when it is shared among many members of a household? In many cases, the devices are not so much "inherited" as they are "used by one less person" - PCs and televisions are good examples of this. As a result, digital devices accumulate data from multiple members of the household over time. By the time someone external to the household comes into contact with the device due to a death in the family, they may wish to simultaneously inherit data from multiple people from the same device. For example, a daughter might inherit data from both her mother and father at the same time from the same family computer.

Participants also remarked on how one person was the "gatekeeper" for household data. Activities performed by the gatekeeper in this role can be part excavation, part privacy advocacy, and part "grief work" [105].

> "My dad, literally immediately following her death, he took a few weeks off and we organized stuff, and went through every single paper and organized

> it...It was something he wanted to do...he might have felt it would be more difficult for me so he protected me...or maybe it was something he wanted to do because it was a way of reconnecting with her." - P21

When designing personal domestic technologies, we must keep the role of the household and its "gatekeeper" in mind.

3.3.4 Inheritance and Emotion

When people inherit possessions from a deceased loved one, they frequently feel an attachment to the possessions which honour, commemorate, and preserve the identity of the deceased [42]. It is easy to understand why, for instance, a son would cherish his deceased's father's wristwatch - it was something personal, kept close to his body, and unique to him. But these properties are shared with other objects as well - for example, his mobile phone. Despite the culturally prevalent "disposable technology" paradigm, and the idea that the data matters more than the substrate it is stored on, do people attach emotion to inherited digital devices?

The results of the study suggest that it depends on the individual. Some people did find personal technologies to be vehicles for maintaining an emotional connection with their deceased loved one, and were comforted by inheriting a loved one's personal device.

> "She was using her father's cell phone after he died. She asked if she could use it as a token to remember him by, because it was his, and it was a good way to remember. It had sentimental value." - P26

The mobile phone is an interesting example because it is so personal, used so frequently, and is carried close to the body (properties shared with some religious relics [42] and jewelry). While this intimacy might make an object more valuable, it does not appear to be necessary. For example, another participant was surprised by how strongly she valued a laptop that her mother never even used.

> "One of the computers, she let me have before she passed because she wasn't using it. After she passed away, the same year, I spilled tea on the keyboard it totally froze and shut down. I freaked out...because it was her computer, even though it wasn't something she used, she had given it to me." - P21

Interestingly, the emotional attachment here appeared to be connected to the functionality of the device, more so than the data it contained or its actual form. This participant then describes her desperate efforts to fix this inherited laptop.

> "I raced to work and corralled my techie friends...and I was bawling at work...they fixed it, and I was thrilled and I felt much better. I had reconnected again, even though there was nothing saved to that computer that was hers, but I felt closer to her because of it." - P21

It is striking how strongly the proper functioning of the device was connected to its meaningfulness as an inherited keepsake; it is as if the continued functioning of the device worked to "keep alive" the memory of her mother. At the same time, this same functional property of computing devices (i.e., the idea that they are replaceable tools) was grounds enough for other participants to completely discount the idea of caring for a computer.

> "There's no emotion attached to a computer, no memory attached to a cell phone - they're very easy to get rid of after death I think. It's not like a favourite vase or something that has a family history to it. It doesn't have beauty or genealogical significance. It's just functional." - P9

These disparate attitudes demonstrate a range of potential perspectives on what makes a device meaningful to inherit.

3.3.5 Discovery and Privacy: Browsing the Files of the Dead

Whether the deceased had a will or not, in no case did a respondent find specific instructions about how data stored on digital devices was to be handled. This was the case even

for the most computer-literate in the sample. Because there were no directions, respondents found themselves combing through hard drives full of the deceased's files, trying to find important pieces of information without invading their privacy. This proved treacherous at times for both practical and ethical reasons. Practically speaking, respondents had trouble deciphering the filing system their deceased relatives had created.

> "She had no sense of directories or computer sense...all files were in one directory." - P25

This lack of organization caused P25 to review every file to determine if it contained important information or not. But even if they had been better structured, it would still not be immediately clear which folders contained important information. When respondents were forced to look through documents one by one, they sometimes encountered information they wish they hadn't.

> "With my mother, she had personal files on there. I skimmed and looked it over...I tried to handle things like I would like it handled in my own case, but from a child's perspective, there are things you don't want to know. There are close things that are awkward and odd to see as you go through, and you don't know if there is something later that you should see. It's tough. At least with diaries you can recognize that they are a diary, and act accordingly." - P9

As P9 notes, the ethical problem was exacerbated by the interface representations. There was no way to flag files as being private or sensitive, and it is unclear whether the deceased would have made this provision even if it were available. Personal computers are thought to be just that - personal. The bereaved family members had to guess as best they could which files were meant for their eyes to see. This search was guided by the privacy attitudes - spoken or unspoken - that their deceased family member might have held.

> "She was completely ambivalent about this kind of stuff, never thought about it. If she had thought about it, she would have left instructions that it should be wiped clean because she was private...but she never thought about the implications of owning a cell phone and numbers on it as a threat to her privacy." - P8

At the same time, this uncertain and cautious searching sometimes revealed new things about the deceased person.

> "You think of your parents in a certain way...and you forget they're just like you. Sitting at her computer and getting a feel for it...it gave a bit of a window into their true life rather than what you thought their life was...the technology gives you that snapshot that physical things don't necessarily give you." - P9

Just as with physical possessions, participants discovered new identities, roles, goals, and fears about the deceased person when they went through these files. These discoveries confronted participants and forced them to reconcile their concept of the person's identity with the newly discovered information. For instance, P25 disliked her relative who passed away, but expressed some regret and surprise after looking through her files and discovering new aspects about her life.

> "We discovered after she died that she had another job we didn't know about, and that she had huge health problems like breast cancer that we didn't know about, and she refused treatment. There's lots of revelations coming out of this." - P25

As with physical possessions, excavating the computer files of the dead can be a process which confronts the bereaved with new insights, feelings, and ethical dilemmas. One way to avoid these kinds of ambiguities might be by providing software that allows

users to craft packages to be inherited or distributed. For example, we might imagine a program that allows a user to assemble a disparate, and potentially evolving, set of digital assets that they wish to give to another person upon their death. In addition to demarcating these assets as valuable, such a system might communicate the status of these assets to other people so that they are aware that an "inheritance package" exists, and can thus take steps to ensure it is maintained. Such a system might additionally permit the user to express their personality in the way that they design the package, thus preserving a sense of identity that they wish to portray beyond their death.

3.3.6 One Computer, Multiple Roles

People commonly use the same computer for both personal and professional activities. For example, a single PC can be used for playing video games, coordinating a volunteer group, and telecommuting to work. Respondents discussed how the multiplicity of life roles as enacted on a single PC raised issues when their family member passed away.

One situation where the computer serves both personal and professional roles is when the individual works at home or independently. When P14's father died, he suddenly found himself responsible for his father's film making business because he was now in possession of the videos.

> "Now I'm in charge of that [movie] catalog for him...[clients] send me a check instead of him...people have emailed me asking for one of his tapes." - P14

The number and types of roles that a computer plays in the life of an individual can change across time. This can make the prospect of bequeathing a computer to another person an uncertain prospect: an individual must not only reflect on how the computer is used currently, but also anticipate how what types of data might be on it in the future. When asked about how she would like her assets distributed upon her own death, P8 - a home business owner - pointed out that her home computer was also her business

computer, but she saw herself slowly changing its primary purpose as she moves from the work force into retirement.

> "I have a home business...it's busy and so when I am in front of the computer, I am working. I can see when I retire that I'd leave a lot more records and organize pictures and use the computer...to record lots of things, my thoughts, my stuff, my wishes, before I ever go." - P8

For other people, the situation could be reversed, with personal data stored on a work computer. This prevented the bereaved from accessing these personal files stored on business property. For example, P21's workaholic mother had personal files at work that her daughter wanted to see.

> "The school never talked to us about anything, at least not to me, maybe to my father..." - P21

Feeling cut off from one of the most important roles in her mother's life, P21 could only hope that her mother's co-workers would make good use of the contributions hidden away on her mother's work computer.

> "When someone dies and you have to replace them - they've done all this work, and who knows, it could be leading to the completion of a new project." - P21

As this demonstrates, data on a computer used primarily in one context (e.g., work) could be important to people in another context (e.g., family). When receiving digital assets, inheritors get more than just data - they inherit the roles and responsibilities associated with that data.

	Small group	*Large group*
Together	Technology gift giving Photo review	Photo collages Family videos
Apart	Telephone Email	Social networking Online memorials and obituaries

Table 3.3: Remembrance activities by group size and distance

3.4 Discussion: Using Technology to Remember

The bereaved commonly use technology to remember their deceased loved ones. This section examines the social and technological mechanisms through which this is achieved.

3.4.1 Remembering Together, Even when Apart

As Olson and Olson put it, "distance matters" [87]; and this distance becomes a large obstacle following the loss of a loved one. Bereaved family members, living in many places, must offer emotional, functional, and informational support to one another despite distance. Group commemoration is an important aspect of bereavement, and different technologies are used for this purpose, depending on group size and distance. I find organizing activities by group size and distance (as in Table 3.3) to be a helpful way to characterize technology use.

For small, co-located groups, participants described intimate, highly symbolic commemorative activities which highlighted the mourners' shared memories of the deceased. A common activity was joining together to look through photos (digital and physical). A more involved activity was digitizing, repackaging, and distributing the deceased's assets as gifts for other family members.

"I selected photos...I scanned them...and printed them out and made gifts for

my siblings." - P21

When these small groups moved apart, shared histories remained important, but photos became less of a focus. Instead, verbal storytelling and conversation became more pronounced. Some families communicated by group emails to express their emotions, and others used the phone.

> "I get my sister on the phone and we'll talk about [mom], and we'll talk about what she'd do." - P8

In larger co-located groups, such as when the entire family is present or when friends are involved, the symbolic nature of commemoration is diminished due to fewer shared, intimate memories. Instead, mourners preferred to use easily-apprehended audiovisual technologies such as photo slideshows or videos. The deceased's social involvement is highlighted through retellings of family history.

> "[Using] videos, emails and scanned photos, [we have] get-togethers where we use technology to 'paint' pictures of our family and their 'doings;' videos of anniversaries and stuff that happened." - P8

One key instance when a large co-located group joins together to commemorate is a funeral or memorial service. Participants described using computers and the internet to create audiovisual assets for use at such an occasion.

> "You know when you go to a wake, they have those collages made, with young and old pictures? We made a huge one of those."- P30

This occasion serves as a starting point for further group remembrance at a distance, possibly after attendees return home or for those who could not attend in person.

> "You see a lot of these online sites now, from the funeral homes or even from newspapers where the obituary is online, and you can post comments. Some

> people respond well, others don't...It was nice for my mother-in-law to read through things that people couldn't say face to face, or to hear from people too far away. On the Internet it's nice to share with other people besides the family - you get a stronger sense of the ripples of the person." - P9

As this quote shows, web technologies become the primary mechanism for sharing memories with many people at a distance. These range from completely public online obituaries (as above), to social networking websites where bereaved family members can more selectively share thoughts and photos with close family and friends.

> "Sometimes on Facebook I see my cousins will have a photo album dedicated to him...I think it's nice, it's a good way to remember." - P26

No matter the group size or distance, the primary "task" of group commemoration remains the provision of social support. These technologies convey the message "I am mourning too," and may comfort the bereaved.

3.4.2 Reconciling Digital Legacies with the Reality of Death

An important part of the reflective process for participants was to reconcile the persisting digital representations of the deceased with the reality of their death. Participants responded to these digital representations with a range of emotions - including regret, surprise, or even horror.

We have already remarked on the benefits and importance of photos for the bereaved. However, photos are purposefully taken, and often explicitly meant to be items for remembrance. One type of media which reveals more surprising findings, and opportunities for technological innovation, is that of voice recordings.

> "I wish I had a recording of her voice, it's the one thing I miss the most." - P21

Voice recordings, unlike photos, are often incidental and not purposefully created for remembrance purposes. In daily life, these recordings are used primarily for leaving voicemails or for functional information purposes. Hearing these incidental voice recordings, or coming across left-behind digital assets, often made respondents pause. Voice recordings conjured up memories very strongly, and took participants by surprise with how powerfully they evoked memories of the deceased. Perhaps this is because the vocalization capacity of the body ends permanently with death, while the visual representation of the body persists.

> "My husband (it was his father that died) kept his father's voice on his voice mail for a long time...we kept his answering machine message until it got too creepy." - P9

The role of the recorded human voice in this quote raises an important point. Currently, personal computer systems indicate people as permanent, structured, swappable data structures ("users"). In our digital legacies, we are represented by static, formatted pieces of information: email addresses, snippets of voice mail, and text messages. Participants reacted emotionally to this kind of representation because it did not match with reality, where we are temporary beings using a machine for a small period of time. Participants were not always emotionally able to respond to technologies which, through their ability for action, breathed life into an otherwise dead persona.

> "I got a call a couple of months from her office after she died, but it was her phone number, and I thought I was having some surreal poltergeist kind of moment...I recognized she passed away and thought 'My mom's calling me' and I froze and freaked out there. I remember that terrified me, but how excited I was at the potential to talk to her." - P21

Indeed, technologies codify and assert the life of their users. Just as texts give life to their authors, digital representations of people can animate the deceased. To remove

the digital representation, therefore, asserted the death of the individual in both the real and digital worlds.

> "Removing his email address from my email really 'finalizes' it and we're not ready to go there yet." - P9

When designing technologies which model users, we rarely take into account that these people will one day die.

3.4.3 Afterlifelogging

Lifelogging technologies have been proposed to help an individual capture and reflect on his or her life experiences [97, 70, 24]. Whether this review process is intended to support memory, tell stories, or discern activity patterns, these databases can be useful resources for the bereaved by acting as an "afterlifelog." In the absence of comprehensive lifelogging technologies, participants described their own efforts to preserve aspects of their dying loved ones.

> "I will tell you, before my dad dies (he's 90, by the way), we're going to get him to tell some stories or jokes so we can have his voice recorded, and maybe we'll video him...and put them with pictures on a DVD." - P8

Some participants who were unable to capture this kind of media about their loved one regretted they did not.

> "There are all sorts of things I wish we had done...I knew she was getting worse but I wasn't accepting she was going to pass, and it wasn't a conversation we ever had. One thing I encouraged her to do was to write us things, or because she was too weak, to [voice] record things...every time I suggested it, she was too tired, 'wonderful idea, but not today...' I don't know if there were

	Considered digital estate?	*Concerned?*	*Took action?*	*Percentage*
Prepared	Yes	Yes	Yes	13%
Knowingly Unconcerned	Yes	No	No	8%
Unsure	Yes	Yes	No	79%
Unaware	No	No	No	

Table 3.4: Archetypes of attitudes towards digital estates

some sort of technology that could help, but she was saying no to getting the equipment, setting it up..." - P21

Lifelogs do not become obsolete upon the death of the subject; rather, these databases can become afterlifelogs and support reflection, mourning, and commemoration. Of course, there are privacy concerns that are associated with inheriting such personal collections of data, and the deceased's right to privacy must be balanced against the potential for this data to support such remembrance activities.

3.5 Discussion: Anticipating One's Own Death

A death in the family can be a traumatic event, and an opportunity for personal reflection. The goal of this section is to describe the personal attitudes of the bereaved towards their own digital estates in light of the death of their family member. We do so by presenting four attitudinal archetypes which represent identifiable patterns in the survey (Table 3.4). These archetypes are presented as analytical categories; a given individual's attitudes may span across multiple archetypes, or fall into none of them. Those who had considered digital assets had an average age of 36.4, and those who did not consider digital assets had an average age of 34.4. The similarity in these ages suggests that these attitudes are independent of an age-related need to draft a will.

3.5.1 Prepared

People who match the "Prepared" attitudinal archetype (13% of respondents) indicated an awareness of their digital estate, were concerned about how their assets would be distributed, and had taken action to ensure they were distributed according to their wishes. The plans for distribution ranged from including digital assets in a legal will (as with P7 below), to creating a backup where family members could access the data (as with P42).

> "I saved everything to an external drive; not password protected; my intentions and directions for managing my personal technologies are mentioned in my will" - P7

> "My photos are stored on a spare hard drive as well as DVDs - my children will share them as well as retain possession of my website." - P42

3.5.2 Knowingly Unconcerned

The "Knowingly Unconcerned" attitudinal archetype (8% of respondents) is aware of their digital estate, but is unconcerned about how it will be handled. Accordingly, they have made no plans or directives for distribution. They see the end of their natural lives as the end of their capacity for action, and any subsequent affairs to be inconsequential.

> "I don't care what happens to my stuff after I die." - P32

> "It is irrelevant to me what happens to possessions after I die." - P44

3.5.3 Unsure

The "Unsure" attitudinal archetype (79% of respondents) applies to those who have considered their digital estates, expressed moderate concern about its distribution, but

have not taken action. Some of these respondents even had wills drawn up for their other possessions, but did not include digital assets in their plans. Even in the absence of a pre-ordained plan, "Unsure" respondents had a good guess about who might inherit their possessions.

> "I haven't thought about it at all. I think my sister would take [my computer], but I didn't make those plans..."- P26

> "My husband and I share all our account passwords so I expect he can find anything he wants after I die." - P25

3.5.4 Unaware

Individuals who are unaware simply have not thought about their digital estate at all. Because the survey raised this issue, all respondents fall into one of the three previous categories. However, there are certainly a large number of people who have never considered their digital estates and have not yet formed an attitude in response to it.

3.6 Opportunities for Design

Based on the results of the survey and interviews, I present a concise list of opportunities for design surrounding bereavement. These opportunities can be thought of as a series of problems to be solved by the research and design communities.

- *The Digital Natives Problem*: For younger people - so called "Digital Natives," many pieces of information that might be valuable to inheritors are digital rather than physical. While older generations do not currently face this problem on the same scale, there will be a growing need to address digital inheritance more systematically as younger people make use of personal technologies of more varieties and with increasing frequency before passing away.

- *The Claiming Data Problem*: Digital devices need better affordances for inheriting - the digital equivalent of "claiming" or bequeathing items is an unsolved problem. We need to blend the benefits of digital devices with the physicality, accessibility, and meaningfulness of personal artifacts.

- *The Will-Drafting Problem*: Digital assets are easily forgotten in the process of drawing up a will. Systems which make the distribution of assets simpler would help ensure that the wishes of the deceased are carried out.

- *The Many People, One Computer Problem*: We must recognize that technologies frequently belong to a household more so than to a single person. When people in the household die, other household members logically inherit the devices, with the "gatekeeper" of the data distributing assets on an as-needed basis. When designing domestic technologies, we must remember that these home technologies will always have at least two users: the primary user, and the inheritor.

- *The Meaningful Devices Problem*: Some people consider digital devices to be less meaningful than other personal items like clothing or jewelry; for other people, these digital devices carry great emotional meaning. If a device is being designed to be treasured across generations, it is important to consider not only what makes the device special, but how and why users might attach emotion to the device.

- *The Role Inheritance Problem*: Whenever a person inherits data, they are also inheriting a set of social and practical role commitments associated with that data. Ensuring that these commitments can be met easily by inheritors is an unsolved design problem.

- *The Social Support Problem*: Communication technologies such as email, social networking sites, and phones are used by the bereaved to provide support to one another following a loss. Digital assets such as photos can help to underpin these so-

cial support exchanges. Tailoring technology to this support process could provide comfort and solace to bereaved individuals.

- *The Reconciliation Problem*: Bereaved people have to face uncomfortable situations when they handle the digital legacies of those who die. When designing technologies which represent living people, we must consider how the technology will represent the person after they die, and if that representation will cause discomfort for the bereaved.

- *The Afterlifelog Problem*: Existing lifelogging technology can be used and reviewed, with new meaning, by family members of the deceased. Reimagining the role of lifelogs for use after the death of their subject - "afterlifelogs" - could provide new, unique opportunities for bereaved family members to remember their loved ones, especially if they provide access to new types of media (e.g., voice). Determining how to find and present the important pieces from this large dataset, while simultaneously ensuring the privacy of the deceased, is also a challenge.

- *The Estate Planning Problem*: Remember that people hold a variety of attitudes towards how their assets will be distributed, with the majority of them unaware that it will even be an issue. Help the "Prepared" make plans, guide the "Unsure" and "Unaware," but do not hinder those who are "Knowingly Unconcerned."

3.7 Limitations

Because a self-selected convenience sample was used for this survey, it is likely that the results will vary in the entire population of bereaved individuals. It is also likely this sample was more technologically comfortable than the general population because the survey was conducted via the Internet. While ethnicity and religious affiliations were not solicited in the survey or interviews, responses may be influenced by these factors.

Finally, the concerns expressed by the bereaved within 5 years of the death may differ from concerns after longer periods of time, or at times closer to the death. Respondents might also not be the best possible family member for detailing what happened to particular items in the deceased's estate, and their memory of the past might be inaccurate.

3.8 Conclusion

This first study in the thesis explored how bereaved individuals inherit, use, and reflect upon personal digital devices after a death in the family. The results of both the survey and interviews provide the HCI community with a foundation for structuring research, adapting existing systems, and envisioning future technologies. These insights may improve the design of personal technologies such that they remain useful tools for the bereaved, rather than sources of discomfort or confusion.

As outlined in the 10 opportunity areas above, there are many potential ways that technology could be designed, adapted, or developed to address aspects of bereavement. In the next chapter, I describe how I selected the "Social Support Problem" as the domain for further investigation in my thesis, and how my investigations in this domain led to considerations for design.

Chapter 4

Understanding Social Support in Bereavement

In the previous chapter, I described a study that examined how the bereaved encounter personal technologies following a death in the family. The responses from that study formed the basis for ten areas for potential technological intervention. All of these areas present challenging and interesting questions for technology designers. In moving forward, I narrowed my focus to address the "Social Support Problem" problem in particular.

This problem space refers to the many ways that the bereaved used communication technologies like email, social networking sites, and mobile phones following a loss in order to console one another and offer support (see Table 3.3). While existing technologies currently meet some of the support needs of the bereaved, we have the opportunity to tailor or create communication technologies that address these needs with more nuance and sensitivity. Current communication technologies such as email and social networking sites are general purpose tools, and while the bereaved may find them helpful and available, their unique circumstances may at times make them inappropriate for discussing grief and exchanging support. These tools may address too wide an audience (e.g., Facebook), or be socially inappropriate in some situations (e.g., phoning or texting late at

night). They may demand too much attention, or fail to convey sentiment appropriately at a distance. Phase 1 suggested not that these technologies are poor, but that there may be room for tailoring and improvement.

Addressing this problem, from the set of ten presented in Phase 1, is an important and actionable first step in exploring technology design for end of life issues. As discussed in Chapter 2, social support has long been associated with positive health outcomes in medical studies, and an established body of literature has suggested that it is also beneficial in coping with grief during bereavement. Designing technologies that provide this support more sensitively may lead to greater adoption, usage, and derived benefit. In turn, such systems may (in the long-term) help bereaved users move towards coping strategies that they find personally useful and reduce the pain of grieving.

From a user-centered design perspective, exploring this space is also a logical first step because the nature of the problem suggests an identifiable set of initial stakeholders - the bereaved, their families, friends, community organizations, and so on. Furthermore, because the bereaved already have firsthand experience with social support processes, their ability to speak from their lived experience allows them to provide more insight into the design of technology that meets their needs. Community groups for social support are also readily accessible, and provide an opportunity to investigate how support is offered at both the personal and the organizational level.

Moving forward, I chose to work with community groups where I performed three focus groups with bereaved parents. I also participated in professional seminars and conferences on bereavement. Based on these experiences, I derive a set of empirically-grounded considerations that speak to issues in the HCI community. Structured into three broad categories - interpersonal communication, new ways of being in the world, and materiality - and illustrated with the results of my fieldwork, these considerations can help designers better understand, interact with, and meet the needs of the bereaved as part of their design process.

4.1 Research Settings and Participants

Before describing the method and findings, I first comment on the research setting and participant selection process. In this stage of the thesis, I conducted three focus groups with middle-aged bereaved parents recruited from two community organizations (see protocol in Appendix C). Two focus groups were performed at Bereaved Families of Ontario - Toronto (BFO) [bfotoronto.ca], and the third was performed at the COPING Centre in Cambridge, Ontario [copingcentre.com]. These organizations were selected as sites for investigation based on the format of their support group offerings and at the recommendation of a local psychologist. Both BFO and the COPING Centre share a set of key organizational values:

1. *Like-loss membership.* Multiple groups run simultaneously, and are split up based on the type of loss. Examples of recurring groups include: parents who have lost an infant, parents who have lost a young or adult child, individuals who have lost a spouse or partner, and young adults (ages 18-30) who have lost a parent or sibling. All members of a group - including the trained facilitator - must have experienced the same kind of loss. This value stems from the acknowledgment that those best suited to provide support must have experienced the loss themselves.

2. *Peer support.* The facilitators of the group are trained by the organization to ensure safety and respect among group members. Importantly, the facilitators are not professionals (i.e., psychologists, counselors, social workers). There is an emphasis placed on, as one BFO volunteer phrased it, "not fixing." Facilitators help start and guide discussion, but do not prescribe actions or treatment for dealing with grief.

3. *One-on-one screenings.* Before attending a support group, each potential member must first complete a one-on-one interview with a facilitator. The purpose of this session is to ensure that the individual is in a psychological state where they are

> ready to participate in a group effectively. The time between the death and the one-on-one varies from person to person, as does the time between the one-on-one and the beginning of the support group. This reflects the organizational understanding that we all grieve differently, and on different timelines. That said, the one-on-one generally occurs within a year of the loss and the participant is usually placed into a group within 6 months after the one-on-one.

At these organizations, support groups usually consist of 10 weekly sessions of 2 hours each. Each week has a pre-determined discussion topic, such as discussing the memorial service or funeral, or dealing with friends and family members. However, group facilitators are free to deviate from these topics based on the group's interpersonal dynamics and interests. Groups range in size from 5-12 people. Both BFO and the COPING Centre maintain strict policies surrounding confidentiality and privacy. For this reason, we were not permitted to observe support group sessions. Instead, participants for this study were recruited by community organizers who volunteered at each of the two locations. At BFO, previous support group participants were recruited by placing an advertisement in the BFO newsletter. At the COPING Centre, focus group participants were selected and contacted by the community organizer from her registry of previous support group attendees.

Both organizations offer support groups to individuals who have experienced a wide range of losses. For the focus groups described in this study, I worked only with bereaved parents. Bereaved parents were suggested by the administrative contacts at both locations for two primary reasons. First, losing a child is so traumatic that parents are likely to seek out support; the organizers at BFO and the COPING Centre thought that they would be very active in a focus group. Second, bereaved parents were seen to represent a group familiar with technology, and therefore able to reflect on their own computing experiences during the focus groups. The focus groups took place on site at BFO and the COPING Centre, and involved a total of 24 bereaved parents who had completed a

support group in the past 5 years (Table 4.1). Community organizers co-facilitated each focus group and were present throughout the focus groups.

Group	Date	Location	Participants
FG1	March 4, 2010	BFO	3
FG2	June 14, 2010	COPING Centre	16
FG3	June 17, 2010	BFO	5

Table 4.1: Focus group participants

Focus groups were conducted at these particular community organizations for several reasons. First, I sought to gain perspective from bereaved individuals who had, or were currently, sought out support, rather than the general population of bereaved individuals who might not feel the same need. Working with people who self-identified as in need of support allowed the opportunity to ask questions regarding their expectations and satisfaction before, during, and after a group, thus situating their responses around a specific shared event. Second, using a focus group approach in some ways mirrored the participants' previous support group experiences. The focus groups took place in the same rooms where support groups usually take place, and with trained facilitators represented as part of the group. This approach allowed participants to respond to ideas raised by others and compare and contrast their experiences in a known and safe environment.

Following a discussion (as outlined in Appendix C), participants were given prototypes for a website and an ambient display that were intended to demonstrate two design ideas (Appendix D). One prototype demonstrated an example of augmenting the existing website for BFO or the COPING Centre to include a social networking component where members could create discussion groups, memorials, and a profile. A second prototype demonstrated the form factor and a mockup of an ambient display in the home that delivered support group messages to a picture frame that showed a photo of the deceased.

Preferences regarding these two ideas were elicited and discussed in the group setting.

All focus groups were audio recorded and transcribed. Unfortunately, individual participant data was not collected as part of this phase, and attribution of quotes to individuals is not possible based on the audio transcription. Each transcript was then analyzed using thematic analysis [4]. No pre-determined themes were used to analyze the transcripts, and emergent themes were organized into categories.

To gain a fuller understanding of the bereavement experience from the perspective of secondary stakeholder groups, I also engaged in immersive activities intended to help familiarize myself with other aspects of bereavement. First, I volunteered to redesign the website for BFO. In so doing, I was able to learn a great deal about how the organization operates through regular meetings with members of their board of directors and communications outreach teams. Second, I participated in a 5-day retreat as an invited guest to the International Work Group on Death, Dying, and Bereavement (IWGDDB) [www.iwgddb.org] to cultivate an understanding of current topics and theories in the professional community. The IWGDDB, established in 1974, consists of prominent international thantology researchers and practitioners working in psychology, psychiatry, palliative/hospice medicine, nursing, sociology, social work, religion, the arts, family counseling, funeral services, and so on. The organization houses a number of interest groups that periodically publish documents concerning key issues in thanatology; at the retreat, I participated in a special interest group on technology and the Internet. These conversations were accompanied by opportunistic observational field work in cemeteries, funeral homes, and religious sites. Finally, I attended two weekend-long seminars on bereavement counseling offered by the Faculty of Social Work at the University of Toronto. These seminars covered historical and contemporary theories of grief, and offered the opportunity to participate in activities that might be offered to the bereaved (e.g., art therapy).

4.2 Design Considerations

Based primarily on the analysis of focus group transcripts[1], I present a set of design considerations. These considerations are grouped into three themes: interpersonal communication, a new way of being, and materiality. All three themes are present in all three of the focus group transcripts. I find these themes house many of the design-oriented findings I uncovered from my experiences engaging with the topic, and give purchase to a larger set of considerations that may fall within these spaces. The goal with these considerations is to provide designers working in this area with a set of issues to think about as part of a user-centered design process. These design considerations are later applied to the design of a website called Besupp in the following Chapter (see Section 5.2).

4.3 Interpersonal Communication

When a person dies, the surviving family members find themselves in a unique social situation both privately and publicly. If we examine the family unit's internal affairs, the death leaves a gap in the family structure. This gap results in a number of changes. Family members can find themselves in a new role (e.g., a sibling becoming an "only child"). It has also been shown that family members frequently have different grieving styles: children, for example, often grieve through play. Some people demonstrate an instrumental style of grief which is focused on "doing," while others might adopt an intuitive style which is more focused on "being" [66]. These variations in grieving styles may push family members apart; furthermore, bereaved family members may place anger or blame on other members. Studies show that the strain on marriage increases following the death of a child [96].

Concurrent with this private social restructuring within the family, the family is placed into a very public position. Friends, relatives, co-workers, and other people who knew the

[1]Quotes in this chapter are attributed to the originating focus group as such: FG1, FG2, or FG3.

deceased will appear "out of the woodwork" to console this family and pay their respects. Considerable interpersonal interaction is required to maintain good relationships with condolers (such as returning phone calls, writing thank-you letters, or receiving guests into the home). These relationships can also become strained due to an incongruency in the amount of time considered to be appropriate for the grieving process. For example, a boss might expect her employee to return to work within a particular period of time, even if the employee feels that they need more time to grieve. In addition, the bereaved family must work with hospitals, coroner's offices, funeral homes, cemeteries, lawyers, and other public institutions in order to properly handle the body and make arrangements for a memorial service.

As we can see, in some cases, the social circumstances facing a bereaved person can be very busy and potentially overwhelming. When designing technologies for the bereaved, an appreciation of the messiness and scale of interpersonal relationships can help ensure that systems are designed appropriately. I describe here two considerations which designers should be aware of when designing systems for the bereaved, and in particular, communication systems.

4.3.1 Circles of Sympathy: Managing Communication Availability

In my fieldwork and research, I have found that bereaved parents frequently constricted their communicational availability and frequency. This might seem counterintuitive; in their emotionally devastated state, we often think that these vulnerable people may need substantial help and sympathy. While the focus groups and research demonstrated that bereaved parents appreciate the sentiment behind gestures of sympathy or compassion, the reality of receiving social support often plays out differently - it is far more nuanced. Bereaved parents described adapting their technology use and daily behaviour to monitor what they say to others, constrict who can contact them, and adjust when they are

receptive to communication. For example, one woman described changing the way she uses Facebook to reduce who can see her status updates, and controlling more closely what she posts:

> "I am on Facebook, and I go back and forth between wanting to say these really personal things which I don't end up saying, and just wanting to say nothing at all." - FG 3

One way to map out the social networks of bereaved people is as a set of concentric circles, with inner circles designating higher levels of openness and trust with respect to the loss (similar to the notion of communicational "clans" by Moncur [75]). For the bereaved parents at the grief support centers I spoke with, the highest levels of trust and support came not from siblings, children, or close friends - but from other people who had experienced a similar kind of loss.

Participants felt that others who had suffered a similar loss were less judgmental, and that they could be more open in their communication. For example, participants described being able to share moments of laughter with the other parents in their support group - an act that often surprises or offends outsiders who presume the bereaved to be constantly devastated. The shared experience of losing a child gave these parents more credibility in the eyes of other bereaved parents. They described being more likely to listen to their suggestions on helpful books, community resources, events to attend, and so on.

> "**Man:** At BFO, it's nice to be with people that have lost a baby.
>
> **Woman A**: Right.
>
> **Woman B**: Yeah, or people who have lost a child or something to suicide... like that's a community in and of itself, right?" - FG 1

While the support group setting permitted an opportunity to communicate unguardedly and openly, it only occurred for 2 hours each week, and over a period of 10-12 weeks.

The majority of the bereaved parents' time was spent managing their contact with family and friends - a much more delicate act. Talking to these "outsiders" was difficult in part because it made parents feel responsible for alleviating the outsider's discomfort surrounding the topic. As a result, the bereaved parent may find themselves in a position where they are consoling the consoler, rather than the other way around.

> "People want to find a way to talk to you and let you know they're thinking about you, but in a way that's not going to make them feel too uncomfortable." - FG 1

This added to the emotional stress associated with communicating with outsiders. Bereaved parents also described how conversation with outsiders was generally avoided - one study found that 80% of statements meant to support the bereaved are ultimately "unhelpful" [25]. Statements that were considered helpful tended to be open-ended and empathetic (e.g., "Let's spend time together." or "Tell me how you're feeling."), rather than closed-form or observations of the situation (e.g., "Time makes it easier." or "She led a full life."). The bereaved parents were well aware of how uncomfortable well-wishing condolers felt, but were unable to help them.

> "Face-to-face was terrifying to people because... What do you say to someone?" - FG 1

Vale-Taylor, in her studies of families coping with a death, also noted the difficulties that the bereaved have with communicating with the outside world: "most interviewees said that they often sought to 'manufacture' reasons to get together with others to give them an opportunity to talk but found that after a while other people were embarrassed by this and they had to try to be careful not to risk losing friends" [110]. This highlights the tension between desiring to communicate, but ultimately being disappointed.

To alleviate this stress, bereaved parents will often purposefully distance themselves from outsiders who have not experienced a loss. One study found that bereaved "fathers

experienced social isolation but also deliberately isolated themselves from human relationships" [1]. Parents achieved their desired levels of isolation in two ways: physically and technologically. By staying out of the workplace and public eye, parents could find a safe place to grieve.

> "We hid out at home a lot, so there wasn't a lot of face-to-face with many people. Just mainly your spouse." - FG 1

Parents also availed themselves of technological forms of isolation - they described turning off their cell phones and using less personal media for communicating in order to prevent lengthy unwanted conversations.

> "I didn't want to make phone calls, I didn't want to have that conversation. So, I'm writing an email telling people that I just lost my kids, and it felt weird at the time." - FG 1

In other words, participants valued the fact that various technologies permitted, or prohibited, different types of conversations to occur. Emails, as mentioned above, were seen as less emotional, and allowed this parent to simultaneously notify all of her friends and coworkers that she would be unavailable, and avoid a series of telephone conversations where she would have to explain her absence repeatedly. They would not have to see her cry, and she could avoid making others feel burdened with her grief. At the same time, email is frequently associated with professional business or mass broadcasts, and was seen to be at odds with the personal profundity of the situation.

It is also important to mention that levels of availability do change over time. People who are seen as extremely helpful in the short-term may be less available in the long-term. For example, many participants in the focus groups described how they continued to talk to some members of their groups past the end of their formal group sessions, but that their contact tapered off over time. In addition, we often think of bereaved parents

needing a great deal of attention soon after the death, and less thereafter. However, as described above, parents needed time to grieve immediately following the death, and then - months later - found that the support that was once there was now lacking: the rest of the world had "moved on." Indeed, just as the grieving parent comes out of their despair, finally ready to talk about their loss, the rest of the world seems to have closed off.

> "You count on the cards, you count on the emails, and you count on people acknowledging your loss. And when it stops happening, it feels really empty. You feel really alone, and incredibly lonely." - FG 1

In sum, while we often think of communication from the extended network as being desirable, reflecting on this design consideration has shown us that it sometimes can be unhelpful and potentially an additional burden. For designers working with the bereaved, an awareness of this shifting, complicated social world can be an asset. Technologies must be designed to accommodate an asymmetry in availabilities and a potential desire for isolation and periods of silence. To this end, we may also benefit from considering that not all kinds of support are treated with equal appreciation - graduated circles of trust and support exist. When communication does occur, it becomes important for systems to transmit sentiment appropriately, while potentially helping outsiders to relate to the vulnerable emotional state of the bereaved. The bereaved choose among email, telephone, texting, and other forms of technology-mediated communications to accommodate their emotional availability, and systems for the bereaved should consider the trade-offs associated with various forms of communication.

4.3.2 Storytelling and Narratives

Sharing stories and memories is a key way in which bereaved parents review, share, and attach meaning to the loss they have experienced. Stories allow the bereaved to place

structure around the life events of the deceased and relate those events to their own life. Stories can also be used to speculate about "what-if" scenarios and attempt to make sense of the death. The power of stories is so strong that professionals may even involve them: "[in] narrative therapy, the story is treated as the basic unit of experience and serves to guide people in making sense of new experiences" [77]. In this clinical perspective, telling the story of the loved one's life, or the story of one's own loss, is a therapeutic activity of the first form.

Sharing stories with others serves multiple purposes. In the focus groups, being able to tell the story of the loss was seen as a prerequisite for active participation in a support group, and an important milestone in the grieving process. Unlike being in the "real world" where the story is often edited and amended so as not to strain relationships, the support group setting allowed participants as much time as they needed to be able to tell their whole story:

> "I always think of this as a form of storytelling - group therapy. It's not that we come here as storytellers, but we can really tell the experience of our loss in detail." - FG 2

Outwardly, making a story visible to others helps to concretize the loss and affirms it in the public history. It says "my child existed." From this, there comes a sense that by existing in a collective consciousness, the child is honoured and the memory "lives on." Over time, the acknowledgment and reaffirmation of the story by others helps to foster emotional closeness and the perception of support for the bereaved. In this case, stories are meant for public or semi-public audiences and are adjusted accordingly.

A second way that stories become powerful for the bereaved is in their ability to make meaning out of coincidence of the world. Like all people, grieving parents created stories not only to tell to others, but to tell to themselves. One mother described how the number 12 influences the way that she privately tries to make sense of her son's death.

> "There are many [memory] triggers for us... and they do affect you. For me, the number 12. My son was a hockey player and he wore the number 12. He died on the 12th. So for me, so that number is a big thing. But to come up to you and say 'I saw the number 12 today,' you know, I don't talk about it, but I see it, and it connects with me." - FG 3

Storytelling also helps the bereaved explore potential "what-if" scenarios both concerning the circumstances leading up to the death, and how the deceased would be experienced today if he or she were still living.

> "My wife did something wonderful, this is on his birthday, she wrote a book about two pages, about what [our son] would be like if he were still alive, how old, what he would be like as a one year old. And she talked about how he would be interacting with every other member of the family." - FG 1

Over time, stories written for oneself or for others to read can both be considered as part of family legacy. As the quote above also demonstrates, one goal for telling stories can be to document and remember family life. Writing stories about family members who have passed away is a way for future generations to learn about their ancestors and genealogy. In bereavement, stories are told and adapted for public, private, and personal reasons, and may be crafted and told for current or future audiences.

Finally, storytelling activities such as those described above can be fruitfully supported by both existing and emerging technologies. Bereaved people are known to use Facebook, specialty memorial websites, and other web-based systems to share stories widely [67, 120]. Emerging technologies such as ubiquitous computing devices for storytelling could also potentially be useful ways for bereaved people to tell the stories of their loved one's life and their own losses [44]. These technologies create opportunities to revisit these stories by placing digital mementos in new contexts, and open up opportunities to frame ongoing life events against the past and future.

4.4 A New Way of Being

Grieving parents find their lives turned upside down by their loss. Buckle and Fleming's work with bereaved parents describes how "[t]he fracturing of one's assumptive world results in substantial psychological upheaval, and the reluctant recognition that the world is no longer safe, orderly, and fair leaves bereaved parents feeling fearful and vulnerable" [17]. As a result of the profound and enduring grief that parents experience, their daily routines and attitudes are changed forever. In the years that follow the loss, the bereaved parents may struggle to regain a sense of normalcy and routine. Working with bereaved people requires an acknowledgement of the profundity of grief, and the design of technologies for the bereaved must accommodate the ongoing, long-term needs experienced during grief. We present two considerations which speak to this set of needs.

4.4.1 Permanence and Continuity

In Western society, we rely heavily upon medicine for remedying the ills we experience both physically and psychologically. Perhaps in part due to this, many people expect grieving parents to "recover" from the loss at some point, and return to their pre-loss habits, attitudes, and feelings - as if the wound inflicted were a physical cut that would heal and, with time, be "good as new." Both our participants and clinicians reported that this concept of grief is increasingly being usurped by an understanding that grief is a process without a clear end [119]. In other words, it is a permanent change in worldview.

Acknowledging this perspective is a helpful way to work with the bereaved. In the focus groups, bereaved parents praised the peer-support model offered by the community organizations, and the emphasis that the two organizations placed on "not fixing." Instead of trying to focus on improvement in mood or returning to a pre-loss sense of normalcy, these groups offered a time and place for parents to simply share and listen.

"For me it was a lifesaver because I could come here and talk about how I

> loved that baby. And you are the only people that could understand that. And because I could talk to everyone about how much I loved him, I could be less frustrated with everyone else and less angry at everyone else. And that's just tortured by the way that we don't get it in our culture about how awful it is to lose a baby because babies aren't supposed to be lost. We just don't talk about that." - FG 2

This, in turn, allowed the parents the opportunity to acknowledge and accept the fact that their lives would never be the same again. One clinical psychologist described that in his practice he often likens the aftermath of losing a child to being like "an alien from Mars." While the bereaved can operate and function, there are many levels on which they feel they can no longer connect to others or their comparatively mundane concerns.

> "So I just felt like their lives were... I was trying to act like my life was able to go on like theirs, like their day to day didn't change but mine did, and I couldn't find that connection with them. But here, I did." - FG 2

If grief is part of everyday life for a bereaved parent, then how do the parents accommodate the loss on a daily basis? One of the theories which has gathered support in the bereavement community is that of continuing bonds [52]. This perspective argues that instead of "getting over," or compartmentalizing the loss, the bereaved instead renegotiate the relationship they have with the deceased. They may still talk to their loved one, include them in family celebrations and rituals, and otherwise continue their relationship with the deceased. While professionals originally perceived this to be potentially a maladaptive response to grief, this perception is increasingly changing. Both the professionals we encountered and the bereaved we spoke with told us that the continuing bonds model rings true; it meshed well with the professionals' encounters in their practices, and with the lived experience of bereaved people in the focus groups and community centers.

As a designer of systems for the bereaved, it is important to share this same value: that the software being developed does not aim to "fix" or "restore" the person to their pre-loss state. We may too easily fall into the trap of designing systems which espouse a sort of medical-rehabilitative model, wherein the user is expected to "improve" over time. Rather, sensitivity to the permanence of the loss indicates that the bereaved would prefer open-ended systems that do not require consistent attention and are designed to operate for long periods of time.

4.4.2 Finding "Something to Do"

So, if the bereaved are in a state where they are permanently changed in thought and emotion, there must be manifestations of this change to be found in their behaviour as well. Indeed, this is the case, as a growing body of research and accounts from the bereaved demonstrate.

The actions surrounding grief have been the subject of considerable study, and trace back to Freud's *Mourning and Melancholia* [36]. Freud argued that we invest life force - the libido - in our relationships with other people; upon death, the goal of grief was to divest and reclaim this energy in a process called anti-cathexis. More modern research captures this same notion, observed under more rigorous and verifiable circumstances, within the idea of "grief work" [105]. The "grief work hypothesis" suggests that grief requires, or is facilitated by, the performance of particular physical or mental actions such as crying, building a grave, or praying. While it should be noted that not all people find these types of activities to be helpful, these sentiments were echoed by participants in the focus groups:

> "Now, I want to do something in memory of him, in honour of him." - FG 1

How might a bereaved person "do something?" What kinds of activities might be interesting for informing design? As noted by Vale-Taylor in her hospice-based study,

"remembrance appears to be a journey made up of many small daily rituals, some of which are generic to bereaved people and some of which are highly individualistic" [110]. One way of considering these activities, for purposes of design, is along two dimensions: group vs. individual, and prescriptive vs. creative. Note that I suggest these labels as devices for thinking about potential systems designs, and not representative of the entirety of activities a bereaved person might undertake as expressions of grief. Further to this point, activities can (and often do) have aspects of all four devices.

Group/prescriptive types of grief activities are those which are shared among a larger social group and come with significant structure intact. One example is a candlelight vigil, where a group of mourners all perform the same simple activity in solidarity. Religious activities like the Jewish tradition of "sitting shiva" are also similarly prescriptive and group-oriented. Another example from the focus groups is the "Trees of Light" event. In this event, BFO members can donate money to the organization and receive a paper dove ornament in return. The member then writes the names of deceased loved ones on the dove and adds the ornament to a large tree in Toronto City Hall during the holiday season (Figure 4.1). The mourner does not need to plan the activity. Instead, the steps and materials are prescribed by engaging in this ritual. The focus is on acknowledging that other people are experiencing the same kinds of feelings, and that there is communal support.

Group/creative grief activities maintain the same collective format, and offer bereaved people the opportunity to come together to recognize and support each other. However, these types of activities involve significant creative processes in parallel and unison. One excellent example is the AIDS quilt, which is described as "the largest on-going community arts project in the world" [aidsquilt.org]. Bereaved family members who lost a loved one to HIV/AIDS can create their own unique square of the quilt, which is then stitched together to form the whole. The AIDS Memorial Quilt Foundation provides information to guide people in creating a square, but the actual design of the square is a creative

Figure 4.1: Doves adorns one of the Trees of Light in the BFO Toronto 2010 ceremony, demonstrating a prescriptive group activity. Photo from [bfotoronto.ca].

Figure 4.2: Panels from the AIDS quilt, an example of a creative group activity. Photo from [www.aidsquilt.org].

endeavour undertaken by the bereaved person. Panels are continually added, and the quilt is placed on display in locations throughout the United States (Figure 4.2). Other creative activities such as painting, writing, or crafting have been successfully used with children and adults as a therapeutic means of "working through" grief in a group format [105].

Individual/creative activities share the same emphasis on creativity and self-expression. However, the steps or format of these activities are not handed down from an outside entity. Rather, they are created, maintained, and developed by an individual to serve his or her own needs. Technology increasingly plays a role in such expressive acts. One woman in the focus groups used a website to create a slideshow of digital images and music:

> "And I did a video montage, and you just upload all your pictures and you pick a song, so I had this special song, and you can play with them. You can make them slide in from the left or right or down, or fade in or dissolve or whatever." - FG1

She later went on to design and publish her own baby book for children who had not been carried to term (Figure 4.3).

> "I don't have a baby book for [my son] because filling a normal baby book just would not feel right, it would feel incomplete. So actually, recently I decided to design a baby book so it would actually be - the graphic designer's doing the pages right now. But um, so one of the things for publishing this book was I was looking at publishers at the beginning, I'm gonna soft publish it now." - FG1

In these cases, the activity's audience is unclear or non-existent; rather, the individual creates their own form of comfort from performing these activities. Artifacts created

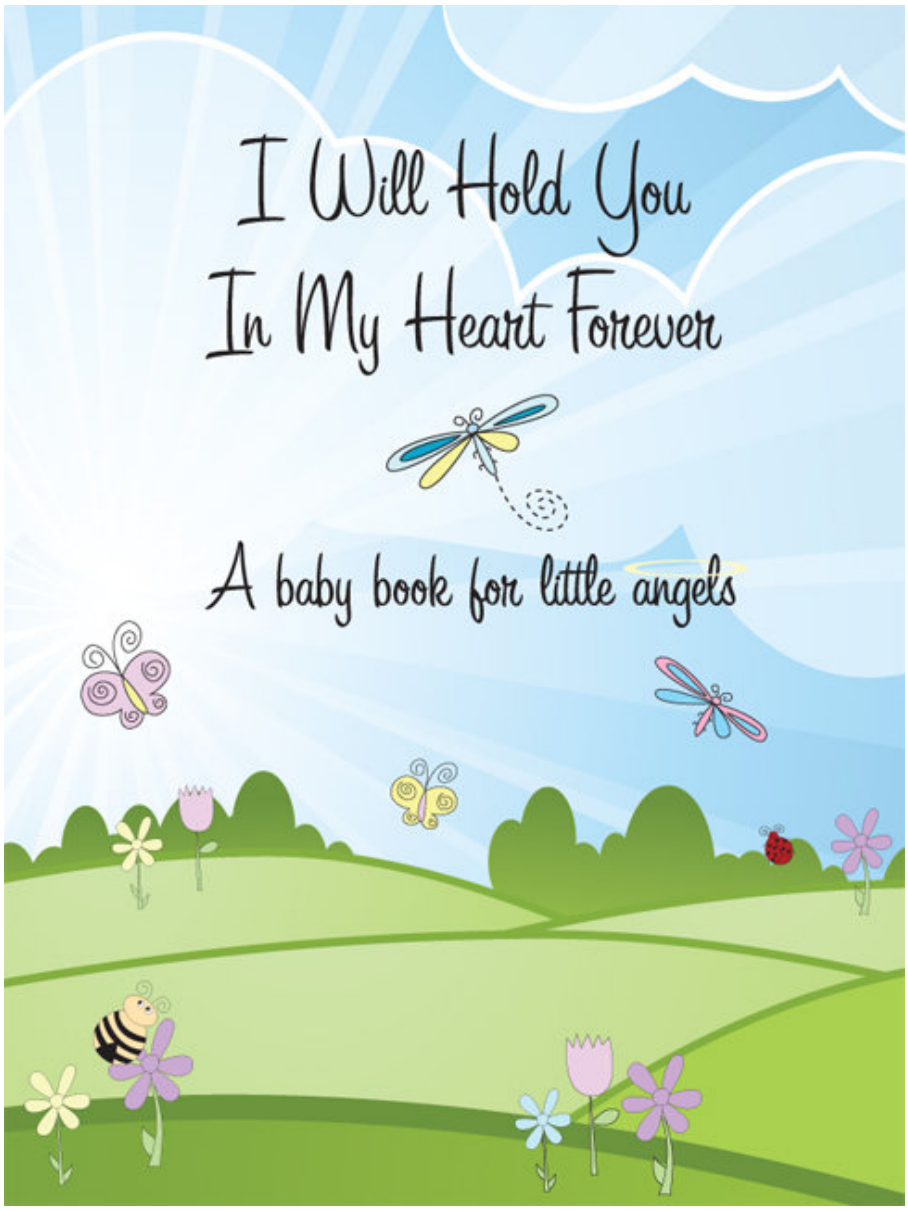


Figure 4.3: Cover for the baby book designed by a participant as an individual, creative activity [http://www.facebook.com/foreverheartbabybook].

during these expressive acts may then be shared with others at a later time when, and if, the individual chooses.

Of course, it is important to note that not every bereaved person may find these kinds of activities beneficial or desirable. Instrumental grievers, in particular, may be more inclined towards these activities due to their pre-existing orientation towards externalizing and channeling grief into activities [66]. In addition, artists and other creative people may find the creation of a new work to be a fulfilling way to honour and remember the deceased. Figure 4.4 shows an art installation observed during fieldwork at a funeral home in Germany. Created from the love letters of his deceased grandparents, the artist created this work as a way to grieve their deaths and symbolize their love for one another.

Individual/prescriptive activities are often suggested by peers, counselors, or self-help books as ways to "work through" grief. Examples of such activities might be keeping a journal or reciting prayers. These types of activities have the benefit of giving the bereaved a set of meaningful actions to perform without requiring the planning or overhead of more creative endeavours. They can be performed at any time as well. Computing and the Internet can provide a continually-present scaffolding for suggesting, organizing, and supporting these types of individual activities.

In examining these different ways of "doing," technology designers can find unique perspectives on how they might design a system. What types of interactive procedures are involved, and who will be able to view or interact with digital artifacts, becomes very important. Interacting with a system can be an opportunity to create and experience grief or other emotions, and in so doing, empower the user to make sense of their experience [45]. For those working in the domestic HCI space, there are rich opportunities: "informal rituals are far more important than the large planned events because the informal rituals occur and serve to sustain people in the context of their daily lives" [110]. Technologies could potentially fulfill a role similar to these rituals, or alter the way that existing home rituals occur.

Figure 4.4: "Reisegepäck I" by Ulrike Oerter, as an example of a creative individual activity to mourn the deceased. Photo taken by the author.

4.5 Materiality

Thus far I have shown how the bereaved face complicated social and psychological worlds of which system designers and researchers should be aware. Recalling the rich ways in which physical and digital mementos were used by the bereaved in Phase 1, I now examine more closely how special objects and places - the material "stuff" of life - is drawn into these practices.

4.5.1 Heterogeneity, Sediment, and Upkeep

The ways in which bereaved people treasure and keep special possessions are elaborate and complicated. The professional death, dying, and bereavement community did not focus on these kinds of possessions until Volkan's 1972 paper on "linking objects" [112]. He describes encountering in his psychiatric practice a number of grieving individuals who formed troubling relationships with particular objects - perhaps a deceased loved one's shirt, handkerchief, watch, or some other trinket. Keeping these objects is not what troubled Volkan - rather, it was the way in which the griever's identity and relationship with the deceased were bound up in the object. If the griever lost or misplaced the linking object, it resulted in considerable anxiety or desperation - comparable to re-experiencing the death.

Since then, additional work has examined how the material plays a role in grief and bereavement. Hallam and Hockey provide a sociological account of how objects mediate our relationships with the deceased, with ourselves, and with the living [42]. Recently, Odom et al. described how inheriting possessions functioned as a social act, influencing acts of communication, remembrance, and ritual performance [83].

While the literature demonstrates the importance of materiality in the lives of the bereaved, I would like to draw attention to the mechanics of working with these objects. In the focus groups and site visits, I noted three thematic ways in which the be-

reaved related to their possessions: heterogeneity, sediment, and upkeep. These notions re-emerged during the focus groups with bereaved parents, and provide an orientation towards the building of "things" for the bereaved.

Heterogeneity refers to the wide variety of materials that are meaningful to the bereaved. From gravesites to the home, the bereaved's choice of meaningful objects was rarely of a singular type of object - for example, only photos or only clothing. Rather, many sizes, shapes, and materials came together in special places in order to scaffold the memory of the deceased. One example from the focus groups came from a woman whose infant was stillborn; she described how she gathered together into a box the small amount of materials that testified to his life:

> "I guess it just gave me something to do. It's what I have left of my child. Like the items in it, for instance, I have the ultrasounds, I have pictures from the hospital when he was born, and blankets, a hat, cards - I keep all the cards people send me - and I think that's what I have in that box. I keep it in the living room. I just want to feel like he's still there. And I keep fresh flowers near it." - FG 2

The assemblage of these items was not a singular occurrence. Rather, this collection bears traces of layering, or *sediment*. New items are added, while others may be removed, over a long period of time. The inclusion and removal of each item in the collection results in a "re-reading" of the other items, as the story of the grief unfolds. An excellent example of this comes from a bereaved father who described the "memory box" placed at his adult child's gravesite.

> "At our daughter's grave, my son-in-law has a concrete box. It's for memories. People who come to the grave, friends, or whoever, leave a card or an object or a note... It's a memory box... To see that people who have been there, which of your friends, it's nice." - FG 3

We see here that it is not so much that the items are collected together at a single point in time, but that the items maintain their cohesion over time, and grow. We may also see similar examples in public memorials such as the one dedicated to Princess Diana [104]. Additionally, the creation of such collections is a way of communicating sentiment among groups of people who are remembering the loss.

However, over time, things wear away. Flowers die, letters and photos become torn, and weeds encroach upon the grave. While we may initially think of this as a problem, or a burden, which impinges upon the beauty of the collection, it in fact plays a key role in the life of the bereaved by allowing for the opportunity for *upkeep*. Maintaining the collection can be an act of love, and a renewed way to signal to oneself and to others that the deceased is remembered. One father described how important this process of upkeep was for him because it brought people together in a shared activity.

> "The cemetery where [my son] was buried has a beautification day once a year in the summer, so everyone [who has family] that's buried there can come, and it's a big get-together thing... everyone gets a butterfly in a box... and you open it up and the sun hits it, and they all fly." - FG 1

As designers of interactive technologies, thinking about these material processes can help to inspire meaningful experiences for the bereaved. Indeed, participants described support group sessions where they were asked to bring in a special memento to share with the group, and how those mementos helped them to connect with one another. A system sensitive to these kinds of experiences will allow for all types of media and materials to be juxtaposed together, allow for new material to be added over time, and realize that the upkeep and maintenance of the collection can be a treasured activity and not necessarily an unwanted burden worth automating away.

It is important to note that in this study, participants primarily referred to physical mementos that they encountered in their personal experiences, rather than mementos

that they shared with others. However, sharing mementos did have a part to play in the exchange of support. Participants described bringing into the group possessions that belonged to the deceased, or otherwise had special meaning to the owner. These mementos were used to tell stories and convey to other members a fuller picture of the individual who passed away. Unlike physical mementos, digital mementos have the benefit of being easily shared, and may offer similar opportunities to tell stories or establish relationships in an online setting. Digital mementos can also be replicated and repurposed in new forms, and provide a basis for meaningful remembrance or support activities.

4.5.2 Display and Control of Mourning Symbols

I have shown how materials play a role in social and psychological processes that the bereaved encounter. A final consideration concerns designing systems that enable the bereaved to control how much they wish to share, and how much they wish to hide, regarding their loss.

A death frequently results in a number of mourning signs. We may place flowers or wreaths, or invite people into the home for religious observation. A person may wear black for a period of time, based on religious traditions, or be expected to cry and otherwise appear saddened.

However, from talking to participants in focus groups, it became clear that there was an important choice involved in demonstrating mourning. Mourning - the outward expression of grief - is a socially mediated activity [36]. The bereaved may choose to express their grief openly and unreservedly in some situations, but choose to contain and hide those feelings in others.

This need to control the visibility of mourning was reflected in the way that items were worn or used in the home. This arrangement of items was a highly personal choice. One mother thought it was important to keep reminders of her child near her at all times.

> "We have photos of him on every floor of the house, and I still sleep with his

> blanket. And I wear his picture around my neck so I always have him near me." - FG 2

Another participant in the same group chose to keep her mourning more private and hidden, perhaps out of fear of judgment from others regarding the way her child was conceived.

> "The only thing we have to remember her is a petri dish and ultrasound pictures, so I keep that together and hidden away. I can't pull out a petri dish and show people that, but that petri dish means so much to us." - FG 2

Some participants fall somewhere in the middle; yet another mother in this same group described keeping photos and clothing in her living room for guests to see, but kept the urn in her bedroom and hidden away from guests. When designing in this space, it is important to bear in mind that the bereaved must have a choice in demonstrating their mourning. There are situations that are made easier by trying to momentarily pass as being emotionally "normal" - for example, during professional dealings or when talking to unfamiliar people. Devices which are designed to be worn, placed in the home, or otherwise displayed as indications of grief need to be crafted in a way that allow the bereaved the opportunity to control their appearance of mourning.

4.6 Limitations

The design considerations articulated above are based primarily on focus groups conducted with bereaved parents who had previously sought support at a community organization, and were generated amid ongoing professional development activities. This approach did not consider other types of loss, and did not involve data collection from a general population of bereaved individuals (i.e., those who did not seek out or attend a support group). Because the experience of grief is so personal and highly variable,

these considerations are not intended to be steadfast rules. Rather, they represent emergent empirically-derived themes that should be applied to other settings and participant groups judiciously. Because of their emergent nature, they require continual elaboration and evolution; following the deployment study in Chapter 5, I update these considerations in light of my ongoing design process. Further, because the focus groups were recruited by facilitators at BFO and the COPING Centre, they varied in size and detailed data concerning the composition of these groups was not collected (i.e., demographic information and participant histories are unavailable). For these reasons they may not meet the requirements for some definitions of a "focus group" [54]. Additionally, the questions raised in the focus groups were based on the memento-based social support exchanges noted in Phase 2; as such, there are likely to be other aspects of bereavement that were overlooked during the discussions. My own presence as an outsider who had not experience a death also influenced the way that participants spoke about their experiences, and may have inhibited some participants from participating more fully or honestly. The thematic analysis of the focus group transcripts was also performed by only one researcher, and my own biases in interpreting the data are likely to be present. Finally, my site visits were quite opportunistic and not systematic, and as such, the observations that I made are not comprehensive in their scope.

4.7 Summary of Design Considerations

Taken together, the design considerations presented above can be seen as a set of issues to think through when developing systems for the bereaved. In sum, these considerations suggest:

1. *Circles of Sympathy and Communication Availability*: The bereaved can find support in many places; talking to peers who have shared experiences can be one of the most powerful ways to exchange emotional and informational forms of support.

Furthermore, sometimes avoiding the use of communication systems is to be expected in bereavement. Shielding oneself from conversations about grief is one way that the bereaved manage their emotions. Systems for the bereaved should connect different types of people to each other in different ways, and expect periods where there is little usage.

2. *Storytelling and Narratives*: Telling stories is a key part of bereavement. To be considered "ready" to delve into aspects of grief in a group setting, the bereaved must first be ready to tell the story of their loss. Reading other people's stories helps to normalize the experience of grief. Telling stories is part of how the bereaved accept the loss and try to make sense of its occurrence. Stories can have many audiences: peers, friends, family, the public, the deceased, and even oneself. Systems for the bereaved should support these multiple purposes and audiences, and consider how stories can be told in new ways.

3. *Permanence and Continuity*: A death is a life-changing event from which one does not "recover," as if it were a temporary physical illness. Rather, it is a permanent shift in the way that one interprets the world. Systems should allow for open-ended exploration of this continuing experience, rather than providing step-by-step solutions to grief.

4. *Finding Something to Do*: One way the bereaved may explore or make sense of their loss is by performing activities alone, or in groups. These activities might be traditionally determined (e.g., attending a candle-lit memorial) or more creative in nature (e.g., painting or sculpting). Systems might consider how they can support a variety of such activities.

5. *Heterogeneity, Sediment, and Upkeep*: The items that are meaningful to the bereaved can come in many heterogeneous forms, which vary in their ability to be digitized. Easily digitized items may include photos or music, but clothes and

other objects still hold meaning and are harder to digitize. Organizing important objects occurs over time, and in sedimentary layers. Each time an item is added, it prompts reinterpretation of the collection. Maintaining the integrity or quality of these objects might seem moot when dealing with digital items; however, these upkeep activities are often symbolic ways to honour the relationship, and designers should look for opportunities to offer such activities.

6. *Display and Control of Mourning Symbols*: Part of dealing with a loss is controlling one's outward appearance. Systems should be designed to be ignored or hidden away so that the bereaved can focus on other parts of their lives, and project a non-grieving appearance to others when they so desire. Systems that broadcast a bereaved person's status should be developed carefully, so that the bereaved have fine-grained control over what is being displayed to others.

4.8 Conclusion

Computing increasingly mediates the way that we approach end of life issues, and particularly the way that the bereaved live, grieve, and communicate. In this chapter, I have reflected on my exploratory fieldwork examining the "doing" and "being" of bereavement from a technology design perspective with an eye towards social support. My reflection on the design process has shown how many of our problem-solving assumptions about grief are less important to the bereaved than a sensitive orientation towards their needs. I have provided a set of considerations for researchers and designers working with the bereaved that may help orient design work. This exploration creates a foundation for technologists moving into this space, ultimately helping to create systems for the bereaved that meet their needs with sensitivity and respect.

As mentioned above, the purpose of providing these considerations is to offer designers a set of issues to think about as they are designing a system for the bereaved. Until

this point, however, the considerations have not been applied in such a process. In the following chapter, I proceed to incorporate these considerations into the user-centred design of Besupp, a prototype system that allows the bereaved to participate in online support groups. In so doing, I trace how design choices flowing from these considerations impacted the user experience during a deployment study, and finally revise the considerations based on what is learned during the study.

Chapter 5

Besupp: Design and Deployment

In the survey and interview study reported in Phase 1, bereaved participants described using technologies such as mobile phones, social networking sites, and email in order to provide and receive social support throughout their grief journeys. Examining this phenomenon more closely in Phase 2 revealed that this process was nuanced and subtle, and that finding support during bereavement took place in a socially and emotionally volatile context. Design considerations (DCs) resulting from this investigation suggested that peers who have experienced a similar loss may sometimes be a better source of emotional or information support than family and friends, and that much of this support exchange among peers occured by telling stories. Furthermore, the considerations spoke to the ongoing nature of the loss, the need for sustained support beyond the earliest months of grief, and the kinds of activities undertaken as a way to remember the deceased and work through one's grief. Among these, organizing and reflecting upon meaningful mementos such as photos was common.

Beginning with these DCs, restated in Section 5.2, and continuing to work in conjunction with BFO, I describe the user-centred design of Besupp, a prototype website for online peer support groups. In this chapter, I report on findings from a 10-week long deployment study in which Besupp was used by three different support groups for bereaved

parents, spouses/partners, and young adults, and trace how the design considerations and decisions impacted the experience of these bereaved users. Based on participant interviews, I describe thematic results concerning remembrance, social support, and other emergent issues. These results give additional depth to the design considerations and how they might be better applied to future systems.

5.1 Early Design Work and Rationale

After selecting social support as a domain at the end of Phase 1 and performing fieldwork in Phase 2, I reflected on the DCs and generated an early set of formative design ideas that might enable support to occur in a more nuanced and sensitive way. One idea was a mobile system that would allow the bereaved to access support anywhere and at any time, speaking to the permanent and continual nature of the loss (as per DC3: Permanance and Continuity). A second option explored using a domestic ambient display as a way to receive messages of support from peers, friends, and family; this was developed on the premise that grieving individuals choosing to ignore traditional forms of communication might prefer a less obtrusive method of delivery (as suggested in DC1: Circles of Sympathy and Communication Availability). A final design idea involved the creation of a website that emphasized the storytelling aspect of bereavement (encapsulated in DC2: Storytelling and Narratives) as part of an ongoing discussion group.

Four one-on-one design sessions with members of BFO's board of directors and volunteer base were conducted to collect feedback on these design ideas and elicit alternatives or other suggestions for new ideas (see Appendix G). These were all middle-aged women who suffered varying losses: one woman who lost her fiancè, one woman who experienced a stillbirth, a mother whose young adult son had been murdered, and a mother who lost her adolescent son. Feedback from these stakeholders indicated that a browser-based resource would be preferred for multiple reasons. First, they felt comfortable with us-

ing social networking sites such as Facebook, and had already developed a set of web resources that they regularly visited. At the same time, they desired a separation from such public, general purpose sites, and wanted a system strictly dedicated to bereavement issues. Websites were also seen as easy to integrate into daily routines, and would be available both at work and at home (in contrast to a customized ubiquitous computing device, for example). Stakeholders associated with BFO were also hesitant about the technical comfort of their client base, and saw a website as the most approachable form of technological intervention. Ultimately, it was decided that a website would be the most appropriate way to improve the support given to BFO's client base, and an accessible platform for exploratory work in applying the DCs.

5.2 Design Considerations

I now describe further how Besupp's concept and features followed as a result of working with BFO and the design considerations (DCs) from Chapter 4.

5.2.1 DC1: Circles of Sympathy and Communication Availability

This DC discussed how the bereaved may find themselves in a position where they may wish to limit their availability to friends, family, and interested others while they are grieving. Key to this was the notion that the most valuable form of communication, in terms of understanding the grief they were experiencing, was with other people who had gone through similar losses. For that reason, I decided to build a system that connected bereaved individuals to one another, rather than to family or friends. This is a common occurrence in online grief support groups and websites (see Section 2.3.2). To enable this communication, a safe space free from "outsiders" was necessary; to that end, Besupp is not an open-registration website and is separate from existing social networking sites.

To join the site, individuals must be manually added by an administrator. Compare this process to general purpose social networking sites such as Facebook, or general grief support websites such as Grieving.com, where anyone can sign up for an account as long as they have an email address. Finally, discussing the loss can be an emotionally exhausting experience. By providing a website that can be accessed at any time, the bereaved can selectively control their exposure to these discussions, and participate as much or as little as they choose.

5.2.2 DC2: Storytelling and Narratives

Telling stories is a foundational part of the bereavement process. From retelling the story of the loss, to narrating the journey one has taken, stories are a key way to communicate the experience of grief. In Besupp, stories are foregrounded in three ways. First, in each user's profile, there is a special field reserved for telling one's "background story" - the details of the loss, the reasons for seeking support, and the loss's impact on the individual. Second, stories are a primary data type in Besupp; users can write, save, revise, and share stories as described below. Third, users can read the stories that other users have shared with the group in order to understand and relate to others through these narratives. Storytelling can also occur in the chat system, or by sharing other types of mementos (such as photos or videos that serve as forms of visual storytelling). Many of these aspects are somewhat similar to features in Facebook or other social networking sites which allow for customizable information to be displayed on one's profile, or the ability to write "Notes" and share these with other members.

5.2.3 DC3: Permanence and Continuity

Grieving after the loss of a loved one is not an event from which one ever completely "recovers." Rather, it is a permanent change in the way one perceives and acts within the world. To that end, I developed an open-ended system that allowed users to se-

lectively employ tools for reminiscing, creating, communicating, and reflecting. Besupp can similarly be revisited as the grief journey unfolds, and provides a way for bereaved individuals to re-join a support group months, or even years, after their loss, reflecting the permanent change in worldview that a loss prompts in the bereaved.

5.2.4 DC4: Finding "Something to Do"

For some bereaved people, channeling grief into meaningful activities can be helpful. Besupp supports several activities that bereaved participants commonly reported performing in the focus groups and early design work. As an individual/creative activity, users can write in the provided journal to collect their thoughts and emotions (similar to a blogging website). In addition, users may collect together photos, videos, stories, and links in their Memory Box (described below), creating a collection of items relevant to their loss. This is a similar concept to social networking websites like Google+ and Facebook, which both provide the ability to add photos; however, the mixture of elements as a collection, rather than a stream of posts, makes the Memory Box more open to review and reminiscence. As time goes on and people in the group share items from their Memory Boxes, the result is an interactive bulletin board that displays the group's collected memories in a format similar to a homegrown memorial. Moderators of the chat group may also suggest particular topics or activities by changing the current announcement; for example, moderators could suggest that everyone in the group write a story about a particular topic, creating a group/creative type of activity. Talking in the chat, of course, can also be seen as group/prescriptive activity meant to express grief (although it could certainly be creative as well).

5.2.5 DC5: Heterogeneity, Sediment, and Upkeep

Many of the practices surrounding bereavement are supported by particular items or places. For example, a mourner may leave fresh flowers at a tombstone, or place a pic-

ture of the deceased near a favorite chair. While many of these items are impossible to recreate digitally, Besupp supports the process of collecting together those items that can be digitized into a Memory Box. The Memory Box can be filled with a heterogeneous collection of photos, stories, links, and videos (and by extension, music). Over time, the user can gradually add more items to the Memory Box, building sedimentary layers of memories. As the collection grows, the user can occasionally keep the collection up-to-date by adding and editing captions for photos and videos, editing stories, and maintaining their links. This bears some similar to research projects such as Timecard, which presents a timeline of an individual's data in an ambient display format [www.richardbanks.com/?p=2043].

5.2.6 DC6: Display and Control

The bereaved often appreciate the ability to be in control of their appearances, both to the outside world and to other members of a support group. In Besupp, all items added to the Memory Box are automatically made private by default. Users can then selectively share the items, one at a time, so that they are visible to other members of the group. These same items can later be unshared and hidden from the group if the user so desires. When on the site, users are represented only by a username; all additional information that they choose to provide is at-will. Because Besupp is a website, users can visit the site privately and when they so choose, thus regulating the visibility of their actions. The ability to preserve privacy in this way follows many of the sharing and privacy settings that have been parts of social networking websites such as MySpace and Facebook.

5.3 Research Goals and Questions

Given the set of DCs from Phase 2, the goal of Phase 3 was to apply these considerations in a user-centred design process. I trace how the considerations translated into design

choices, and how these choices affected system usage and user reactions.

Feature	**Google+**	**Facebook**	**Besupp**
Persistent (a)synchronous group chat	Yes	Yes	Yes
Group chat moderator	No	No	Yes
Online user notification	Yes (via GChat)	Yes (via Messenger)	No
Shared/private photos	Yes	Yes	Yes
Shared/private stories	Yes (Stream only)	Yes (Notes)	Yes
Shared/private link collection	No (Stream only)	No (Timeline only)	Yes
Shared/private video collection	No (Stream only)	No (Timeline only)	Yes
Shared/private journal entries	No (Stream only)	Yes (Notes)	Yes (private only)
Open registration	Yes	Yes	No
User-defined groups/circles	Yes	Yes	No
Private messaging	Yes (single-user posts)	Yes	No
User profiles	Yes	Yes	Yes

Table 5.1: Comparison of features in Besupp, Google+, and Facebook. Note that the Besupp design and the term "Circle" were in place before Google+ launched its limited beta in July, 2011.

It should be noted that Besupp's design makes use of existing web standards and conventions, and does not involve new forms of interaction or technology (see Table 5.1 for a feature comparison). While novel form factors or interaction techniques could have been explored (and indeed, were shown to participants in early design work), embarking on this path was considered to be unapproachable for participants. Further, by introducing new interaction techniques at the same time as applying the DCs, it would become potentially difficult to disentangle a participant's response to the form factor from the response to the design choices based on the consideration. Finally, while BFO clients were familiar with the web, BFO administrators noted that few were aware of the existence of online support groups. By partnering with BFO, I had the opportunity to work with people who were seeking support, but had not yet done so through the Internet.

Similarly, online support groups for bereavement are well-established (see Table 2.2 for a comparison of such sites). A study in this phase could have examined how existing systems such as GriefNet or Facebook do, or do not, support the DCs from Phase 2. However, such a critique would rely heavily upon participants' responses regarding how they have used such systems in the past, or intend to do so in the future. These types of questions can be difficult for participants to answer reliably due to their retrospective or hypothetical natures. Further, obtaining an account of the design process for these sites is potentially difficult; third-party system designers are likely not to maintain or share credible documentation regarding the design choices they made in their process.

By creating an independent platform that borrows concepts from existing systems, I was able to (a) better articulate the design process and how the DCs influenced it, and (b) collect high-quality data regarding usage. In that sense, Besupp acts as an instrument used to study how the bereaved encounter digital mementos and online social support. Going into the study, I prepared a set of research questions based on the DCs (Table 5.2). These questions are subsequently addressed in the results of the study.

5.4 System Design: Besupp

Besupp (short for "bereavement support") is a custom-built website designed specifically for bereaved individuals seeking an online support group experience similar to the format offered by BFO (Figure 5.1). A mobile version of Besupp was also built that offers a subset of the functionality as the desktop version, but uses a layout more suitable for mobile devices.

Besupp's functionality is divided into two major feature sets: the Memory Box, and The Circle. For implementation details, please see Appendix E.

Design Consideration	**Research Questions**	**Section in Results**
DC1. Circles of Sympathy and Communication Availability	How often does communication occur? When does communication occur? Do participants send messages at times when support might otherwise be unavailable (e.g., late at night)? How does communication differ from face-to-face groups? How does communication differ from speaking with friends and family? What digital mementos are shared with peers? What is the role of the moderator?	Sections 5.6.1, 5.8.4
DC2. Storytelling and Narratives	Who is the audience for stories? What is the purpose of the stories? What kinds of stories are most usefully communicated online? How is the telling of a story different online? How do visual media such as photos and videos play a role in storytelling?	Sections 5.8.5, 5.7.2
DC3. Permanence and Continuity	How does usage change over time? When in the grief journey would this be most helpful? What are the benefits and barriers associated with an online support group in the long term?	Sections 5.9.4, 5.9.1
DC4. Finding Something to Do	Does working with digital mementos help participants address their grief? How are digital mementos used individually versus in a group? Do participants use Besupp to create new group or individual activities? Do participants want to be given prescriptive activities, or invent their own creative ones?	Sections 5.7
DC5. Heterogeneity, Sediment, and Upkeep	What kinds of digital mementos are uploaded? How much variety is there in the quantity and qualities of digital mementos? What was not placed into the system? Were items added slowly, or all at once? Did users return to mementos to view or update them repeatedly?	Sections 5.7, 5.9.4
DC6. Display and Control of Mourning Symbols	Does Besupp cause unwanted grief reactions in public places (e.g., at work)? How is sharing and unsharing used to maintain control?	Sections 5.9.2, 5.8.2

Table 5.2: Research questions for Besupp study.

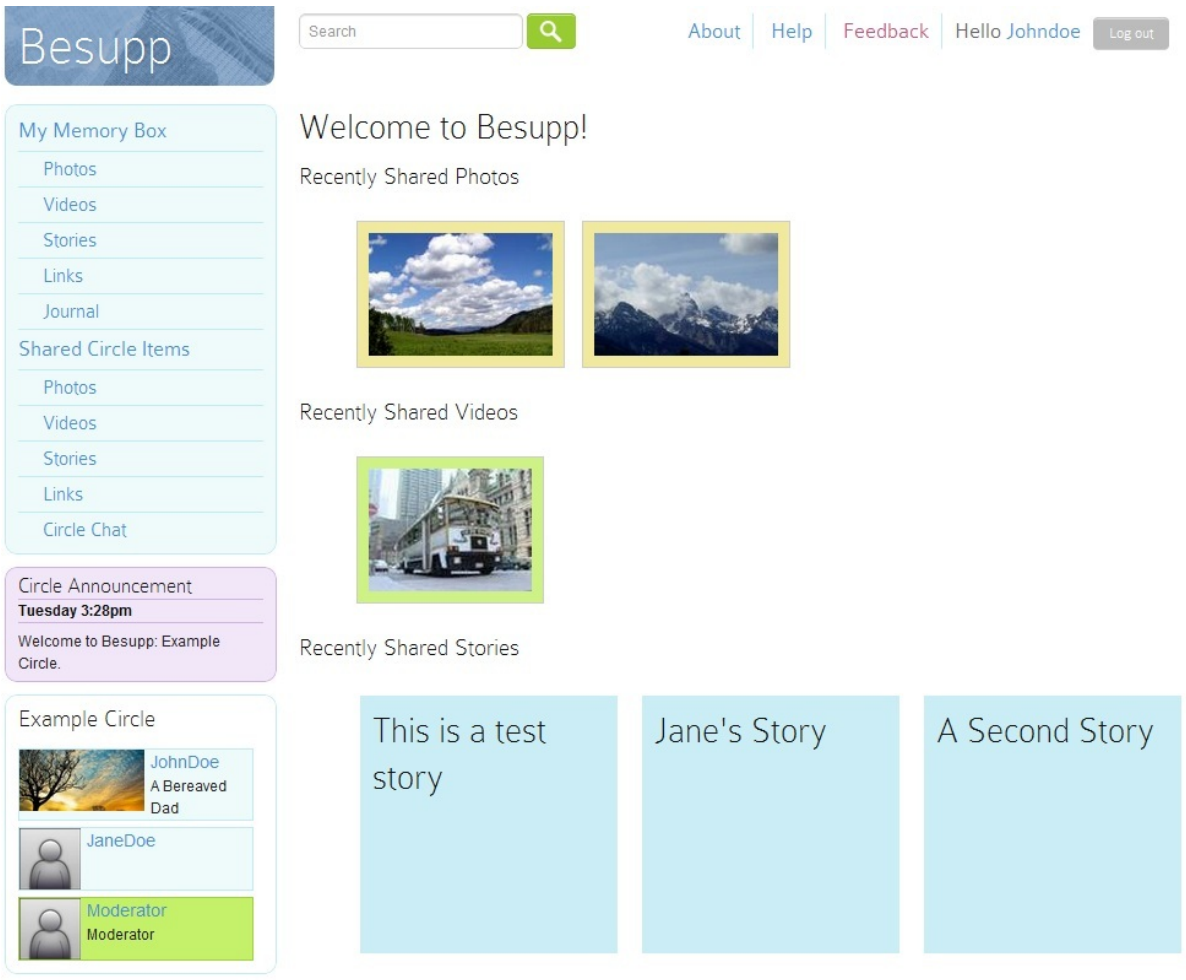


Figure 5.1: Besupp home screen for an example group, showing recently updated items.

5.4.1 Memory Box

The Memory Box serves as a user's private space on the website. Inspired by bereaved individuals from the focus groups who kept physical memory boxes, it provides a virtual container for mementos related to the individual's loss. Users can include five major types of mementos in their Memory Boxes: photos, videos, stories, links, and journal entries. Photos can be uploaded from the user's computer or imported from an existing URL such as Facebook or Flickr (Figure 5.2 shows the gallery view in the Memory Box). Videos cannot be uploaded due to technical constraints, but users can provide a link to the YouTube URL in order to import a video into the Memory Box. This also provides a method for users to include music in their Memory Box by linking to a YouTube video of a song. In the Memory Box, stories are comprised of a title and story text. Stories can be sorted according to creation date and title. Users can include links to other resources on the web that they find meaningful or helpful: for example, creating a link to a website containing poetry. Finally, the Memory Box provides a private journal in which the user can write their own thoughts. All of the mementos in the Memory Box can be edited or deleted at any time, and captions can be provided for photos and videos.

The Memory Box also contains a feature that creates an in-browser slideshow that slowly crossfades between a random collection of the photos, stories, videos, and journal entries. This feature is intended to simulate the feeling of shuffling through a shoebox of precious memories.

5.4.2 The Circle

The Circle is the shared, public part of Besupp; this term was chosen based on DC1's notion of "Circles of Sympathy." All items in the Memory Box, with the exception of journal entries, can be shared or unshared with members of the Circle. Users can then browse the collection of shared photos, videos, stories, and links. The Circle mirrors the

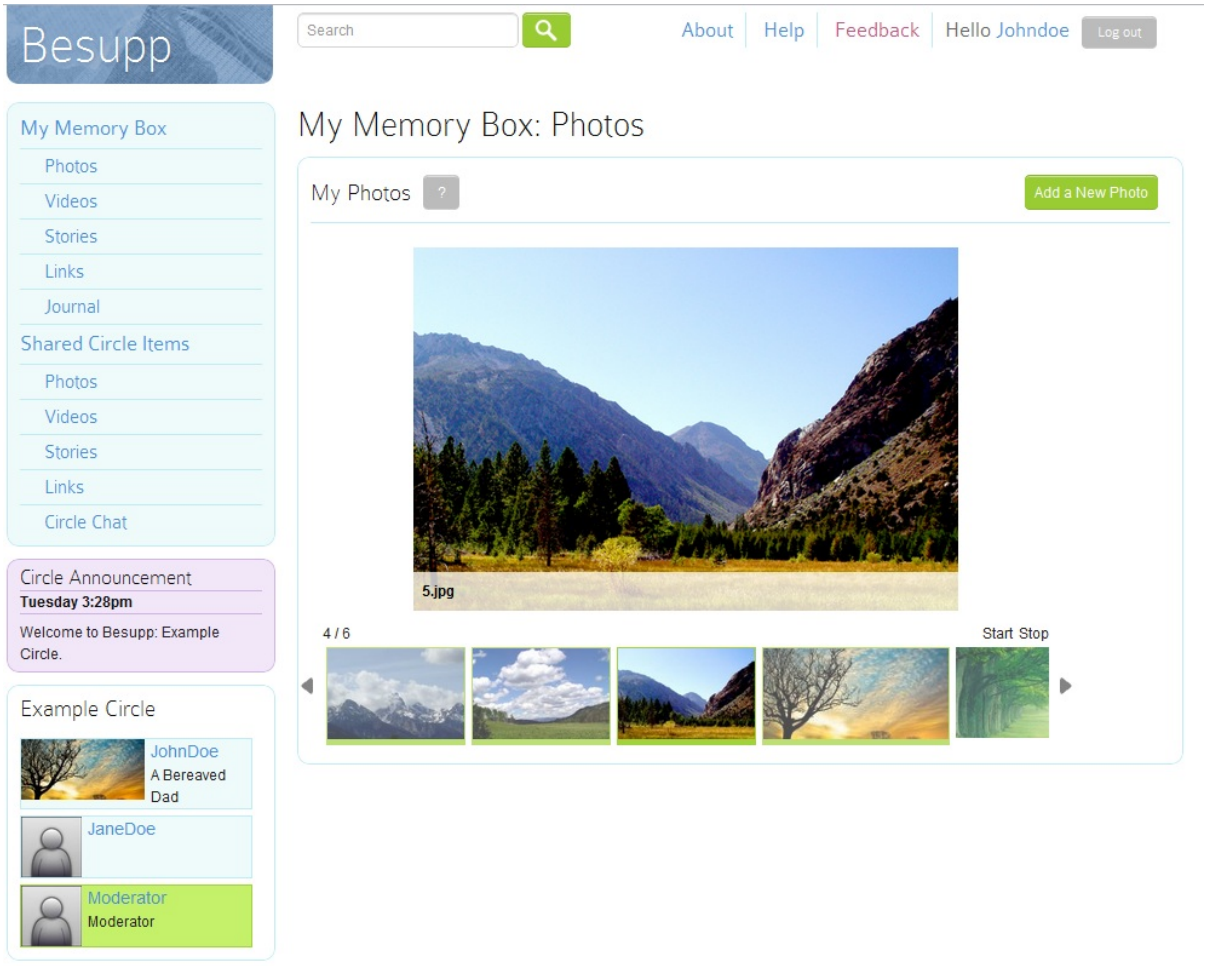


Figure 5.2: A collection of photos as displayed in the Memory Box for an example user.

Memory Box in terms of presentation and functionality for photos, videos, stories, and links. However, a "bulletin board" containing a random collection of shared mementos is provided instead of the slideshow described above for the Memory Box (Figure 5.3).

Each user is assigned to one thematic Circle (e.g., bereaved parents) by an administrator, and can view a listing of the other people in the Circle. Users cannot create or add themselves to a Circle without being screened by the administrator[1] Each user has a profile that is visible to all members of the Circle. If they so choose, users can provide a profile photo and basic background information (name, age, gender, email). Users can also set a brief "role" tag in their profile, such as "bereaved mom." This role is visible in the listing of all users in the Circle. Finally, the profile contains a field for the user to enter their own background story.

Each Circle can contain one or more users designated as a moderator. Moderators are authorized by the site administrator to help monitor and guide members of the Circle. Unlike normal users, moderator messages appear in a highlighted color in the chat. Further, they can set a Circle Announcement that appears on each page in order to demarcate current topics the Circle is discussing.

The Circle Chat is, in many ways, the heart of the site (Figure 5.4). Circle Chat is a custom persistent chat system where users can post messages to all members of their Circle. Once sent, messages are instantly displayed on the Circle Chat page where they remain for seven days before being moved to an archive page. In this way, the chat functions both asynchronously and synchronously. When sending a message, users can attach items from their Memory Boxes; these attached items are then shared and displayed in line with the sent chat message.

[1]In the deployment study, participants were manually assigned by the researcher to Circles based on the type of group they attended at BFO. In a more realistic context, a staff member at BFO or another community organization would perform this.

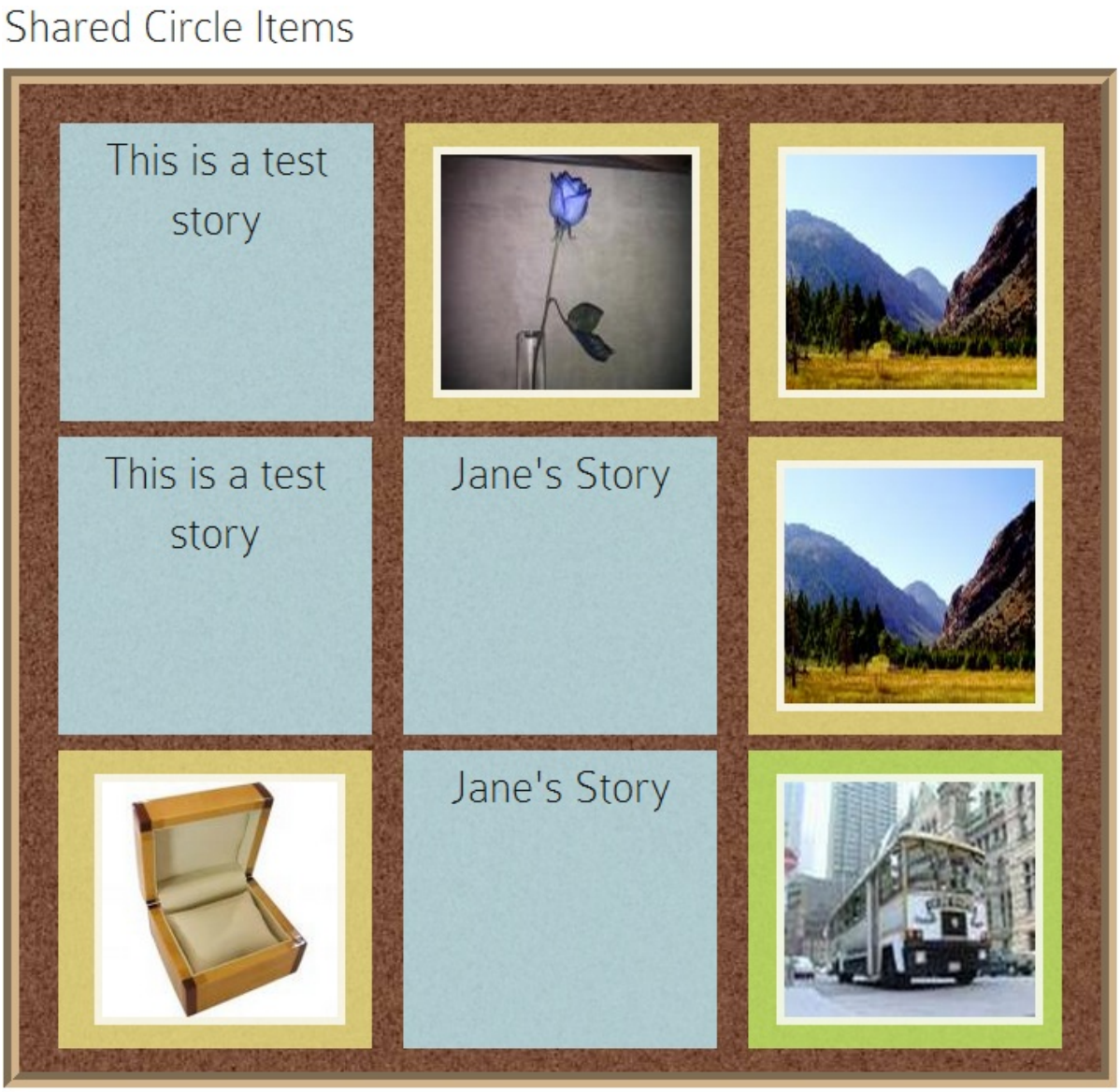


Figure 5.3: The bulletin board for an example Circle, showing all shared items.

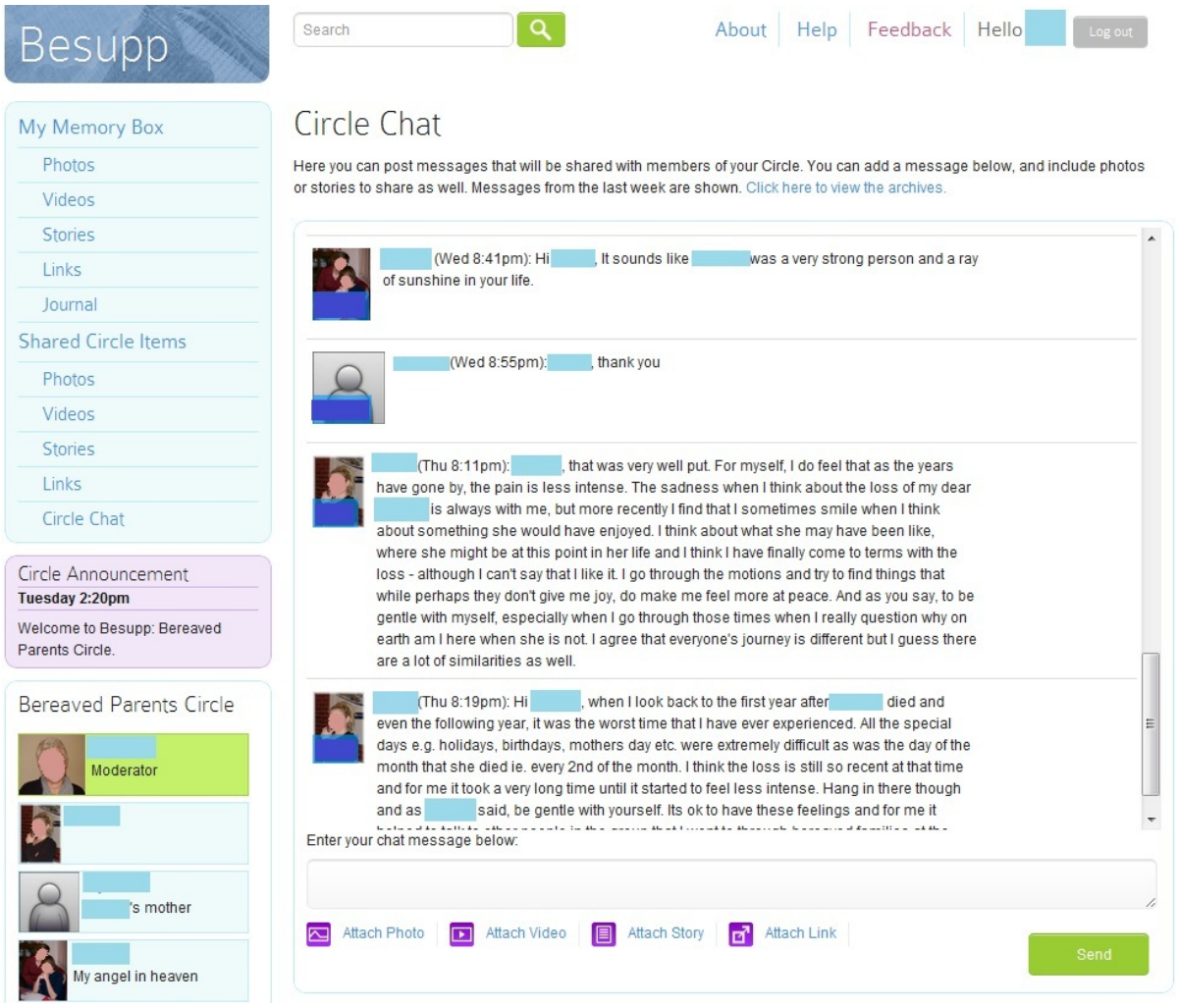


Figure 5.4: An example of Circle Chat for the bereaved parents group.

5.5 Deployment Study

Having given an account of Besupp's features, operation, and design rationale, I now describe a 10-week long deployment study of the system. Outwardly, Besupp was a high-fidelity interactive functional prototype of a system concept with the goal of providing a platform for online bereavement support groups. At the same time, Besupp was itself an instrument for studying aspects of bereavement as they relate to technology adoption and design. To that end, the primary research question driving this study was "What can we learn about designing technologies for the bereaved based on an examination of Besupp's usage in a real-world setting by bereaved participants?"

Working with coordinators at BFO, we determined that the audience for such a website would be individuals who had previously completed a support group, but desired ongoing, long-term support. This was chosen for several reasons. Participants who had completed a group were more likely to have reached an emotionally stable point in their grief, and already understood the "ground rules" that were introduced during their face-to-face groups (e.g., non-judgmental listening, an emphasis on "not fixing"). This also increased the potential pool of participants during recruitment.

In the previous study, I worked exclusively with bereaved parents in the focus groups. During discussions with BFO staff, it was suggested that members who previously participated in one of three types of groups be included as potential participants in the current study. These were deemed to be more representative of the range of BFO's client base, and additionally allowed for more participants to be included in the research. The three groups identified were as follows:

- *Young Adult (YA)*: youth between the ages of 18 and 30 who experienced the loss of a parent or sibling[2];

[2]Note that this combination of sibling loss and parental loss is a carryover from the way that BFO organizes this type of group. In the current study, only YA4 lost a sibling, while the rest lost parents.

- *Bereaved Parents (BP)*: individuals of any age who had experienced the loss of an infant or adult child, or of a child who was not carried to term;

- *Spousal and Partner Loss (SP)*: individuals of any age who have lost a spouse or romantic partner.

BFO coordinators circulated a recruitment email to their database of YA, BP, and SP members with an original limit of 5 years since the loss. The initial response rate did not yield enough participants to meet BFO's minimum support group size of at least 5 members for the SP and BP groups. As such, the limit of 5 years was lifted and the recruitment advertisement was circulated a second time, yielding enough to conduct three simultaneous support groups using Besupp. Each group had one facilitator who completed BFO's intensive facilitator training process and had moderated previous face-to-face groups. Coincidentally, all participants were female. Of the 24 participants who signed up for the study, 19 participants successfully completed the study[3] (see Table 5.3). The number of years since the loss had occurred varied among participants. The most recent loss occurred 5 months before the study, while the most distant was 19 years ago. Eleven of the 19 participants endured the loss less than 5 years ago. None of the participants in the study knew one another before the beginning of the study.

5.5.1 Method

A 10-week long deployment study was conducted, with each of the three support groups (YA, BP, and SP). At the beginning of the study, all members of each group were invited to an in-person meeting, where they had the opportunity to meet one another and the researchers. After obtaining consent, each participant was given a demonstration of Besupp and provided with a set of instructions and a username and password (Appendix F).

[3]The original participant numbering is used in reporting these results. Successful completion means logging in at least once per week of the study, completing the 3 interviews (with one exception), and completing the questionnaires at the beginning and end of the study.

ID	Age	Years since group	Years since loss	Facebook	Smartphone	Tech Comfort	Occupation
SP1	36	N/A	11	Yes	No	4	Community organizer
SP2	59	1	1	No	No	3	Dog sitter
SP4	47	2	3	No	Yes	4	Stay-at-home mom
SP5	36	1	4	Yes	No	3	Employment coach
SP6	58	0	7	No	No	2	Retired, broadcasting
YA1	31	N/A	7	Yes	No	2.5	Middle school teacher
YA2	23	3	11	Yes	Yes	4	Communications manager
YA3	29	1	4	Yes	No	3	Book editor
YA4*	27	1	2	Yes	Yes	3	Headhunter
YA6	25	3	5	Yes	Yes	3.5	Communications
YA7	32	2	4	Yes	Yes	4	Student
YA8	24	2	3	Yes	Yes	3	Lawyer
BP1	55	N/A	12	Yes	Yes	4	Stay-at-home mom
BP2	50	5	6	No	No	4	Insurance underwriter
BP3	67	N/A	20	Yes	Yes	3	Retired, teacher
BP5	66	14	16	Yes	No	3	Homemaker
BP6	50	3	4	Yes	Yes	3	Bank, clerical
BP7	53	0	1	Yes	Yes	3	Risk manager
BP9	66	1	4	No	Yes	3	Retired, program coordinator

Table 5.3: Besupp participant information. Number of years rounded up to nearest whole year. Technology comfort measured on self-reported scale of 1-4 with 4 as most comfortable. The first participant in each group (SP1, YA1, and BP1) is the moderator. *YA4 is the only member of the young adult group to lose a sibling; the remainder lost one or more parents/step-parents.

A brief group interview was then held with the participants in order to collect their initial responses and predictions concerning the site (Appendix J). This also provided an opportunity for participants to meet each other face-to-face before continuing online, reinforcing the connection between a BFO-style group and Besupp. For the individuals who were unable to attend the group meeting, a one-on-one meeting was arranged in order to provide the same information and collect individual responses to the questions.

Following the initial introduction to the site, individual semi-structured interviews were conducted with each participant during Weeks 1 and 2 of the study (Appendix K). An interim interview was conducted with each participant during Weeks 6 and 7 (Appendix L), with a final round of summative interviews performed at the conclusion of the study on Week 10 (Appendix M). Additionally, two questionnaires were administered to each participant during Week 1 and again at Week 10. The first questionnaire (Appendix I) was the Multidimensional Scale of Perceived Social Support (MSPSS), which provides measures of the individual's perceived level of social support with three subscales: support from friends, support from family, and support from a "significant other" [123]. The second questionnaire (Appendix H) was the Core Bereavement Inventory (CBI) [18]. The CBI measures perceived levels of bereavement phenomena, with subscales including the experience of mental images concerning the death, feelings of separation from the deceased, and grief symptoms.

Participants were asked to use the site in as realistic a manner as possible, and were compensated $10 per week.

5.5.2 Analysis

The 56[4] individual interviews were the primary form of data collection. Interviews were transcribed and analyzed using thematic analysis [4]. Questions in the interviews were

[4]Each of the 19 participants participated in 3 individual interviews, each lasting 30-60 minutes. BP5 missed the interim interview and completed only the initial and final interviews.

organized primarily according to the two parts of the website: (a) the Memory Box, which concerns remembrance and mementos, and (b) the Circle, which concerns social support and interpersonal dynamics. Emergent themes were also noted and are included in the results below.

Backups of the database and user logs were created at the mid-point and conclusion of the study. Custom queries were created to generate usage statistics, and explored using Microsoft Excel. The MSPSS and CBI questionnaires were scored and analyzed using Microsoft Excel as well.

5.6 Quantitative Results

I first present the quantitative results from the system logs and the questionnaires, before delving into the qualitative results in a separate section.

5.6.1 Usage

Over the course of the 10 weeks, 531 unique logins were recorded across the 19 participants (Table 5.4). While the BP and YA groups had a larger number of logins, examining the means and standard deviations suggests this is because the SP group had a smaller number of participants, and not due to variations between groups. The time on site supports this as well, although SP4's usage seems to indicate that while she logged in infrequently, she spent a great deal of time on the site when she did, raising the mean and standard deviation for the SP group.

The correlation coefficient between the number of logins and the number of years since loss was -0.45 (with moderators excluded), indicating that there was a medium negative relationship. This medium correlation suggests that users in the sample with fresher losses logged in more frequently.

Over time, the number of logins per day followed a recurring weekly pattern (Fig-

ID	**Total Number of Logins**	**Average Time on Site (mm:ss)**
BP1	39	4:01
BP2	37	6:21
BP3	6	10:16
BP5	5	11:46
BP6	57	6:28
BP7	28	2:38
BP9	35	14:13
BP - Total	207 ($\mu = 29.6$, $\sigma = 18.7$)	55:43 ($\mu = 7:57$, $\sigma = 4:14$)
SP1	57	4:44
SP2	12	N/A
SP4	7	25:30
SP5	32	3:06
SP6	22	3:52
SP - Total	130 ($\mu = 26.0$, $\sigma = 19.8$)	37:12 ($\mu = 9:18$, $\sigma = 10:49$)
YA1	45	3:02
YA2	16	9:00
YA3	22	10:05
YA4	23	8:17
YA6	4	N/A
YA7	36	10:03
YA8	48	3:49
YA - Total	194 ($\mu = 27.7$, $\sigma = 16.0$)	44:16 ($\mu = 7:21$, $\sigma = 3:08$)
Grand Total	531 ($\mu = 27.9$, $\sigma = 17.0$)	2:17:11 ($\mu = 8:04$, $\sigma = 5:41$)

Table 5.4: Number of unique logins by participant as calculated from log files. For SP2 and YA6, data for time on site was unavailable from system logs due to browser incompatibilities.

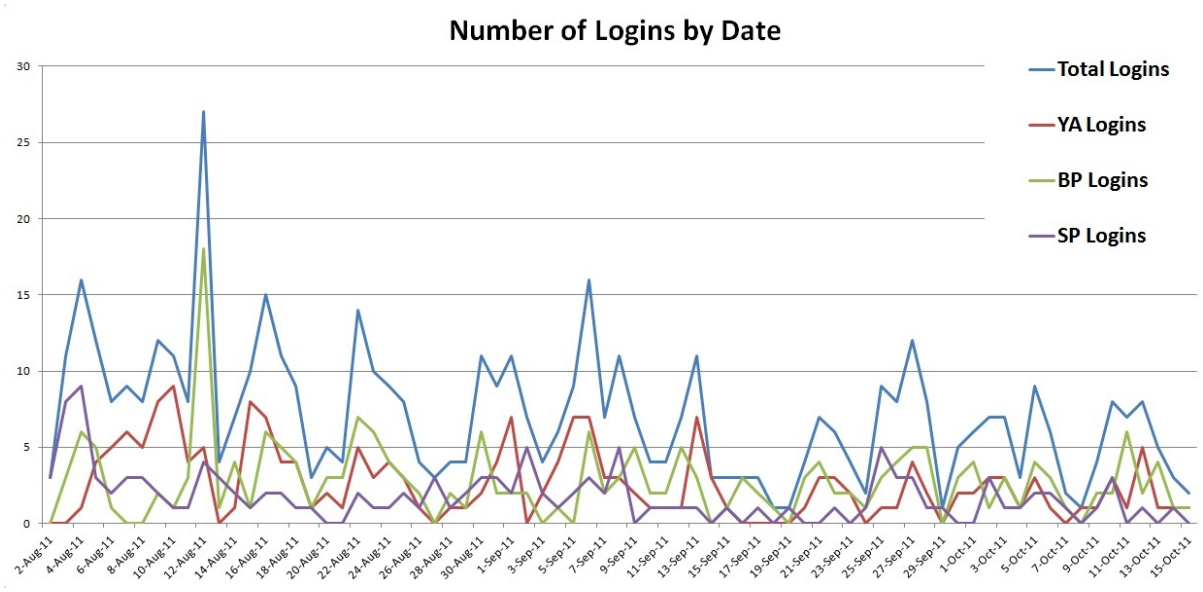


Figure 5.5: Total number of logins per day, broken out by group.

ure 5.5). Each subgroup appears to have followed a similar pattern. Examining the number of logins by day of week shows that the number of logins peaks on Tuesday and Wednesday and slows down on weekends (Figure 5.6).

Visit durations are measured as the amount of time the user remains on a page without their session timing out or navigating away from Besupp. Across all users, a visit lasted 8 minutes and 4 seconds on average. Individual users varied in the length of time they spent on the site (min = 2:38, max = 25:30).

With respect to the Memory Box, photos, stories, and links were the three data types that were used and shared the most frequently (Table 5.5). Notably, no videos were added by any user. Three participants created a total of 5 journal entries (recall that journal entries cannot be shared). There are caveats to the sharing statistics however. In the YA group, both of the shared links were by a single user, and one of these was to a YouTube video. In the BP group, 4 of the shared stories were from a single user, with the other two from a different user. In the SP group, all 9 of the links and all 6 of the photos - both shared and total - came from the moderator of that group. This is to note that while sharing is reported in the aggregate, a small number of users uploaded and

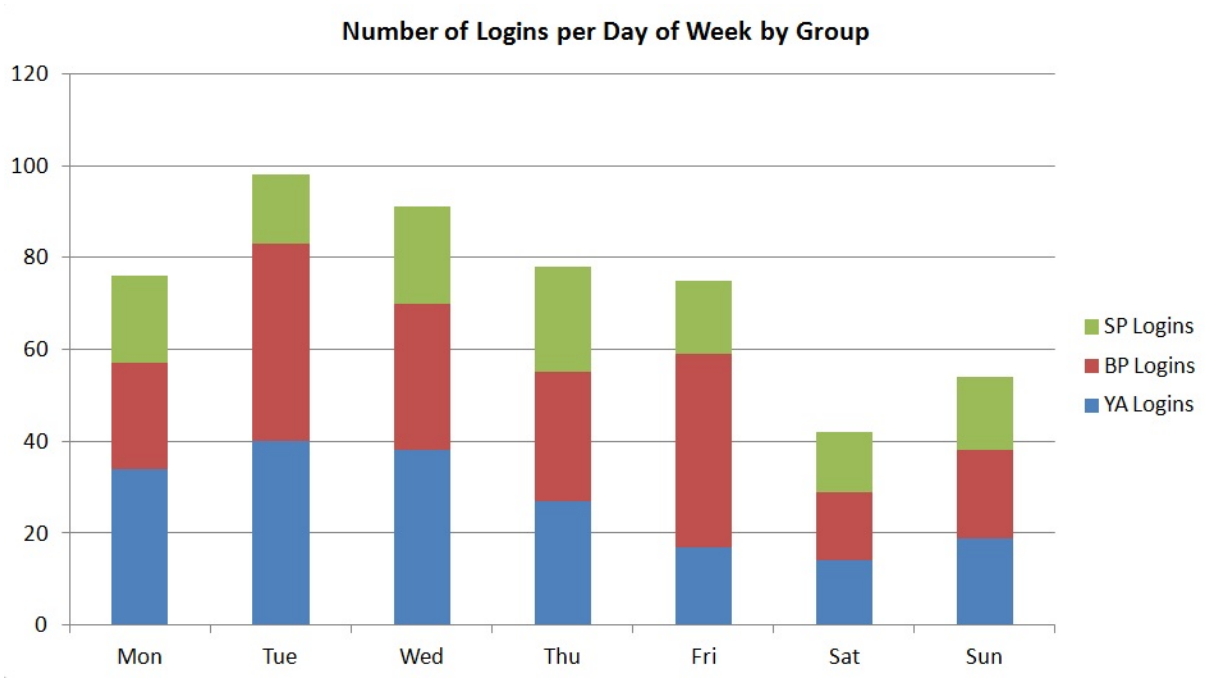


Figure 5.6: Number of logins per day of week and broken out by group.

shared most content, and that sometimes content overlapped (e.g., creating a "link" to a YouTube video, or a story that links to a website).

In total, 281 messages were sent in the Circle Chat over the course of the 10 week study (Table 5.6). Participants posted an average of approximately 18 messages per week. The average number of messages per user was 8.1 ($\sigma = 6.1$). Messages were sent most frequently between Monday and Thursday ($\mu = 24.3$, $\sigma = 2.2$) and were reduced

Group	**Photos shared/total**	**Stories shared/total**	**Links shared/total**
YA	$12_1/16_1$	$0_0/1_0$	$2_0/5_0$
BP	$7_3/11_4$	$6_0/8_0$	$0_0/0_0$
SP	$6_6/6_6$	$5_2/5_2$	$9_9/9_9$
Total	$25_{10}/33_{11}$	$11_2/14_2$	$11_9/14_9$

Table 5.5: Besupp sharing statistics by group. The number in subscript is the number of items uploaded/shared by the moderator of the group.

Group	**Messages Sent**	**Mean (SD) response times (in hours)**	**Mean (SD) length (in words)**
YA	62	26.1 (27.6)	146.2 (127.2)
BP	180	9.7 (21.1)	42.6 (50.4)
SP	39	41.2 (56.8)	71.2 (52.5)
Total	281	17.6 (34.0)	69.5 (85.4)

Table 5.6: Besupp message statistics by group.

on weekends ($\mu = 11.3$, $\sigma = 4.2$) (Figure 5.6). Approximately 65% of all messages were sent later in the day, between 4PM and midnight. Another 33% were sent between 9 AM and noon, with the remaining 2% between 6AM and 9AM. No messages were sent between midnight and 6 AM.

In the first week of the study, a participant requested that the input limit on the message box in the Circle Chat be lifted. Soon thereafter, users began to write multi-paragraph messages (Table 5.6).

The Circle Announcement feature permitted moderators to indicate the current topic of conversation by changing the text that appears in the sidebar above the list of Circle Members. This feature saw relatively little usage however. The BP group did not use it all. The moderator of the YA group posted 4 different announcements, while the moderator of the SP group posted 2. As Table 5.7 shows, the YA moderator used this feature to introduce three topics that are normally presented at BFO groups (items 1, 2, and 3). The moderator of the SP group used the feature slightly differently, introducing current events (item 4) and asking for comments on a link she shared from her own Memory Box (item 5). Finally, the YA moderator sought to address the ending of the group (a practice also common at BFO) with item 6.

Item	Group	Week	Announcement Text
1	YA	1	Welcome everyone! Let's get the ball rolling with introductions as people begin to feel their way around and get comfortable.
2	YA	4	How have (if at all) relationships in your life with friends, family, partners, changed since the death of your loved one?
3	YA	6	Do you choose to share your story with new acquaintances, friends, relationships in your life? How much do you choose or choose not to share?
4	SP	7	It's a significant anniversary today. 9/11 - 10 years. How have anniversaries and significant days been for you?
5	SP	8	I shared a link - what do you think of the article? Does it ring true for you?
6	YA	9	How are you feeling knowing this study is coming to a close?

Table 5.7: Circle Announcements set by moderators.

5.6.2 Questionnaires

Questionnaires assessed two constructs: perceived social support, and bereavement phenomena. The questionnaire results showed little change in terms of perceived social support and bereavement phenomenology. As noted in Table 5.8 and Table 5.9, the Core Bereavement Inventory (CBI) and Multidimensional Scale of Perceived Social Support (MSPSS) measures did not detect any large changes in group measures. As a group, mean scores on all subscales remained stable. As noted in the interviews below, many of the participants reported that they felt they had already passed the most intense stages of grieving, and that their current social support situations outside of Besupp did not change.

5.7 Qualitative Results: Remembrance

Thematic results are presented according to the two categories of questions in the interviews, which were influenced by the two major pieces of functionality in the site. The first category concerns remembrance as accomplished primarily via the Memory Box. The second piece of functionality, the Circle, underlies a line of questions regarding social support. Having presented a summary of the log data, I now turn to the first theme investigated in the interviews: remembrance. In Besupp, remembrance was conducted primarily through the Memory Box portion of the website, which provided a place to store and review digital mementos. Storing these mementos in the Memory Box was intended to help individuals reminisce on their own and share mementos with others in a supportive context. In terms of usability, most participants thought the Memory Box made good use of an existing mental model regarding storage of loss-related mementos.

> "I like the term 'Memory Box.' I liked the idea...and the analogy of the physical box with pictures and notes. That totally makes sense." - SP1, final interview

Participant	**Week 1**				**Week 10**				**Change**			
	Images	*Separation*	*Grief*	*Total*	*Images*	*Separation*	*Grief*	*Total*	*Images*	*Separation*	*Grief*	*Total*
SP1	6	4	3	13	3	2	3	8	-3	-2	0	-5
SP2	15	11	11	37	9	9	6	24	-6	-2	-5	-13
SP4	10	9	5	24	10	7	5	22	0	-2	0	-2
SP5	13	8	6	27	8	9	7	24	-5	1	1	-3
SP6	15	10	11	36	10	11	7	28	-5	1	-4	-8
YA1	8	8	6	22	9	7	4	20	1	-1	-2	-2
YA2	10	12	9	31	14	11	9	34	4	-1	0	3
YA3	8	9	6	23	7	7	5	19	-1	-2	-1	-4
YA4	10	8	8	26	10	8	8	26	0	0	0	0
YA6	9	6	4	19	7	7	5	19	-2	1	1	0
YA7	14	8	5	27	11	10	5	26	-3	2	0	-1
YA8	13	9	7	29	13	11	7	31	0	2	0	2
BP1	9	2	2	13	8	1	3	12	-1	-1	1	-1
BP2	10	10	6	26	9	9	6	24	-1	-1	0	-2
BP3	13	10	6	29	14	13	6	33	1	3	0	4
BP5	6	7	3	16	9	11	9	29	3	4	6	13
BP6	8	6	5	19	10	6	4	20	2	0	-1	1
BP7	10	12	7	29	12	13	10	35	2	1	3	6
BP9	7	5	5	17	7	4	4	15	0	-1	-1	-2
SP mean (SD)	11.8 (3.83)	8.4 (2.7)	7.2 (3.63)	27.4 (9.81)	8 (2.92)	7.6 (3.44)	5.6 (1.67)	21.2 (7.69)	-3.8 (2.39)	-0.8 (1.64)	-1.6 (2.7)	-6.2 (4.44)
YA mean (SD)	10.29 (2.36)	8.57 (1.81)	6.43 (1.72)	25.29 (4.19)	10.14 (2.73)	8.71 (1.89)	6.14 (1.86)	25 (6)	-0.14 (2.27)	0.14 (1.57)	-0.29 (0.95)	-0.29 (2.36)
BP mean (SD)	9 (2.31)	7.43 (3.46)	4.86 (1.77)	21.29 (6.6)	9.86 (2.41)	8.14 (4.63)	6 (2.65)	24 (8.83)	0.86 (1.57)	0.71 (2.06)	1.14 (2.54)	2.71 (5.47)
Total mean (SD)	10.21 (2.86)	8.11 (2.64)	6.05 (2.44)	24.37 (6.95)	9.47 (2.67)	8.21 (3.34)	5.95 (2.04)	23.63 (7.32)	-0.74 (2.75)	0.11 (1.79)	-0.11 (2.31)	-0.74 (5.4)

Table 5.8: Measures on Core Bereavement Inventory questionnaire [18], including subscales, collected at baseline (Week 1) and at study completion (Week 10). Higher numbers indicate stronger intensity. Maximum scores: Images = 20, Separation = 15, Grief = 15, Total = 50.

Participant	**Week 1**				**Week 10**				**Changes**			
	Family	*Friends*	*SO*	*Total*	*Family*	*Friends*	*SO*	*Total*	*Family*	*Friends*	*SO*	*Total*
SP1	25	26	28	79	27	27	28	82	2	1	0	3
SP2	13	19	18	50	21	14	8	43	8	-5	-10	-7
SP4	24	25	24	73	24	26	26	76	0	1	2	3
SP5	23	28	24	75	20	27	24	71	-3	-1	0	-4
SP6	7	5	8	20	4	6	5	15	-3	1	-3	-5
YA1	6	22	24	52	12	22	24	58	6	0	0	6
YA2	8	6	14	28	18	8	4	30	10	2	-10	2
YA3	25	22	4	51	27	21	16	64	2	-1	12	13
YA4	18	25	28	71	21	26	28	75	3	1	0	4
YA6	11	25	18	54	14	22	26	62	3	-3	8	8
YA7	26	22	26	74	25	21	25	71	-1	-1	-1	-3
YA8	20	20	20	60	20	20	22	62	0	0	2	2
BP1	21	18	19	58	19	16	15	50	-2	-2	-4	-8
BP2	21	22	20	63	21	23	24	68	0	1	4	5
BP3	21	19	24	64	22	20	24	66	1	1	0	2
BP5	17	13	15	45	22	17	21	60	5	4	6	15
BP6	28	28	28	84	28	28	28	84	0	0	0	0
BP7	26	24	26	76	23	24	23	70	-3	0	-3	-6
BP9	22	22	20	64	24	24	24	72	2	2	4	8
SP mean (SD)	18.4 (7.99)	20.6 (9.34)	20.4 (7.8)	59.4 (24.76)	19.2 (8.93)	20 (9.57)	18.2 (10.83)	57.4 (28.02)	0.8 (4.55)	-0.6 (2.61)	-2.2 (4.71)	-2 (4.69)
YA mean (SD)	16.29 (8.06)	20.29 (6.55)	19.14 (8.23)	55.71 (15.24)	19.57 (5.44)	20 (5.63)	20.71 (8.3)	60.29 (14.57)	3.29 (3.73)	-0.29 (1.6)	1.57 (7.02)	4.57 (5.09)
BP mean (SD)	22.29 (3.64)	20.86 (4.78)	21.71 (4.5)	64.86 (12.5)	22.71 (2.81)	21.71 (4.27)	22.71 (3.99)	67.14 (10.51)	0.43 (2.64)	0.86 (1.86)	1 (3.79)	2.29 (7.97)
Total mean (SD)	19.05 (6.88)	20.58 (6.43)	20.42 (6.64)	60.05 (16.8)	20.63 (5.74)	20.63 (6.14)	20.79 (7.59)	62.05 (17.3)	1.58 (3.66)	0.05 (1.99)	0.37 (5.36)	2 (6.46)

Table 5.9: Measures on Multidimensional Scale of Perceived Social Support questionnaire [123], including subscales, collected at baseline (Week 1) and at study completion (Week 10). Higher numbers indicate stronger perceived levels of support. SO = "special other." Maximum scores: each subscale = 28, Total = 84.

While most participants found the site accessible and appreciated its design elements, there were several more profound concerns regarding the inclusion of reminiscence as part of the system concept. I detail these concerns first, and then turn to some of the properties of the various types of mementos upon which participants commented.

5.7.1 Concerns with Digital Mementos

The inclusion of mementos in a social support system was met with some hesitation. While the early design work suggested that having a separate website for bereavement-related assets and activities would be valuable, participants' low usage rate and attitudes conveyed a different story. Involving digital mementos as a part of a social support setting did not appear to be particularly successful. BP6 summarizes several of these concerns:

> "I look at it more as a sharing tool. Like what I put in there, stories or something like that, I always share with other people. I don't think I'd just put stuff in there just for me. The only reason I put stuff in there was the way to get it into the shared part... Own my own drive, I have a folder of poems I like and stuff like that. A folder of [my son's] stuff. I have that already in Word so I don't know, if I have that on my computer already, why would I put it on here?... I don't know if the site will run forever in reality. I know this will close, but if I were on a site like this I have no guarantee that it'd always be there. The only reason is to share it with other people." - BP6, final interview

There are several concerns raised in this quote that contributed to the limited success of the Memory Box feature. I examine each of these concerns in turn, along with other concerns participants expressed regarding digital assets and mementos in social support.

Digital Assets and Mementos in Social Support

First, participants saw the Memory Box as subservient to the functions of social support, rather than a standalone tool that they would find personally helpful for looking through photos, revisiting stories, and so on. As a result, the Memory Box was perceived as imposing an extra step when users wanted to directly share assets with other members of the Circle. Even then, the inclusion of journals and links inside of the Memory Box revealed some confusion and a blurring of the distinction between talking about the loss, and talking about grief.

> "A lot of times when we're talking in the groups or even chatting, what is important is the emotions and the grief journey that the bereaved person is on... Memory Box puts that emphasis on the person that you lost, which is important, but... the journal would be about what is going on for you right now. That's not about memories. That's about me, and not about [my partner] at all." - BP1, final interview

In other words, some of the assets participants chose to include in the Memory Box were not actually mementos. Instead, they were resources or artifacts that arose in response to the loss. A link to a blog for widows did not appear to make sense when placed alongside photos of the deceased, for example. Furthermore, participants were concerned about sharing aspects of a deceased loved one's life in a group context:

> "I'd do the sharing cautiously because you have this memory and I don't want to just put it out there. [My husband] was still a private individual. Though I am happy to share my grief...I don't want to just throw him out there as exhibit A. These are my relationships, not his." – SP4, final interview

> "I feel more private about it than I thought I would. I thought that [sharing photos] would diminish how special it is. To someone else they'd just look

> like photos of people. To me, they're important pieces of memories." - YA3, final interview

These quotes illustrate the distinction between the creation and maintenance of current relationships with members of the support group as part of the grieving process, and the private nature of mementos that come from the loss itself. Including the Memory Box, at some level, drew participants backwards towards the loss rather than forwards towards coping.

> "Personally I am ready to start talking about the future... grief and loss are different things. If we're meeting to talk about the loss, then that's the past, what they were like then. Grief is **now.** It's what we're doing now and what we will be doing for the rest of our lives. You don't stop, but it changes. At the support group one of things you should get out of it is how to cope, and lean on each other. It's not just talking about the person [who died]. You get tired of it at some point, you know." - YA4, final interview

Preference for Physical Assets

Second, participants saw the Memory Box as a redundant and inferior way to remember their loved one. When asked why the Memory Box was not used more, they reported that they did not perceive a need to create an online repository of this sort - they already had mementos of their own in their homes and saw no reason to duplicate them online. The physical versions of these mementos were not only seen to be more valuable, but were more accessible (i.e., no need to scan them) and resilient against loss (e.g., by a computer crashing).

> "I like tangible things. I put things into physical boxes and books and albums. I like them there because I like to walk by the table and see it there and sit down and open it. I also feel I have control over what is there instead of a

> website going on, or being deleted or whatever. I like the tangible of something there. I also didn't feel the need to share with someone in the chat." - BP7, final interview

Further, there was a quality to physical versions of various assets that could not be duplicated online. Indeed, many of the most valuable assets are those that do not have a digital version:

> "When I have his shirts in my closet, I'd rather go touch his shirt when I miss him, but I have the luxury of doing that which many people do not... if cousins or extended family miss him, they can't smell him or feel his shirt. The Memory Box would be great for them." – SP4, final interview

In this comparison, SP4 notes how digital mementos would be seen as a substitute for physical assets. Even when the type of memento could be easily made digital - as with text input - the actual act of producing the asset was seen to be less fulfilling. YA1 attempted to use Besupp for some of her journaling, but found it to be a different experience from writing in a paper journal:

> "I did start to type some journal type things to add privately to the memory box and I just... I found that I was working through it more when I wrote on paper... the typing to me - it just... I started it and it was too easy to leave it. My first instinct is to go to pen and paper and I felt weird typing a journal entry from a real journal into the computer. If I chose to write in an evening, and I could put that into the Memory Box as an entry, it felt strange to sit and type it out as if it were an essay I had already written." - YA1, interim interview

The Fate of Mementos

Third, participants expressed concern about what would happen to their mementos at the conclusion of the 10-week study. While participants were assured that a DVD backup of mementos would be provided and that reasonable steps would be taken to ensure that Besupp endured past the end of the 10 weeks, they felt there was little point in uploading items to a website that would be potentially taken down.

> "Because I know the site won't be there forever, I don't put the effort into it I guess, because it's a test site. If I was going to make that effort I'd put in some photos." - SP5, final interview

This concern presents itself more generally in response to the entire system, beyond mementos, and is discussed further in Section 5.9.1.

Emotional Rawness

Fourth, a user may seek support but not be at a stage where they feel comfortable working with digital assets. In this study, only one participant found it too difficult to organize her mementos or engage with the system because of the freshness of her loss:

> "I find it difficult. To put a memory or photos into the box you have to go through the pictures and all. Some things I don't know if it's too soon, or I'm still in the grieving stage or whatever. I just can't seem to look at pictures right now... I can't even look at them let alone upload them. I chalk it up to being that it's still pretty raw for me... I thought I could do it when I started. I thought it would help me, but can't even do simple things. It's just not good." - SP2, final interview

This participants in particular was quite close to the time of her loss, and dealing with mementos was not something she was able to handle.

Technology Comfort and Problems

Finally, while most participants rated themselves familiar with technology (Table 5.3), adding mementos was often seen to be technically too difficult. For most participants, there were few digital mementos available to upload or import from other sites. This meant that they would have to find a scanner, learn how to use it, and subsequently upload the assets. These steps were often seen as too cumbersome or difficult.

> "I was going to try to add some stuff and never got around to it. It would have been scanning stuff in and didn't have a chance to do that. Time was the problem. The time and the lack of some of the technology. I have a scanner at home and was going to hook it up but never did. Don't even know if that would work... so I would have to do it at work and I have been working at home a lot. It'd be easier if i had the tools...especially if I did have a scanner, I could see scanning lots of stuff into that rather than creating a memory album or something like that." - BP2, interim interview

Further, some participants were unfamiliar with the file types, formats, and sizes of the photos they had on their computers. While Besupp could have included better error handling for such events, participants became frustrated when trying to add items to the Memory Box and were not inclined to keep trying. For example, BP7 attempted to upload a copy of a very large, high-resolution photo:

> "I tried adding a photo and it was taking forever. I tried again and then I just gave up, since I have all my other stuff elsewhere." - BP7, interim interview

Taken together, the interviews and logs indicate that the Memory Box was not frequently utilized, and played a relatively minor role in a social support setting. These findings indicate some of the potential areas that researchers and designers might consider when running studies with the bereaved or building systems for their needs.

5.7.2 Types of Mementos and Assets

While the Memory Box was not frequently used, participants did remark on their experiences with the various types of assets. For some, uploading content to the Memory Box was a more positive experience. YA2 described that going through her photos and stories gave her an opportunity to "focus on the good times," while BP9 enjoyed the ability to "do stuff" and "create something new." In these cases, the Memory Box itself was not so much valued as was the process of selecting and organizing the items to go within it.

As mentioned previously, photos and stories were the two dominant types of mementos that were used. I now review some of the ways that participants created and encountered these mementos, along with the other three types: videos, links, and journal entries.

Stories

As Table 5.5 shows, only 11 stories were shared in total, and no stories were shared in the YA group. However, all 19 participants wrote a "background story" as part of their user profile. In this context, stories served multiple functions. First and foremost, the background stories helped participants get to know each other, and to recall the details of others' losses.

> "Some of the stories are quite brave. What people have gone through. Yeah, I think you can certainly identify with the losses." - BP3, final interview

Identifying with these losses was a key way that participants achieve a sense of normalcy (see Section 5.8.5). While no Memory Box stories were shared in the YA group, the moderator offered some explanation regarding her personal experience with them:

> "I wish people would have used [stories] more... but at the same time I didn't...anything I wanted to share in that way I shared on the board, on the Circle Chat. I typed my story into my profile, but...anything I wanted to keep private I didn't want to type out, and anything I wanted to make

> public I put on the chat, so I didn't use the stories...I think there's a place for telling stories and we use those in the face-to-face groups as well. But the deeper connection comes when it opens up to a conversation. That is what facilitates the deeper connection with people." - YA1, final interview

As YA1 points out, the goal of writing stories was to share them with other people (rather than to keep them to oneself. In other words, the stories that were told had audiences. In Besupp, stories in the Memory Box contained thoughts and questions, rather than narratives. For example, one participant in the SP group had a child with a man who died after they had split, and used the stories section to write out her questions dealing with her circumstances:

> "We are quickly approaching [his] 'death day' and I am never sure what to do. How do I mark that day? Is it time to take our 4 year old to the cemetery, or is she still too young? Do I send flowers to his parents or is a phone call a better idea?" - excerpt from a story written by SP5 on Week 2

Posing these kinds of questions in a story then led to a conversation in the Circle Chat, as the group moderator explained:

> "It started discussion. When [SP5] shared her story, it was about the anniversary of the day her partner died. So that started a bit of a discussion on what to do in an anniversary." - SP1, final interview

This reveals something about one type of storytelling in bereavement support groups. In the lay sense, storytelling often refers to presenting a narrative with a start, end, plot, characters, and so on. In this system, the stories were also used as ways to convey current or ongoing thoughts or experiences, with a goal of receiving feedback from the Circle – something resembling a letter to an "advice column" more so than a "story." Being able to link to a story directly from the Circle Chat appeared to help with this as well:

> "I think it makes sense if it's the kind of story where you want other people to comment on it, or you want to start discussion... a link you wanna say 'Hey this is interesting because...' and comment on it in some way." - SP1, final interview[5]

Summarily, the background stories opened up opportunities for participants to introduce themselves, and relate to one another. However, the storytelling that occurred is better characterized as unfolding in conversation rather than as a form of closed-ended narrative.

Photos

Photos were the most commonly used type of digital memento in Besupp. Overall, participants shared 25 photos out of the 33 that were uploaded to the Memory Box (Table 5.5). Selecting and sharing these photos was a nuanced process for many participants, and the photos served multiple purposes. First, in continuing with the notion of stories above, photos were used as a form of visual storytelling and as an additional way to share with the group.

> "Yeah I mean the first thought was to put no picture. I liked the anonymity of it all. I felt quite guilty that I didn't have a photo of my mom or stepmom to share, so I thought that I should put **something**. The second thought was to put a picture of myself, but I felt silly doing that since the site is about more than just me... it didn't share enough of my story." - YA1, interim interview (her emphasis)

One of the main ways that this story was told was by uploading photos showing the user with the deceased person, foregrounding the nature of their relationship. In choosing

[5]Only threes items were attached to chat messages throughout the course of the study. One was a link to this story, and the other two were web links. All were created by SP1.

a profile photo to appear on the list of members in the Circle, for example, 5 participants selected photos that showed themselves with their loved one, 4 chose photos of their loved one only, and 2 chose photos only showing themselves. In other words, 9 of the 11 profile photos showed the deceased loved one.

In performing this "visual storytelling," several participants chose photos of only "happy memories." Here, BP1 describes why she chose to upload two photos, one for each of her two sons who died:

> "It's a picture I really like because he's got such a devilish grin on his face. Even going through treatment [Son1] was such a happy child... I'm not especially fond of that one either but because [Son2] looks sad, his eyes are so sad, he looks a little hopeful." - BP1, interim interview

Participants consciously avoided photos where their loved one was frail, or sickly, and photos which other people in the Circle might judge poorly. Participants carefully chose what to share in order to tell a story that was simultaneously accurate, but selective.

While the photos and stories were clearly part of the storytelling process, at no time did a user attach these to their Circle Chat messages. In most cases, these photos needed to stand on their own as forms of storytelling. As SP5 put it, looking at photos felt "one-sided" because the person telling the story was not there to explain (even though users could write captions for photos).

While the primary reason for uploading photos to the site was to share them, users were appreciative of the ability to selectively share and unshare the items in their Memory Boxes. Only one instance of unsharing was noted, and this was in reference to a photo. YA3 uploaded a photo of a unique tattoo that she and her sisters received after their mother died. She originally shared it, but then comments:

> "It's kind of funny about that! It's not for the most mature reason. I don't want people to copy it! It's something unique and private and when I talk to

> people I know and they see it, that's one thing. With people I don't really know and I can't necessarily explain the context... I don't want to share it. I don't want them to copy the idea unless I get to know them first!" - YA3, interim interview

Photos helped to reveal information about participants to one another and foster a sense of connection, but there were types of photos that were deigned appropriate to share - or not.

Videos

No videos were uploaded to the Memory Box. When asked why, participants remarked that they had no videos of their loved one that they wished to share and lacked the technical knowledge of how to create them.

> "Videos, if I had access, I would put my son's band's song from the funeral. I would have put that song on there." - BP6, final interview

> "I felt a bit of pressure to enter something... but because I don't have any videos I feel like I should have some. I know lots of people do have videos. I've never had my own video machine and just last year I figured out how to do video on my Blackberry. I'm just not a techie." - BP9, final interview

Participants generally saw videos in a positive light, and explained they were omitted primarily because of technical know-how and availability. However, some participants also remarked that videos were too intense to be included successfully in an online environment where feedback from others could be readily ascertained:

> "Video captures the sound of their voice. The way they move. Things that capture more than just a moment in time. It's more intense than I can get into in this kind of program." - YA3, final interview

Links

Only in the SP group did the moderator (SP1) share a series of links. Most of the links were to websites and blogs about being a widow. The other participants found these links to be quite helpful, as a form of informational support:

> "I love the access to the bigger world of grief. The US conferences and whole world of information and speaking you get access to. That was good to have someone in the group who knew about that." - SP4, final interview

The only shared link that was not in reference to a support group or grief-related website was a link to SP1's deceased partner's art portfolio, which was hosted on an external website. SP1 noted that this was done to help others get to know her:

> "You have to share some of yourself so that other people can see you've been through it. That's the model of mutual support. I shared that bit not because it was appropriate but it was about them." - SP1, final interview

Journals

Three participants created a total of 5 journal entries. In interviews, participants frequently saw journaling as a possible activity for others, but not for themselves. SP4, one of few participants who did use the journal, saw writing as a form of comfort:

> "I like it better than writing in a journal at the end of the day. I like that it's live and changeable and dynamic and that other people can access it....So this was a way to just put it down somewhere. It felt like somebody was listening, somebody could hear my frustrations... Sometimes I don't want to share just the bad stuff with other people but it's hard to keep it all in inside... I guess that was really like a conversation with myself... The journal entry was a way to take a breath and see where my head was at." - SP4, interim interview

5.8 Qualitative Results: Social Support

Turning away from the mementos stored in the Memory Box, I now review some of the themes that focus on social support as experienced in Besupp.

5.8.1 Venting

The bereaved often turn to friends and family as a source of emotional support. However, repeatedly discussing the emotions associated with grieving may be perceived as burdensome, and may cause strain in existing relationships. Besupp provided a place to go where that strain could be avoided. Participants valued the ability to log on and "vent" to sympathetic others when they felt their needed to:

> "It was really late at night and it's not like I can call anybody. I don't want to bug anyone but I just needed to vent. So this was a way to just put it down somewhere. It felt like somebody was listening, could hear my frustrations because I wasn't going to bug anyone else with this." - SP4, interim interview

> "It's good to be able to have an outlet that I wouldn't usually have and knowing that there are people who would respond, and that I wouldn't get the response I get from loved ones which is 'Stop complaining all the time!' " - YA2, interim interview

While Besupp provided a place to express these emotions, the lack of a timely response to these thoughts became problematic.

> "It's like talking to the air and then expecting a response later. There's no response later and then you keep checking the site to see if there's a response. It takes too long you know. Not really for me." - SP2, final interview

In a way, the value of Besupp was in having a dedicated space to express such emotions as they occurred. While a response to these expressions might take a long time to arrive, the ability to at least externalize them appeared to be helpful for some participants.

5.8.2 Self-Editing

Like many face-to-face support groups, sharing stories and emotions was a large part of the experience on Besupp. Choosing what to tell and share became a deliberated process, in comparison to the spontaneity of a face-to-face group where participants might "blurt out" their thoughts with less forethought. In interviews, participants frequently reported revising what they were about to say before sending it to the chat room. The ability to take one's time in crafting a response was a key difference between face-to-face and online support groups:

> "In the face-to-face groups they were very careful to keep things moving... With the chat room people can dwell on whatever they choose to...I think it gives you a chance to work things through in more detail maybe than in face-to-face...You respond to your own stuff too in addition to other people."
> - BP9, interim interview

This self-editing and control was not just in reference to what was said in the Circle Chat, but also with regard to photos. Photos tell stories, and participants wanted to present a particular version of their own story.

> "He died when he was 23. The one I have shown here he was 6 or 7. I chose not to add any pictures of him from high school and on. There's a picture of me at my wedding with [him], and it's a great picture. But I'm in a wedding dress and I'm not married anymore so that's confusing, and also [he] was overweight and the picture I showed he's a tiny kid... One of the reasons he died was due to H1N1 but because he was obese he had complications. Most

> people would be healthy enough to fight that off but because of his weight he wasn't able to. There are a lot of parts of that I don't like talking about with people I haven't met. I'd rather not share that, or deal with that part of the story." - YA4, interim interview

In an online support group, the bereaved have the opportunity to more carefully craft the image that they wish to convey to others. In a face-to-face group, one cannot control so easily the reactions or emotions that discussing grief can cause.

5.8.3 Rate of Conversation

While having a place to vent and carefully craft one's story was valued, the slow rate of response was problematic. Indeed, all participants noted that the amount of activity on the site was less than they had expected. As noted in Table 5.6, the time between messages was on the order of days. Compared to a face-to-face support group, this rate of participation was considered to be quite slow. Participants attributed this low rate of exchange to a range of factors. Generally speaking, this included busy lifestyles, travel, and technical difficulties (e.g., computer crashing). Administratively, almost all participants thought that the group was not big enough to keep discussion flowing (even though these numbers were on par with numbers in face-to-face groups). The following exchange occurred in the BP Circle Chat during Week 7:

> **BP1 (moderator) (Tue 9:31am)**: I've also been thinking about this website and how different it is from the groups. I think if we could try and check in once a day, it would help. Otherwise when someone makes a post, it is kind of left hanging, particularly if it directed at someone specific, and that person doesn't check in for awhile. What does everyone think?
>
> **BP9 (Tue 12:51pm)**: Maybe we could meet once a week with a selected topic like the group did.

> **BP6 (Tue 7:25pm)**: I agree with BP9, I think it would be good to have a topic which we could share our thoughts and feelings on each week.
>
> **BP2 (Fri 5:47pm)**: Re. your message of Tues re. being left hanging, yes, I agree... it would be nice to meet at a certain time/day. Let me know when and I will try to be there.

As shown above, the BP group used Besupp to facilitate more synchronous conversations. The BP group scheduled a chat session where three of the members logged into Besupp at a pre-determined time (a Wednesday at 7:30pm). This real-time chat explains the relatively large number of messages sent by the BP group (180) in comparison to the YA (62) and SP (39) groups. In the follow-up interviews, participants reflected upon the real-time chat favourably:

> "I did check from time to time and there wasn't always a lot in there. The one day that we did make a date to go online and talk there were only 3 of us, but we did do the chatting for about an hour. That was really good. It was kind of like being in a group. It was similar to that experience." - BP2, final interview

Participants suggested a range of alterations to the system that might support more conversation: meetings might be more scheduled, or more participants might be involved in the group. Others thought that the chat system might support availability notifications and instant messaging. In addition, participants wanted moderators to take more prominent roles in stimulating and directing conversation.

5.8.4 Moderators and Structure

On the whole, the presence of a moderator in the Circle was seen as critical by both non-moderators and moderators alike. Moderators were primarily valued as safeguards

against inappropriate or harmful behavior. While we did not observe this in our study, users perceived a need for vigilance regarding harmful behavior (e.g., suicidal intentions), and a need to prevent the imposition of spiritual or religious viewpoints onto others (e.g., in the case of a suicide). Overall participants were pleased to have moderators available, but wanted them to take a direct role in structuring the discussion. Participants frequently remarked that the moderators should choose a conversation topic and ensure that people contributed to the discussion.

> "A lot to do with interaction from an admin. Someone to keep the conversation going. In this type of environment either creating a type of structure that everything follows, the way BFO does with Week 1 is Topic A, Week 2 is Topic B. And a topic list of 15 things or something for your admin. Then, every time the conversation died down then you can introduce something new to keep things going. In some cases I didn't add anything else because I was the first to weigh in and I didn't have anything else to say until the next topic came up. People would really benefit from the structure. People are lazy, let's be honest. If we have something that prompts us and says 'Hey! It's Besupp! We're talking about stories this week. What can you share?' then that'd definitely help." - YA3, final interview

> "Well I know [BP1] tends to hold back from guiding people. She didn't seem to want to make any strong suggestions or say 'We will do this' or 'We will do that.' I think that would have helped a couple of times. She'd make a suggestion and when people didn't respond right away she'd get annoyed and take it back again. It was hard for her to be too directive, but it would have helped probably." - BP9, final interview

Moderators themselves found the lack of participation to be problematic. The moderator of the YA group noted:

> "Personally I found it frustrating because I wanted to do the job. I wanted to moderate. But there was nothing to do really. I found it frustrating having the enthusiasm for something and having no ability to prompt that... I hoped people would run with it, and that didn't happen." - YA1, final interview

The Circle Announcements (Table 5.7) were intended to help moderators create discussion topics. While the moderators were the three most active individuals on Besupp, there remained an inability to create and maintain a discussion.

5.8.5 Normalization

The main value participants derived from Besupp was as a form of emotional support through the "normalization" of their grief. Normalization refers to a process where an individual comes to recognize that their thoughts and emotions are not strange, and that other people experience them as well. Reading the background stories and talking about their feelings and challenges in the chat were described as helpful ways to feel like they were not alone and that what they were experiencing was valid and shared:

> "I liked reading what people were saying on there... and responding as well and reading everyone's loss. I didn't like enjoy it, you know, but it normalized things, and it was good to relate to people in that way and know that people are going through grief even long after the passing." - YA8, interim interview

While this normalization did occur, participants felt that having a support group online made it difficult for them to establish emotional connections with other people in the group, and felt that it was taking a comparatively long time to "warm up" to others.

5.8.6 Helping Behaviours

While many of the activities concerning mementos were not heavily used, the Circle Chat offered a form of "something to do" that was more successful. Participants used

the Circle Chat to offer support and give back, with little desire to "receive" it. For example, BP5 lost her son 16 years ago, and has since become an active member of BFO, volunteering to conduct one-on-ones. She saw Besupp as a place to share the wisdom of her experience even more widely.

> "I always thought the site would be good to share. Because talking and sharing helps you with your grieving process and helps others with the grieving process. It shows them they are not alone. That their feelings are similar. Many people think that their loss is so unique... I thought sharing would make the people understand that others have gone through this and they are better off after a certain period of time." - BP5, final interview

The moderator of the BP group similarly described her motivation for volunteering as a moderator both in Besupp and in BFO groups:

> "Comes out of a feeling of being able to help others. I have been through so many of these things that I can show them that you can carry on, it's possible. With my experience, and it makes my experience meaningful." - BP1, final interview

This form of group activity allows the bereaved to draw on their experiences within a safe environment. Designers developing social support systems might think about how to support this type of use case more fully.

5.9 Qualitative Results: Emergent Themes

In the previous two sections, I presented the results of interviews as they related to the two major components of Besupp: remembrance with the Memory Box, and social support with the Circle. In this section, I remark on themes that emerged during interviews that refer to more general aspects of the system and/or study.

5.9.1 General Attitudes towards Technology

Previously, I discussed a series of barriers that inhibited the creation of digital mementos. In addition, participants had more general concerns with using technology for bereavement-related activities. First, some participants associated using a computer or the web with workplace activities.

> "It's weird logging in for something like this... Typing, for me... it's more formal. I equate it with doing a job or doing work, or something that is going to be shared, typing an essay, doing those things, sending emails...the actual sitting at a computer and typing seems much more of a public and work related thing than curling up with a journal" - YA1, interim interview

> "I was snapping into my work persona, which I guess is a little bit more cheerful. I didn't realize I was doing it immediately. There's a style you get used to...every once in a while I had to stop myself from making a cheerful comment like 'Let's move on' or 'Let's do this.' Work is always focused on getting something done." - BP9, final interview

> "Part of it is that I'm on my laptop all day long, so I'm not big on spending hours in the evening on my laptop." - BP7, interim interview

While the deployment study was only 10 weeks long, participants remarked on how it fit into their lives at this point in their grieving process. The relatively low usage rate led to interesting conversations with participants about its efficacy, and how their grief - and need for support - fluctuated. Despite a perceived need for support, a second barrier identified by participants is the high amount of emotional effort required to use Besupp. For some participants, this left them feeling drained and brought back negative emotions:

> "I'm not sure that Besupp was a vehicle for my needs are...I don't even know what my needs are, you know? People ask if this helps or that helps, and it

> sucks where I am right now. I don't know if it's going to suck more or less if I do something." - BP7, final interview

> "It was very hard for me emotionally and way harder than I thought it would be after hearing everyone's story. I felt like... pretty upset about it truthfully. It was hard for me to come back...hearing all the sad stories again was really hard for me to take because I'm in a different place now. If this study was for first timers rather than people in a group already it'd be a totally different reaction... I met up with one of my friends who I met through my first group... she said it might not be a positive experience, a good thing for you, because you're taking on other people's sadness again and you already have your own... people using it seem to be getting a lot out of it but for me I'm just a bit heartbroken." - YA4, interim interview

In a way, this highlights the benefits of a weekly 2-hour support group: it limits the time that participants are exposed to thoughts and emotions of grief. The constant availability of Besupp shifted the onus of managing exposure onto the user, making it more difficult to disengage from these emotions.

Third, while the creation of a separate space for bereavement activities was initially met with enthusiasm, participants remarked on how the website made social support seem more formal than it is in face-to-face groups. For example, YA4 felt she could not share certain items she associated with her brother because they were not somber enough for a bereavement website:

> "There are some songs he liked from the 90s, like 'Mambo Number Five' by Lou Bega. I thought about uploading that from YouTube, but I didn't know how seriously to take it. That's the problem with grief... I laugh a lot when I talk to his friends and we talk about happy memories. It's not sad but there's something about when you call it 'grief support online' that you should be

> doing your 'grief work.' And I'm not sure if Lou Bega has anything to do with grief work." - YA4, final interview

She then went on to contrast this with a moment of levity that naturally emerged from a conversation that occurred in her BFO group.

Fourth, participants were concerned about the duration of the study, and did not believe that 10 weeks - an amount of time on par with face-to-face support groups - was enough to establish a close connection with the other people in the group, and get to the real work of the support group.

> "10 sessions/weeks is not very long. It took a long time to get into things. That's perhaps why not a lot of people are using the Circle Chat. It takes us time to emotionally adjust to what we're doing. It's not necessarily the forum that is the problem. If it were ongoing for a year that in the 2nd half of the year you'd see people using it a LOT more. It's just getting comfortable, and the Circle Chat is the best way to do that. It's already time consuming to log in a few times a week and write and read for 20 minutes." - YA4, interim interview

Finally, participants hesitated to invest their time and energy in a group that would potentially disperse at the conclusion of the study, and wanted to avoid the feeling of being "let down" by the conclusion of a group.

> "I don't think saying only 10 weeks is... I don't like that somehow. Once again it's just another group that's going to end. You're going 'Oh I'm going to get involved and then lose the support again.' That's what you feel when there's a time to it. Literally it could go on forever. But again would a moderator want to do it forever? Probably not." - BP1, final interview

5.9.2 Mobile Use

Although the mobile version of the website was available and explained to participants, only BP9 used the mobile version, and logged in on the mobile client 3 times. YA7 and BP1 reported using their mobile phones to access the desktop version of Besupp, however. For BP1, a moderator, having the mobile version allowed her to keep tabs on the conversation occurring in the chat:

> ". I wasn't home so I thought I would check in and see what was going on there, if there was anything I needed to know or help with like that. It was useful to have it on the go - I think so." - BP1, interim interview

On the whole, however, mobile devices were not used for accessing Besupp. This low usage is attributed to several reasons. Most prominently, only a few participants had a data-enabled smartphone. Of those who did, most described using it only for email. When asked why they eschewed using Besupp on their phones, some mentioned concerns about using a mobile device to chat about a sensitive topic that demanded attention and long-form text responses, and the inadequacies of entering text on mobile devices.

5.9.3 Online and Offline

All participants in the study had completed at least a one-on-one interview at BFO, and all but SP2 had completed a face-to-face support group at BFO. For all participants, Besupp was the first online support group experience they had encountered. As mentioned, a group interview was conducted at the beginning of the study for each of the three groups. At that time, participants had the opportunity to meet other members of the group. However, some members could not attend the scheduled meeting, and some of the attendees later dropped out of the study. Participants in each Circle then did not have an opportunity to get to know one another before starting the study, and essentially met each other for the first time online. This is likely why mementos were

used primarily for self-disclosure and sharing stories (as mentioned above). This raises the question of how to offer online support groups in contexts where face-to-face groups may also be available. Indeed, the study could have examined participants who had just completed a face-to-face group, or participants who were just beginning a face-to-face group, or participants who had finished a group together several years ago. If the study had explored a group that had existing face-to-face relationships, participation might have been higher.

Another option explored by the members of the BP group was to coordinate a face-to-face meeting outside of the study. Near the end of the study, one of the participants invited everyone in the Circle to her home for a get-together by posting a message to the Circle Chat during Week 9.

> "**BP2 (Wed 10:53pm)**: You are welcome to come to my house or we could meet somewhere. Date Tuesday Oct. 18th. How is 6:30 p.m. or 7:00 p.m."

Some members of the group then proceeded to exchange email addresses and organized the occasion outside of the Besupp system. At the conclusion of the study, the moderator from the SP group also provided her email address for ongoing support exchanges. As technology designers we might think about how to allow for support to be provided in both face-to-face and virtual environments simultaneously or consecutively.

5.9.4 Timing of the Study

As noted in Table 5.3, most participants experienced their losses 2 or more years ago. For this group of participants, Besupp was seen as a potentially useful tool, but not for them at the current stage of their grief journey. Rather, they believed it would be much more helpful closer to the time of the loss. Indeed, a medium negative correlation ($r = -0.41$) was noted between the number of logins and the number of years since loss, suggesting that non-moderators with fresher losses logged in more.

> "I like the idea to have it as an option again, given that I'm 4 years into grieving my mom. I don't know that it would be as necessary for me, but... I'm thinking 4 years back I was searching desperately in the middle of the night and everyone was asleep. And I was online trying to find something... so I think it's a necessary tool to have, but more for people who are freshly grieving. But again there are times where I'm like 'Who do I talk to?' and it'd be nice to know that it's there, but I don't know that I'd use it." - YA2, final interview

Many participants believed that they would have garnered greater benefit from Besupp if they had participated within 6 months to 2 years following the loss.

In the current study, two participants - SP2 and BP7 - experienced their losses less than a year ago and represent participants who are at the timing suggested. However, these two freshly grieving participants found the system to be difficult to approach for a range of reasons. Among these reasons, they felt it was difficult to connect to the other people in their groups who were further along in their losses.

As mentioned above, SP2 could not even bear to look at photos, let alone add them to a Memory Box. She found the slow pace of conversation problematic, and thought that the online group was far too impersonal. She described difficulty in finding good support groups in her community as well. When asked what could be changed about the system or the study, she responded:

> "The site isn't for me. Even if you changed whatever, I wouldn't be able to do this as much as I think I should... I'm not able to participate constructively because to me I find that it's a very personal experience and it's very hard to think that someone else would think the same way as me." - SP2, final interview

BP7, on the other hand, had completed a group at BFO. She noted that she had difficulty connecting with the other people in Besupp because she felt the group was less diverse and less organized than her experience at BFO. She suggested that people even closer to the time of their loss would find more value, and saw Besupp as somewhat redundant given her previous support group experience.

> "Maybe some people very new in this world would find value in it... I suppose if you didn't have a group like the BFO parents group I went to, then a vehicle like this might serve a similar sort of purpose. But having been part of such a group before and exchanging emails, I already have those connections." - BP7, final interview

Overall, most participants using Besupp imagined it would be more useful closer to the time of the loss. Of the two participants who were closer to the time of the loss, one preferred face-to-face groups and the other had difficulty finding any group at all from which she could derive value. The responses from the participants would suggest that online support groups could be best applied within the first year of the death, but would require significantly more involvement from peers who experienced very similar losses.

5.10 Reflection on Design Considerations

In designing Besupp, I applied the design considerations (DCs) from Phase 2 and documented how they impacted aspects of conceptual and interactive design. Here, I revisit the considerations in light of the results presented in the preceding sections, and describe how these DCs might be adapted or better articulated based on my work.

5.10.1 DC1: Circles of Sympathy and Communication Availability

This DC originally remarked on two key points. First, the bereaved value talking to one another, and that the value derived is different from the kinds of support given by friends and family. Second, they must manage their availability to other people regarding their grief and may choose moments of isolation or silence. Both of these points were borne out in the results. Participants found the Circle Chat to be the most engaging part of the site, and enjoyed learning about the other people in their Circles. They appreciated the safety and confidentiality associated with this form of group, but did wish that there were more people involved to bolster discussion or to provide better "matches" with respect to the type of loss.

Participants rarely reported any change in how they talked about their bereavement with their friends and family throughout the course of the study. While there were a few occurrences where participants reported diverting their grief-related discussions to Besupp in order to vent, it seemed that friends and family still remained steady sources of support. It was also suggested in this DC that the bereaved would find more value in the informational resources shared by other bereaved people, in comparison to their friends and family. While this was not able to measured directly, some participants did appreciate learning about new resources from the people in their Circles.

As the usage rates and themes above mentioned, the rate of conversation was somewhat slow and there were times when participants avoided using Besupp because they did not want to deal with their feelings of grief. This suggests that the opportunity to choose isolation and disconnection - a key part of this DC - was exercised throughout the study.

5.10.2 DC2: Storytelling and Narratives

This DC suggests that telling stories about the loss and other events is a primary way in which peer support is conducted. Three ways to tell stories were provided in Besupp: the background story, the Stories feature of the Memory Box, and by telling stories in Circle Chat. The results suggest that the story of the loss differs significantly from the other types of storytelling. All participants contributed this through their background story, and participants found reading these to be a good way to normalize their own experiences and relate to other people. Aside from the background story, the Stories feature itself was not used frequently; when it was used, narratives were rarely written. Instead, the Stories feature was used to share poems, ask for advice, or post text from a memorial service. This raises the distinction between storytelling and story writing; the former is an act meant to engage, in the moment, a group of people in a shared narrative. Writing a story, on the other hand, invites reflection and does not necessarily involve the same sense of audience and community.

While storytelling should certainly be supported, this DC might also ask designers to think about various forms of storytelling. In the Besupp study, storytelling was wrapped up in conversations that unfolded in the Circle Chat. We might consider how to allow storytelling to occur among a group of as part of an ongoing discussion, in addition to writing and reading stories on one's own. Another form of storytelling originally overlooked by this DC was visual storytelling. Selecting and uploading photos helped participants "put a face with a name" and conveyed the story of the loss more vividly than words alone. Designers might think about how to allow these various forms of storytelling to co-exist and blend in future systems.

5.10.3 DC3: Permanence and Continuity

Permanence and Continuity referred to the idea that a loss is a permanent change in worldview, and that the grief it causes it does not ever completely disappear. While a proper examination of this DC would only be possible with an extremely long-term study, participants remarked on how Besupp might have fit into their lives at different points in their grief journeys. Most found that it would have been more helpful closer to the time of the loss because they had not yet learned to cope with their feelings of grief. For those participants who were closer to the time of their loss, this online support group was not seen to be helpful because it was difficult to relate to people who were further along in their grief journeys.

Participants in Phase 2 remarked on the need for sustained support beyond the initial year or two since the loss. In the Besupp study, this peer support was made available to several participants who were beyond 2 years. Contraindicating the results of the focus groups in Phase 2, participants did not feel a strong need for support after all. Most had found a "new normal," and while they continued to grieve their losses, they were able to cope without the need for peer support.

In designing systems for the bereaved, one should consider not only their unmet needs (e.g., the ongoing need for support), but also their strengths. Systems might be designed to acknowledge effective coping, and adapt to provide a different set of services or opportunities.

5.10.4 DC4: Finding "Something to Do"

In this DC, I suggested that systems might provide activities that allow the bereaved to express their grief. I remarked on how types of activities might be creative or prescriptive, and performed in a group or individually. In Besupp, I originally assumed that working with mementos could be an activity that involves all of these types. While

there were some participants who saw working with digital mementos to be a positive way to approach their loss and their grief, most chose not to do so. Some participants had already performed such activities with physical mementos, while others found the technology was too difficult for them to operate. Still others did not want to invest time working with a temporary website. That said, using digital mementos to create various types of artifacts such as scrapbooks, movies, or webpages remains a popular option beyond the participants in this study.

Two activities that were not originally considered in the design of Besupp, but which emerged as interesting forms of "something to do," involved working with other people. While Besupp sought to provide a mutual exchange of support, helping people who were earlier in their grief without expectation or desire for reciprocation was not predicted. Participants who logged on with the sole purpose of consoling others demonstrated a charitable form of activity. The second activity - giving back to BFO - was similarly charitable. Some participants saw their involvement with research as a way to help other bereaved people to find a way to cope. Many participants did not find Besupp to be useful for them, but insisted it would be useful for others. Creating systems that allow the bereaved to give back by offering their time or the benefit of their experience can be a positive way to support those looking for something to do in memory of their loved one.

5.10.5 DC5: Heterogeneity, Sediment, Upkeep

This DC remarked on the nature of mementos, and suggests first that mementos may be of many varying types (heterogeneity). This was clearly evidenced in the Besupp study, as participants often remarked on their own personal collection of physical mementos as being difficult to digitalise (e.g., a sweater). For the types that were available digitally, photos unsurprisingly emerged as the most common form of memento. By permitting videos, links, stories, and journal entries, Besupp sought to allow more diverse types

of mementos as well. Digital mementos were significantly less diverse than anticipated. While novel systems should continue to explore new forms of digital mementos, and how they can be presented to the bereaved, comprehensive support for digital photos should be a priority in future reminiscence systems.

Sediment referred to the layering on of digital mementos as time passes. Participants did not include enough mementos over time in order to speak to this topic in detail, but users appreciated that the Memory Box was "not something you need to do all at once" (SP1, interim interview).

The notion of upkeep referred to the idea that revisiting and caring for mementos could be a meaningful way to remember the deceased. In Besupp, users rarely revisited the items that they, or others, uploaded. Correspondingly, the slideshow feature of the Memory Box was rarely used, as was the Circle bulletin board. The lack of "upkeep" activities may be a result of the short duration of the study and the small number of mementos uploaded, as well as the difficulty associated with learning a new technology.

5.10.6 DC6: Display and Control

This DC originally referred to the idea that systems should permit the bereaved to control external indicators of their grief and mourning. In the Besupp study, participants demonstrated some new forms of display and control that enrich this DC.

Creating a separate website for bereavement activities was one way that participants could control their exposure. Participants did appreciate the ability to use the website at a time and place that they chose; for example, SP4 only logged on at night once her children were tucked into bed so that she could reflect without necessarily bringing up the subject with her children. To allow participants more privacy, an indicator of a user's online status was not shown (i.e., User A cannot tell if User B is currently logged in). When conversation and sharing was slow, however, participants wanted Besupp to prompt them more proactively (e.g., by sending an email each time a new message or

memento was posted) and to show the online status of users so that they could "meet up" and engage in conversation.

Participants controlled the image they projected to other users on the site. With respect to controlling the visibility of various mementos, participants appreciated the ability to share and unshare at will (even though only one instance of unsharing was noted). They initially agreed that the "private by default" standard placed on uploaded mementos was appropriate; however, as time went on, it was noted that some participants uploaded items to their Memory Boxes with the assumption it had automatically been shared with the Circle. Some of the more active users also suggested that sharing could be controlled on a per-user basis, rather than a blanket "shared with Circle" or "private." In the Circle Chat, participants could take their time editing their messages before sending them. They could also specifically control each part of their profile, and only add the information they desired.

In system design, giving bereaved users control over the image they project to others remains key. At the same time, participants may wish to cede some of this control in order to allow more opportunities for interaction to occur.

5.11 Discussion and Reflection

The design and deployment of Besupp serves as a case study in designing technology for the bereaved. Having given an account of how Besupp was built and deployed, I now reflect on my process as a researcher-designer working with this unique community. Here, I share the lessons I have learned with other designers and researchers.

To begin with, I would first remark upon the nature of social support exchange online. Connecting the bereaved with one another did help to achieve a strong sense of normalcy and a rapid build-up of trust in a small online community. Looking back on the results, one can identify forms of social support that originally were not considered. For example,

many of the people using Besupp in the deployment study saw themselves as beyond the need for support from others; instead, Besupp enabled them to proffer their compassion and experience to a group of receptive others with fresher losses. What makes this so surprising, especially in comparison to other online forums where this sort of help is routinely offered, is the amount of intimacy and even emotional pain that accompanied such gestures. Participants revisited aspects of their grief journeys from years ago in order to connect to, and comfort, others. This raises a question of audience: when we design for the bereaved, perhaps we need not only design for those who are currently in need, but also for those who have the compassion and desire to share their time and experience. The ability to share these stories even years after a loss remains at the heart of bereavement support.

Besupp seemed to provide a "third space" for reflection and communication. Away from the judgment of family and friends, and away from the time constraints of 2-hours-per-week face-to-face groups, participants took up Besupp in a repeating cycle. A user could log in, take their time putting words to a thought or feeling, log out, recharge for a few days, and then revisit later. Indeed, what users (and I, as a researcher) perceived as a low usage rate seemed to actually reflect this inner emotional cycle. Larger cycles likely also exist where weeks, months, or even years pass before support is needed again. As designers, we might consider what this means for the success of the systems we build. A low rate of adoption or usage is not necessarily a sign of poor design; on the contrary, it may simply be part of working within an ongoing coping process and journey towards self-support. We must bear in mind that the bereaved already have many ways of meeting their needs away from computers and mobile phones. Indeed, other attempts to create online communities have found similar reactions from their users, and have questioned the definition of "success" in an online group context; indeed, Halverson, Erickson, and Sussman write, "As designers, we may be able to create the equivalent of online places, but... how they are used – whether they are inhabited and 'settle,' simply

used as convenient ad hoc resources, or somewhere in between – depends on the group and their practices" [43]. Indeed, Besupp and online grief support resources may be best characterized as "ad hoc resources."

This prompts the question: how do technologists provide services that will be valued, especially given such established and helpful supports? Based on the experience described here, I would suggest avoiding a tendency to replace such supports. At the outset, some participants saw Besupp as a potential replacement for a face-to-face support group, and were dismayed when the depth of perceived connection was less than in a face-to-face setting. My own experiences would suggest that we should not conceptualize technology as a way to replace support groups or precious mementos. Rather, it is more helpful to envision technology as a complementary, optional component of a richer, more comprehensive set of practices and places for experiencing grief. For example, augmented reality systems that merge the presence of physical mementos or places with digital assets could be one way of creating a tighter integration between parts of the bereavement experience.

This would again bring into focus the notion of the size of the group. In this study, I opted to mirror the size of existing face-to-face groups at BFO. In retrospect, these groups were almost certainly too small. However, allowing a more open registration process would lead to issues of depersonalization, security, and visibility. Translating the values that BFO has concerning confidentiality, trust, non-judgment, and peer support would almost certainly be strained as more people joined. Other designers might consider the tradeoffs between supporting small groups versus large, and synchronous versus asynchronous forms of communication. Small groups may work better in synchronous online settings, with asynchronous messaging used in larger groups.

As described in this design process, Besupp was a prototype system built for purposes of exploration. As one might predict, there were several lessons concerning more technical aspects of system/interface development. Chief among these was the way that data types

in Besupp were structured and presented. Following cues from Facebook and the HCI literature on photo sharing and storytelling, I imagined these two data types would be readily available to our users. In reality, participants noted that they had few digital photos that related to their loved one or their grief process, and additionally lacked access to a scanner to create digital versions. Even copying and pasting stories from a Word document or webpage was avoided due to the associated overhead. Scanning in a story (e.g., in a PDF) was also avoided, as the data structuring made it unclear whether it was a photo, a story, or something in between. Tools for automatically importing photos and text from a hard drive or other cloud services would be helpful components of future systems.

More broadly, perhaps the focus on digital artifacts - photos, stories, videos, writings, and so on - was in some sense to miss where the real action was. To cope with their grief, Besupp users wanted to talk to one another - not look at potentially painful copies of physical mementos. The mementos that were uploaded were important predominantly because they helped users share about themselves and learn about others. The findings in Chapter 3 showed that digital mementos could help connect the living with the deceased; this study has helped to clarify the degree to which they could connect the bereaved with one another.

5.12 Limitations

There were a number of limitations in the current study. First, due to scheduling conflicts with participants, interviews meant to take place during Weeks 1, 5, and 10 often took more than one week to complete (so for some participants, Week 1 interviews took place in Week 2, Week 5 in Week 6, and so on). Because all interviews could not take place instanteously, participants would have been exposed to a different online experience depending on the timing of their individual interview. Further, because the questions

raised in the interview addressed particular aspects of the design, raising these questions may have impacted the subsequent usage of the system. It should also be noted that the study was extended from its original 8 week duration to a 10 week duration in order to collect additional usage data due to the associated delay in performing interviews. For example, when asking about a feature, participants sometimes mentioned that they would "try harder" to use that feature; in these cases, participants were assured that they should use the system as realistically as possible, and their lack of use was not seen as a failure of participation. Each moderator also ran their group differently, and the amount of moderator activity likely impacted the amount of activity exhibited by other participants. For example, the moderator of the YA group changed the Circle Announcement four times across the study, the BP moderator changed it only twice, and the BP moderator never changed the Circle Announcement at all.

5.13 Summary

In sum, this study applied the DCs from Phase 2 to the design of an online social support system that could be instrumented and monitored in order to collect usage data and participant reactions. The study found that mementos have limited applicability in an online peer support environment because they placed emphasis on the loss, rather than coping with ongoing grief. Further, these mementos may be emotionally difficult to work with, can be considered less meaningful substitutions for existing physical mementos, and some users may have concerns regarding the privacy and stability of digital assets. However, despite low usage rates and potentially negative emotional reactions, some participants found benefit in revisiting their digital mementos as part of participating in the group, and valued the opportunity to share mementos insofar that they helped them to normalize their own losses.

In terms of social support, participants primarily valued the ability to vent to compas-

sionate others to avoid straining existing relationships, and saw Besupp as an opportunity to offer the benefit of their own personal experiences to those with fresher losses. While slow rates of conversation and the limited duration of the study were seen to impede investment in the system, participants consistently saw value in offering online support groups to those seeking bereavement support, and most participants believed that they would participate in a support group experience online again.

While it is not surprising that little change occured in perceived levels of support or grief-related emotions, this study has presented a rich account of the range of experiences, expectations, and patterns of use exhibited by bereaved users. We have learned that peer support systems may be most useful if participants are able to connect to people with very similar losses and experiences of grief within the first 1-3 years of the death, but must be able to build and maintain trust. Digital mementos may be more usefully applied to social support systems that connect family members and friends to one another around a shared memory of the deceased (rather than peers). Ultimately, systems must be designed in a way that complements existing resources and forms of support, while maintaining an awareness of changing user needs over time.

5.14 Conclusion

In this chapter, I described the design process in creating a website for memento-based bereavement support. I have traced how Besupp was built based on the design considerations from the focus groups and fieldwork presented in Chapter 4. Starting with those sensitivities, I have detailed the design decisions that were made in applying them to Besupp. Following a 10-week deployment study, I have reflected on these decisions and considerations, and shared a set of lessons which may help HCI researchers and designers interweave aspects of digital inheritance and reminiscence with processes of online social support.

Taken together with the earlier fieldwork presented, this deployment study has helped to paint a fuller picture of the use of technology by the bereaved. In the following discussion, I reflect on the three studies as a whole and comment on themes concerning temporality, identity, materiality, and research ethics/methods.

Chapter 6

Discussion

The three studies described above provide a starting point for thinking more deeply about personal technology and the end of life. Indeed, the findings raised a broad set of concerns and directions for future work. These concerns span many areas of computer science, including security, software engineering, and human-computer interaction.

In this discussion, I revisit these issues by using a framing presented in a recent paper with co-authors Will Odom, Richard Banks, and David Kirk. In that paper, we mapped out some of the prominent themes in HCI at the end of life, and identified the bereaved as a primary conceptual stakeholder group [73]. We also identified four key themes that recur in work concerning HCI and the end of life: temporality, identity, materiality, and research ethics and methods. Looking back on the studies presented, I discuss my findings along these four themes.

6.1 Temporality

An understanding of how bereavement changes across time is critical to designing technologies that address the needs associated with bereavement. Even if one does not ascribe to the idea that grief is a sickness that will be healed with time, the emotions, behaviours, and goals of people who have lost a loved one do change as more time passes. In Phase 2,

I presented a design consideration concerning the idea of "permanance and continuity" (Section 4.4.1, p. 90). This consideration spoke to the idea that a loss was a life-changing event. While the bereaved move towards a new sense of what is considered "normal," the reality of the loss continues to affect their thoughts, emotions, activities, and environment. In Phases 2 and 3, participants noted that online support groups could provide a more sustainable alternative to face-to-face support groups for those seeking support over the course of years or even decades following a death. Participants liked the idea that even though their face-to-face groups were completed, they had an opportunity to talk openly about their grief in a place where they wouldn't necessarily strain existing relationships.

Besupp sought, in some part, to provide such a place. For the most part, however, when a participant checked the Besupp website, there was relatively little being said. Conversation was slow, and participants seemed to be hesitating to share mementos. Sensing this hesitation, participants often then logged out of the system. Another barrier to sharing on Besupp was that many participants felt they had nothing to share, or that they did not particularly want to deal with the emotional burden associated with discussing grief.

This speaks to a tension concerning time as it relates to social support in bereavement. For purposes of discussion, let us imagine a hypothetical bereaved mother whose son died 7 years ago. On the one hand, she sees great value in having support available to her at this point in her life. On the other, there is little incentive – and indeed, an emotional disincentive – for her to seek out the support by logging into a website and talking about feelings of grief with which she has coped for 7 years. At the macro level, long-term support is appreciated; but, in daily living, accessing support can be an emotional drain.

Based on my studies, it may be helpful for designers to think about temporality in the life of a bereaved individual on four scales:

- *Time of Day*: System logs showed that Besupp was used as part of the bereaved's

daily routines. While it could be a place to go in the middle of the night, I did not observe that type of behaviour. When building systems in this space, it can be helpful to think about how to best build upon these kinds of daily, or even weekly, routines. For example, we might consider how a remembrance system can be meaningfully integrated into bedtime rituals, or woven into religious practices that call to mind the deceased.

- *Time of Year*: While the study in Phase 3 only lasted 10 weeks, reports from participants during this phase (and Phase 2) referred to their desire to reflect on yearly events. Anniversaries, birthdays, death days, and holidays like Mother's Day are times that support might be more appreciated. Beyond singular holidays, we must also consider recurring patterns in the seasons and social practices. For example, in Phase 3, the bereaved parents started a conversation about "back to school time" and how they coped with this time of year. System designers should be aware of these shifting timeframes and their relevance to providing the right kinds and amount of support.

- *Time of Life*: As years go by, we can often identify various chapters or milestones in our lives. Again, designers should be aware of these symbolic markers in the systems that they create. For example, one woman in Phase 3 lost her mother when she was in her early twenties. Since that time, she married, but described how much she missed her mother during this special milestone in her life. She valued being able to bring this up with other young women in her support group whose mothers had died. Similarly, she didn't see support as particularly helpful during the study, saying it's "[n]ot the greatest time right now either, because of the stuff going on in my personal life and marriage has ended, work is very busy. Don't have a lot of room for this in my brain or heart right now."

- *Time since Loss*: Tying together all of these temporal markers is of course the time

since the death occurred. All people grieve on different timelines and in different ways, and how and when a system is used will certainly reflect this. People who are experiencing fresh losses might be searching for opportunities to learn or talk about grief, while others who are years down the road may have developed a way to cope with their grief - a "new normal." The movement between these two states is gradual and difficult to predict, but systems designers should expect a slow, but real, change in user needs and preferences.

The upshot of this discussion is that the need for technology-mediated support is strongly tied to time. Systems for the bereaved should be designed in a way that permits a range of engagement levels depending on the time in a person's day, year, or life. Technology can potentially play a powerful role in helping the bereaved achieve a sense of a "new normal" [72].

6.2 Identity

Computing increasingly influences the ways that we portray ourselves to other people, and reflect on our lives. Indeed, in the four conceptual stakeholder groups originally identified in our paper, we perhaps made these groups seem too rigid – that a given person was either included or excluded from these groups at any given time [73]. This theme of identity draws attention to the fact that identity is situated, dynamic, and co-created among people (as in Goffman's notion of life as theatre [41]).

For the bereaved, a death very often results in a changing sense of self at multiple levels [17]. In my fieldwork in Phases 2 and 3, bereaved parents remarked on the first time they were asked "How many children do you have?" This seemingly innocuous turn in conversation becomes difficult to answer as an individual grapples with questions about what it means to be a parent. Similarly, in Phase 1, I noted the ways that a death forced the bereaved to take up new roles and responsibilities (Section 3.3.6, p. 63). The

moderator of the bereaved partners/spouses group in Phase 3 described how she usually raises financial concerns in the groups that she runs:

> "[There are] financial challenges that happen when a spouse dies, especially since everyone in our group are women... in my group I noticed that is always a conversation that comes up. And most often when it's a female partner who lost a male partner." - SP1

The bereaved undergo a process where they must negotiate new roles handling finances, or mangaging digital assets, or appearing in social situations. Indeed, these studies have layered nuance upon our conceptualization of the bereaved as a type of user.

6.2.1 Identifying as Bereaved

During the initial exploration that took place in Phase 1 of the thesis, the working definition of "bereaved" was anyone who self-identified as losing a family member in the past 5 years. In developing that study, the cap of 5 years was selected for two reasons. First, 5 years seemed to be enough time for inheritance procedures to be completed and for the "dust to settle." Raw grief responses were likely to have subsided within that timeframe as well. Second, capping the inclusion at 5 years was a way of trying to improve participants' recollection of the events surrounding the death. If more time had passed, then the ability to remember what happened accurately would continue to degrade. In Phase 3, a similar cap on the length of time since the loss was initially imposed, but later lifted. The removal of this restriction was not only due to a low response rate to the initial call, but also because we received a handful of eager responses from individuals who wanted to participate even though their loss occurred more than 5 years ago.

Further, in Phase 1, participants self-identified as having lost a "family member," with no pre-determined limitations placed on who was considered "family." For example, one woman reported on the death of her husband's ex-wife – a relationship that we might

not normally consider in this kind of research. At the same time, this woman was actively involved in managing the estate, preparing the memorial service, spreading the news, and so on. She performed many of the activities normally associated with being a bereaved family member, but her emotional reactions were different from those we normally associate with the death of a loved one.

In Sudnow's work from the 1960s, he remarked on how claiming the status of bereaved was a delicate social act, with the community providing varying levels of sympathy and support to those considered more or less affected by the death [107]. The examples above illustrate how conceptualizing the bereaved as a stakeholder group can be difficult; indeed, work in disenfranchised grief has begun to explore these kinds of conditions [27].

In the online setting, however, one can simply join a grief support forum without necessarily needing any validation from community members. The upshot of all of this is that the availability and anonymity of the Internet allows one to selectively identify oneself as bereaved. Online, a user can can control the audience that witnesses their mourning, a key design consideration raised in Phase 2 (Section 4.5.2, p. 103). Indeed, in Phase 3, participants remarked on how Besupp could be used as a place to vent and then get on with their lives, secure in the knowledge that they could return and find support when they needed it. This shares some similarity with Turkle's explorations of teenagers going online to try out different – often taboo – identities in a safe space without jeopardizing their existing relationships with friends and family [108].

Looking back on the work in this thesis, a different picture of a bereaved user emerges. The people who use systems designed to support activities associated with bereavement may not actually see themselves as bereaved or even as grieving in many of their dealings. They may be looking for opportunities to explore emotions that linger decades after a loss in a safe space away from friends and family, or they may seek to share the benefit of their experiences with others (as noted in Phase 3). Their goals may be more administrative or organizational in nature, such as planning a memorial event or selecting a funeral

home (as seen in Phase 1). A thanatosensitive design (TSD) orientation then should acknowledge the reality of death, but also acknowledge that life goes on.

6.3 Materiality

The objects and data that the bereaved encounter following a loss can be a rich site for technological innovation. In this section I remark on some of the properties and arrangements of "things" that were encountered throughout the thesis.

6.3.1 Digital Together with the Physical

While digital assets can be treasured mementos (as shown in Phase 1), they are part of a larger set of evocative objects and places. As participants in the Besupp study in Phase 3 remarked, digital copies of physical items seemed to be redundant in terms of the emotional comfort they provide. Further, the heterogeneity of treasured items (as noted in Phase 2) means that some helpful items cannot be meaningfully made digital (e.g., BP2 described her attachment to a sweater her daughter once wore). Despite the finding in Phase 1 that 54% of respondents thought digital mementos were as meaningful as physical ones, digital assets are never likely to supplant or replace physical items. Similarly, virtual "places" are not likely to be as special as visiting geographical locations in person: the chapel where one was married, or one's childhood home. While the digital cannot replace these memories, future work should examine how digital assets can support these kinds of situated emotional connections. Support comes from not only other people, but from one's connection to memories. While these connections – between two people, or between a person and an object – are increasingly mediated by the digital, they remain part of a richer ecology of support.

6.3.2 Inheritance of Data

In Phase 1, participants saw value in some of the data that they inherited from their loved ones, but not all. Because of the large amount of information that could potentially be inherited, it becomes difficult to tell what is important out of an individual's digital footprint, and what can be discarded. There are a number of approaches to managing this type of problem. Services can be provided that leave this responsibility up to the individual, in the same way that items in a will may be expressly left to a particular inheritor. Websites like Entrustet and Legacy Locker both adopt this approach. A user must manually create an entry in his or her account for each of the items that they wish to leave behind, or maintain a list of credentials that can be given over to the inheritor. This type of approach is a logical first step towards solving this problem that takes advantage of existing models of legal inheritance, and does so with a relatively common web services architecture.

Beyond this first step, the studies in my thesis suggest alternative ways that inheritance could potentially be performed that would involve the bereaved inheritors more actively. For example, in Phase 1 I discuss how digital artifacts do not have affordances for claiming (Section 3.3.3, p. 58); we rarely know what data is stored on a loved one's account or hard disk, and there is little technical support for allowing this kind of claiming to occur. It is unclear how to mark an asset as valuable and worthy of inheritance, from both the standpoint of the bequeather and the inheritor. New forms and purposes of data complicate this further, as the deceased's data may be strewn throughout the cloud, the web, and local devices – each with their own set of credentials and security permissions.

This notion of inheritance was touched on in Phase 3 as well, but in a different manner. Generally speaking, inherited data may serve many purposes: dealing with finances or household administration, preserving a family history, finding important accounts or numbers, etc. In Besupp, there were a few examples of inherited digital assets being

used as mementos. One participant shared a link to her deceased partner's art portfolio, a website that has been maintained beyond his death. She remarked on how she visited the website now and then to remind herself of his art. This portfolio website would likely not have been "handed down" to her because it was an artifact of his professional life as an artist, but still served a role as a memento. Meaningful assets were considered meaningful not because the deceased ascribed meaning to them, but because the bereaved did. Determining how to identify the set of assets that are desirable to be inherited and making arrangements for them to be passed down remain open questions.

6.3.3 Moving Materials from Stage to Stage

At present, many of our personal technologies are designed in a way that encourages their replacement after a relatively brief period of time. This rapid rate of upgrading and replacement can sometimes cause data to be "lost:" not in the sense that the data is deleted, but that in migrating to a new device, data is neglected and forgotten. In Phase 1, for example, the web survey and interviews highlighted how bereaved respondents found themselves inheriting personal technologies such as personal computers, mobile phones, and TVs/VCRs (Table 3.2, p. 53). While these devices were often listed as "inherited" in the questionnaire, the interviews revealed that the inheritors were not actively using these dated models or the data stored on them. Participants in Phase 3 of the Besupp study also reported that they did not upload mementos for three reasons: the time associated with creating a digital copy of a physical item, a lack of technical expertise to do so, and a lack of desire to replicate an item they already owned. Ironically, we prize our computers for their ability to store, copy, and backup valuable mementos and family heirlooms, but at the same time, their rapid replacement and evolving standards can make it inconvenient to "go back" to access these mementos. In a lifespan-oriented approach, computer scientists might consider not only the need for "deep storage" [51] to ensure this data is secured, but also the need to make these types of data more accessible

to other applications and systems (e.g., digital memorials, family trees).

As outlined above in discussing the results of Phase 1, current inheritance procedures are unclear or missing altogether. We must begin to think more closely about how it is that we maintain data not simply for a few years, but for an entire lifetime. We must also consider how we can mobilize this data at different periods in our lives to ensure that potentially precious artifacts are not being discarded. Then, when a person passes away, procedures must be in place that allow these cherished items to be retrieved by a family member and used (e.g., in a memorial service) and similarly preserved.

As new forms and configurations of data appear (e.g., tweets from Twitter, posts from Facebook), opportunities to employ these in the service of remembrance also emerge. At the same time, there is work to be done in permitting existing types of data – such as videos, music, and sounds – to be more easily captured, organized, and accessed in the context of bereavement for purposes of remembrance. We might also consider how different kinds of mementos are more, or less, difficult to confront at an emotional level. For example, photos might be difficult to look at (as was the case for SP2 in Phase 3), but writing may be easier to approach.

6.4 Research Ethics and Methods

The end of life is a new domain for technology research and design. Based on my work, I remark on some ethical and methodological considerations encountered, and suggest techniques for addressing these.

6.4.1 Grief Reactions During Research

In a TSD process, issues may arise that are beyond those normally encountered in technology design and deployment studies. Emotional reactions can occur in this context, and researchers must be aware of these likely events. In one set of focus groups in Phase

2, two participants chose to leave during the first few moments of the group session. While no reason was given for their departure, a facilitator later explained that their loss was quite recent. Another event discussed in the results of Phase 3 refers to an instance where Besupp stirred up emotions that a participant thought had passed; these reactions caused the participant to avoid Besupp for a while her emotions calmed.

I raise these points for several reasons. With respect to the ethical conduct of studies, researchers and designers working in this space must maintain a heightened awareness of the potential for such reactions, and understand the types of ethical obligations to which professional thanatologists adhere [73]. Such studies benefit from the inclusion and expertise of grief and bereavement specialists on the research team when encountering these issues. Further to this point, researchers and designers might be advised to target interventions and research studies towards individuals who are at an emotional state where they can participate without severe emotional distress. However, the inclusion criteria for such studies cannot be strictly about time since loss; people whose losses are distant may still experience strong reactions, and the same levels of awareness are needed regarding their state.

Researchers and designers from different disciplinary backgrounds may also benefit from professional development courses in bereavement counseling. In Phase 2, attending the bereavement counseling classes offered by the Faculty of Social Work helped me by reviewing active listening techniques and suggesting ways to handle various situations that might arise when speaking with a grieving individual. Another way that others might help to manage grief reactions during research is by partnering with established groups that have expertise dealing with these issues. Organizers at BFO and the COPING Centre provided me with a sense of how to approach the bereaved, and helped to facilitate the focus groups in Phase 2. Their presence provided a safety net in the event that emotions ran high, and is a recommended technique for future work. I now turn to these community groups in more detail.

6.4.2 Working in a Community Context

A community bereavement support context provided structure and expertise. Because these organizations performed their own screening during one-on-ones, it provided a level of assurance that participants recruited from these organizations had reached a state where they were ready to talk about their loss. Further, because BFO and the COPING Centre both operated their own centres, participants could meet at these predetermined spaces for focus groups during Phase 2. Having the staff members of these organizations present during the focus groups helped to establish trust and security for the bereaved individuals volunteering for the study. Establishing this trust can be difficult, but is essential to the success of a TSD process. Later, in Phase 3, participants trusted the members of their online support groups in Besupp because all had been part of an earlier BFO support group. Those earlier groups made confidentiality a priority, and this transferred to the online context during Phase 3. Staff members also helped to consult on the design and development of Besupp, and offered a form of early evaluation in the design process.

As described above, these two organizations helped to structure the studies by conducting recruiting and offering places to conduct interviews and focus groups. At the same time, this came with expectations surrounding the outcomes of the studies and the software that was being developed. Participants frequently mentioned participating because they wanted to give back to these two organizations. As a third party researcher, of course, I could not make promises concerning the direct, short-term benefits of participation to these entities. In Phase 3, participants often asked when BFO would begin to use Besupp as their means of providing an online support group experience. When it was explained that Besupp was a research prototype and that the study was independent of BFO, many participants expressed a desire to see Besupp become part of BFO's services. At the end of the study, a significant number of participants ended up donating their stipend for participation back to BFO. Bereaved participants seemed motivated to

give back to the organizations that had supported them in their times of grief, and as technologists, we might consider how we can give back as well.

6.4.3 Methodologies: Evaluation and Time

As mentioned in the section concerning temporality above, all people experience bereavement in different ways and at different rates. Because participants in these studies were all at different points in their grief journeys, it is difficult to draw conclusions about the wider applicability of the design considerations and effectiveness of Besupp. Methodologically, it is near impossible to obtain a cross-section of individuals who all experience similar losses (e.g., matching the time since death, cause of death, relationship to the deceased, cultural/religious factors, age, technology comfort, gender, etc.). This variety of grief responses and participant demographics makes intervention-based studies difficult, especially when they are conducted longitudinally. While longer studies (on the order of 1-5 years) would be more informative, grief can progress differently for each participant within even that span of time.

While conclusive studies are infeasible at this exploratory stage, and the literature remains mixed on the efficacy of support groups in the first place, the interaction between the bereaved and technology can be addressed more readily from a qualitative perspective, as in Chapters 4 and 5. Rather than showing the efficacy of the system design, the exploratory work presented here provides a rich description of the issues, themes, and challenges that users encounter. These can be applied to future design efforts, and while scientifically-established statements regarding the efficacy of these systems are likely to elude us, it remains worthwhile to understand the mechanisms through which value is derived from technology during bereavement over time.

Chapter 7

Conclusion and Future Work

In this thesis, three studies were carried out in order to establish and explore the process of designing technologies that sensitively engage with death and bereavement, focusing especially on social support for grieving individuals. The first exploratory study in Phase 1 demonstrated that the bereaved currently employ technology to meet a number of different needs, and established 10 problem areas that would benefit from attention from technology designers. Phase 2 explored one of these - social support - more deeply, and developed a set of thanatosensitive design (TSD) considerations arranged around bereavement and the end of life more generally. In applying these considerations in Phase 3 to the design and deployment of Besupp, I sought to validate and refine the concepts presented. That study revealed a set of lessons learned that could be applied to a range of TSD projects and settings. The discussion then reflected on all three studies along the themes of temporality, identity, materiality, and research ethics and methods. In each of these I sought to provide insight into emerging issues associated with bereavement with the goal of informing future work in this space more broadly.

In this concluding chapter, I first identify what TSD is, and is not, and provide an updated definition of the approach. I then present a set of TSD considerations that capture major lessons learned from my earlier work. I finally suggest that TSD's most

valuable characteristic is how it can act as a tool for reorienting design towards human development and multi-lifespan use.

7.1 Reflecting on Thanatosensitive Design

My original articulation of TSD was worded thusly: TSD is "a novel, 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" [71]. Since that original definition, I have performed design work that engages with the bereaved, and believe that I can now offer a better description of TSD based on these experiences.

I begin by stating what TSD is *not* meant to be:

- *A step-by-step procedure.* TSD is not meant to be a manual or algorithm for designing systems that engage with human mortality. Indeed, all design work involves making decisions that are grounded in a particular context and setting, and designing around death is certainly not an exception. Further to this point, TSD does not seek to identify stages or parts of a design cycle (as in user-centred design). Rather, it is complementary to, and compatible with, user-centred design (as in Phase 3).

- *A guarantee of "better results."* A TSD approach to developing software does not necessarily mean that the system will perform "better" in some way than other approaches. Indeed, what I have shown in this thesis is that what is considered a "better outcome" is highly contingent and difficult to measure. Future work which compares directly the two approaches may be plausible, but would still be difficult to interpret for this reason.

- *A property of a system or procedure (i.e., a classifier).* While what I have described in this thesis is a case study in TSD, I do not wish to make the claim that some

systems *are* thanatosensitively designed, and others *are not*. Such a claim may be misconstrued that a TSD approach somehow "solves" handling of death in a system (which it does not). Also, because we are human, we cannot ever entirely separate our design choices from our own encountering of death. Dividing systems into these two sets of camps draws an arbitrary distinction that may not reflect actual use. For example, if we assume that Facebook is not the result of a TSD approach, that does not lessen its value and heavy adoption for purposes that address the end of life.

- *A replacement for design processes.* As mentioned above, TSD is not a prescriptive procedure for doing design work. User-centred design, participatory design, and other approaches retain their value in this setting, and can be fruitfully applied when addressing the end of life. The empirical work presented in this thesis draws heavily upon social science and user-centred design methodologies.

- *A limiter on stakeholder groups.* When considering TSD, it is possible that one might equate it with designing for a particular stakeholder group such as the bereaved (as in my thesis). However, the bereaved are only one stakeholder group that are affected by how systems handle death, and even drawing a clear line around this group is difficult (as discussed in Chapter 6).

Having stated what TSD is not, I now describe what it *is*.

- *An orientation/approach to design.* TSD is a way of approaching a design problem that bears in mind the facts of mortality, dying, and death. It can be applied to any given design problem and prompts designers to consider this part of the human condition when creating a system. TSD encourages designers to investigate multiple ways of approaching an understanding of death in system design, including consideration of the humanities and social sciences.

- *A lens.* TSD brings into focus particular aspects concerning death when investigating a design space. It may prompt designers to think about how users would encounter their system in the context of their own, or someone else's, eventual death. It can be applied selectively during a design process, and "swapped out" for other lenses. For example, in a TSD approach to a system such as Facebook, it seems likely that designers would identify new types of users, use cases, and scenarios and accordingly provide a more comprehensive set of tools.

- *A domain.* "Thanatosensitive design" provides a heading for an emerging class of research and design projects that investigate death. A comparison can be made to "sustainable design," which similarly does not set forth a procedure for doing work, but instead asks designers to consider ecological factors as a design is formed.

- *A reflexive stance.* TSD, when being applied as a lens to a given design problem, may prompt designers to question their own personal experiences with death in order to understand how they impact the choices they make. Someone who has encountered a traumatic death, for example, may see a problem differently from someone who has not.

- *Part of a larger set of approaches to designing for the human condition.* TSD, as I explain later, is an approach that addresses only one part of the human condition: death. There are other topics that are so deeply human and ingrained into our being that may benefit from similar approaches.

- *A tool for thinking about lifespan-oriented design.* Most importantly, TSD is a tool for thought. It can act as a gateway into questioning how systems might be used throughout, and beyond, a lifetime. By raising death in design, we implicitly raise questions about other parts of the lifespan such as birth and old age, which can potentially lead to additional insights useful for design.

Thinking about how a system might handle death is a growing concern, both in research and in practice. By overlooking this concern, systems open themselves up to "fringe" or "extreme" use cases that result in challenging or stressful situations (recall P21 in Phase 1 whose mobile phone indicated her dead mother was calling her). One might say that because of the infrequency of these cases, time and resources during the design phase are not well-spent on handling them. For the moment this may be, but for designers of any system that is intended for use for any lengthy period of time, or on any large scale, these are real cases that will occur and intensify in frequency in the coming years. Having a technician handle the death of each user on a case-by-case basis might be possible for the time being, but for systems on the scale of Facebook, this seems unlikely in the coming years.

7.1.1 Thanatosensitive Design Considerations

In the studies described in Phases 2 and 3, the goal was to convey the richness to be found in designing systems with the bereaved in mind. From this account, I distill and restate these considerations as a more concise set that can be more readily "picked up and used" by designers. Some of these considerations may also be relevant for end of life situations besides bereavement. TSD processes developing systems to support the dying, for example, may find these of relevance.

1. *Don't try to "solve" a user's grief.* Losing a loved one is a process, and a permanent change in worldview. Designing systems which seek to "fix" the person's grief as if it were a problematic medical condition - no matter how well-meaning the intention - can be potentially disrespectful and maladaptive. Instead, consider open-ended systems that support ongoing, expressive use.

2. *Design systems to be ignored at times.* We may often imagine the bereaved desire constant companionship and must talk through their feelings in order to achieve

peace. While communication is important, designers must allow the bereaved to choose silence, disconnection, and isolation. The time spent avoiding technology is as important as the time spent deriving value from it. When building systems for the bereaved, ensure there are clear ways to ignore or turn off the system. Systems should be designed to be easily picked up again after long periods of disuse.

3. *Avoid straining existing relationships.* Friends and family may not be able to provide helpful support because of the complications of pre-existing relationships, or the inability to relate to the lived experience of the bereaved. When developing technologies that encourage communication during bereavement, one might also consider community-based resources such as support groups, clergy, or grief counselors.

4. *Support storytelling.* Storytelling is a rich process for the bereaved, and serves many purposes: from recalling a fond memory to trying to understand why the death occurred. New technologies can allow the bereaved to tell stories in ways they could not before: through photos, videos, or other forms of computer-mediated communication. Further, listening to these stories can be a productive way to imagine new opportunities for technological innovation (e.g., through storyboarding and scenario development).

5. *Distinguish between loss and grief.* Technologies which memorialize the deceased may form the basis for interpersonal support, but at the same time, it is important to distinguish between the loss of a loved one, and coping with ongoing grief. Coping with grief is a daily activity, and the bereaved may be looking for ways to find a "new normal" rather than ways to remember their loved one. Talking about a loved one's life is better suited to systems that connect family and friends, while learning to cope with grief is better suited to systems that connect bereaved peers.

6. *Allow relationships to continue beyond death.* When a loved one dies, the relation-

ship does not evaporate. Rather, a new asymmetry is introduced which changes the way that the relationship is conducted. Remembrance systems might consider how to support continued activities between a bereaved individual and their deceased loved one, such as sending messages to the deceased.

7. *Make making possible.* For some people, taking action can be a powerful way to express grief, create meaning out of the death, and connect with supportive others. By offering users the opportunity to create, personalize, and build a meaningful artifact - be it digital or physical - systems can support bereaved people in a very practical and useful way. Include a range of prescriptive and creative activities, and allow them to be done either alone or in a group.

8. *Provide ways to "give back."* For the bereaved, the act of offering support can be as valuable as benefiting from it. Use cases that allow the bereaved – especially those with many years since their loss – to help others by sharing their their experiences should be considered in social support systems. Technology can create opportunities to give back to organizations and people that have provided help in the past.

9. *Recognize that meaning can come from anywhere.* The bereaved use a wide range of cues - photos, clothing, jewelry, music, places, times of the year - to reflect on their loss. Systems seeking to support the bereaved in creating digital memorials or legacies should be built to accommodate this heterogeneity of materials, times, and places, and allow these reminders to be added slowly over time. Consider allowing users to engage with these cues in different ways (akin to the upkeep needed for a grave) as a continuing way to nurture the relationship.

10. *Offer control over online sharing and appearances.* The bereaved must manage their outward appearance and control how much indication they give to others about their emotional state. In some situations, the bereaved do not wish to be seen as

a person in mourning (e.g., in professional dealings). Further, some mementos are extremely private, while others are meant to be publicly viewed. When designing systems to be used by the bereaved, be sure to give the bereaved fine-grained control over how they appear to other people who may or may not be using the system.

11. *Complement existing resources.* In dealing with social support and mementos alike, technologies should not be seen as a replacement for existing mementos or forms of support. Online support groups are not a replacement for the connections forged in face-to-face settings, and digital assets are not replacements for physical possessions. The capabilities of technology should be used to augment existing resources; for example, an online support group may be a strong complement to existing face-to-face groups.

12. *Acknowledge that a system's value changes over time.* Frequent and widespread usage of a system is often considered a measure of success. When studying bereavement, low usage rages do not necessarily mean that the system is poorly designed or conceived. Rather, the system's value comes from knowing the support is available when it is needed. Only over a very long period of time will the true success of a system for the bereaved become clear, and even then, its value may not be identified from quantitative evidence alone.

13. *Remember that life goes on.* While losing a loved one is a tragic and emotional event, we must remember that the bereaved continue living their lives - just in a different form. System designers must remember the bereaved are still friends, relatives, employees, and neighbors; grieving is only one part of their lives. Overexposure to a system that addresses this topic can be potentially unhelpful.

7.2 Future Work

This thesis presented three exploratory studies concerning technology's role in bereavement. In each study, a series of decisions had to be made regarding the participants, methods, tools, and topics that would be involved. In this section I outline potential studies that could be conducted that would be logical extensions of the work presented here.

7.2.1 Online Support Groups

There are a number of ways that the deployment study in Phase 3 could be conducted again with different participants, timing, and systems. A number of variables could be adjusted and compared with the findings in this study. Variables might include:

- *Timing of providing online group support.* Online group support (with a system like Besupp) could potentially be provided at the beginning of a face-to-face group; one might examine how this changes group dynamics and levels of perceived support in comparison to groups without an online component. Similarly, online support might be provided at the end of the 10 weeks of face-to-face support as a way for the group to carry on virtually. A study might examine whether providing this transitional form of support correlates with higher levels of perceived support in the months and years following a face-to-face group. Based on the work described here, it would seem likely that timing the intervention in this way would lead to higher usage rates. Performing such studies over longer periods of time might also be worthwhile, as it seems that the utility of an online support group might wax and wane as time passes.

- *Size of group.* Future work might plausibly explore groups of much larger size. One exploration might study an open-registration system ("Facebook for the bereaved") in an effort to improve the amount of communication and connect people with more

similar losses. Another might allow for all members of a community organization (like BFO) to join a single shared group (e.g., bereaved parents) regardless of the timing of their original group. In this case, we might imagine mid-sized groups on the order of 30 to 500 people. Such studies would also permit for larger numbers of participants to be recruited, and perhaps allow for generalization of findings.

- *Participant characteristics.* There are many variables concerning potential participant selection for such a study. One might investigate recency of loss - do people with more recent losses report higher levels of perceived support or value in an online environment in comparison to those who are further along? Another might examine individuals who are experiencing prolonged or complicated grief, as compared to those who are not. The type of death may also be a factor - for example, traumatic verus non-traumatic losses. Online systems for support groups could also be designed in a way that performs matching among users in order to identify people who have very specific, similar losses (e.g., a system that matches young single mothers who experienced the traumatic death of a son in a car accident in the last year). With large-scale systems, matches of this specificity can potentially be made; a follow-up study might ask whether the support dynamic between such close matches is preferred to less specific types of matching (e.g., bereaved parents). Further, people who utilize groups such as those at BFO and the COPING Centre are likely different from the general bereavement population. Follow-up studies might examine the utility of online support groups for those who have, or have not, been part of a pre-existing support group or community organization. In the Besupp study, all participants were female. Follow-up studies examining gender differences might also be worthwhile, as would studies that examine groups with different age brackets or technology comfort levels.

- *Structure.* In Besupp, we provided some structure in form of a moderator and a

set number of weeks for the group to occur. However the kinds and amount of structure could be examined in future work. Future work might explore permutations with multiple moderators, community-selected moderators, or no moderator at all. Further, we might explore whether groups vary if there is a strict discussion topic each week, or if the topic is left open. Groups that last for a set number of weeks might also be interesting to investigate as compared to groups that continue indefinitely.

- *Awareness and transparency.* In Besupp, participants were given very coarse information about the implicit actions of other users, as per the DC6 regarding control over mourning symbols. For example, participants had no way of knowing how long it had been since other users had logged into the system. However, a system that incorporates traces of user behaviour in the community might encourage more usage and lead to better conversation. An awareness feature like the one in Babble [31] that shows the amount of time since contribution to the Circle might lead to more sustained usage or better understandings of community behaviour.

7.2.2 Beyond Online Communities to Family and Friends

Much of the work thus far on social support online has focused on a single community or website, and rarely explored how that community fits into a larger network of support. In this thesis, we saw that support comes from many people, and from many places. Bereaved individuals who have experienced a specific type of loss may be able to support one another in ways that family and friends cannot as the "Circles of Sympathy" design consideration (Section 4.3.1, p. 83) in Phase 2 mentioned. However the kinds of support offered within a peer setting, and especially online, are often limited to emotional or information forms of support. Participants described the importance of their friends and family, even if they were not emotionally available in the long-term, or could not com-

pletely relate to the experience of the grieving individual. Future work might plausibly explore connecting family and friends together in contrast to connecting peers. Indeed, connecting the various circles of supportive individuals – friends, family, peers, coworkers, clergy, etc. – around a single person or loss remains a rich area for exploration. At the same time, working in this context has its own set of challenges, as these existing social structures involve people who may have very different needs in their grief, and perhaps see limited need for social support in the first place.

7.2.3 Other Aspects of Bereavement

This thesis focused primarily on "The Social Support Problem" as identified in Phase 1. While I chose to focus on this problem area, there are 9 other potential problem areas that technology-focused interventions or studies could address. Among these, examining the personal information management practices of the bereaved - especially as they relate to inheritance - would be particularly interesting. Because the web survey and interview study did not include detailed observation or recording of computer usage, a follow-up study might involve home visits and observational work to identify and catalogue the digital assets that the bereaved inherited, in an effort to address the "The Claiming Problem." This could provide a first step towards building open, flexible software tools that facilitate the process of inheritance from multiple devices and accounts.

Building on this theme, there remain many questions regarding what to do with the online presence of a deceased individual. Future work might focus on developing software that helps the bereaved to secure or delete the "digital footprint" of a deceased loved one. For example, software that automatically secures or "memorializes" Facebook, Twitter, email accounts, and so on can help the bereaved save time, and potentially avoid problems that occur with these types of services. More comprehensive solutions would also help the bereaved handle the paperwork associated with taxes, financial accounts, insurance claims, medical records, and so on.

While aspects of digital mementos were discussed in this work, the primary focus remained on how they were used in the context of social support. Remembrance, as an activity in its own right, remains a rich topic for exploration by technologists. Current design work has begun to examine this area (as discussed in Section 2.3.1), but as new forms of personal technologies and practices develop, so too must associated technologies for remembering. Future work might explore further this notion of "Afterlifelogs," and how the bereaved encounter the various forms of personal data that attest to a life in these formats.

7.3 Summary

This thesis is, to my knowledge, the first computer science doctoral dissertation that systematically explores how the bereaved use technology, and how design considerations impact their experiences. This type of research is described in the context of a novel orientation to design and research called thanatosensitive design (TSD). This thesis contributes to HCI and computer science by showing that computing plays a role in bereavement, and that this role is only beginning to be understood. From this early understanding, it identifies 10 areas where technology can create or help to solve the problems encountered following a death of a loved one (Chapter 3/Phase 1):

- *The Digital Natives Problem*: As young people grow up with technology and pass away, better tools must be built for handling digital inheritance and remembrance.
- *The Claiming Data Problem*: Systems must allow inheritors to be able to easily identify and access data once owned by the deceased.
- *The Will-Drafting Problem*: Systems that work in conjunction with legally-binding wills must be developed to include digital assets.
- *The Many People, One Computer Problem*: Inheriting data from a single device

can involve inheriting from multiple people. Systems should allow for inheritance to occur on a user-by-user basis.

- *The Meaningful Devices Problem*: Personal devices are often not considered "precious" enough to inherit; hardware and user interface designs that evoke personality and aesthetics should be priorities if a system is meant to be inherited and treasured.

- *The Role Inheritance Problem*: Inheriting data means inheriting new roles once performed by the deceased. Systems should consider how to ease this transfer of responsibility.

- *The Social Support Problem*: Exchanging social support online usually occurs via appropriated systems such as email and message boards. Custom systems should be built that allow for new modes and expressions of support.

- *The Reconciliation Problem*: Users should be able to craft digital packages to be inherited by particular individuals; in so doing, they may control who sees their data, and how it is displayed.

- *The Afterlifelog Problem*: Personal data that is generated throughout a lifetime can be repurposed to become mementos, but the scale and variety of this data is unwieldy and requires better management, curation, and long-term storage tools.

- *The Estate Planning Problem*: People generally do not consider digital assets when planning their estates. Understanding why this is the case, and how to better support it, can ensure that precious data is not lost following a death.

Taking the social support problem as a basis for further exploration, fieldwork and focus groups were conducted (Chapter 4/Phase 2). This resulted in 6 design considerations:

1. *Circles of Sympathy and Communication Availability*: The bereaved can find different kinds of value in talking to different audiences; talking to peers who have shared experiences can be one of the most powerful ways to exchange emotional and informational forms of support. Different technologies are carefully selected depending on the bereaved's emotional availability and goals. Communication systems for the bereaved should acknowledge the variety of sources of support, provide ways to selectively deliver messages or disconnect altogether, and expect periods where there is little usage.

2. *Storytelling and Narratives*: Reading, listening to, and telling stories are important parts of bereavement. Stories can have many audiences: peers, friends, family, the public, the deceased, and even oneself. Stories help to normalize grief experiences, make sense of the death, and create legacies for future generations. Systems for the bereaved should support these multiple purposes and audiences, and consider how stories can be told in new ways.

3. *Permanence and Continuity*: A death is a life-changing event from which one does not "recover," as if it were a temporary physical illness. Rather, it is a permanent shift in the way that one interprets the world. Systems should allow for open-ended exploration of this continuing experience, rather than providing step-by-step solutions to grief.

4. *Finding Something to Do*: One way the bereaved may explore or make sense of their loss is by performing activities alone, or in groups. These activities might be traditionally determined (e.g., attending a candle-lit memorial) or more creative in nature (e.g., painting or sculpting). Systems might consider how they can support a variety of such activities, and especially how they might allow the bereaved to help one another.

5. *Heterogeneity, Sediment, and Upkeep*: The items that are meaningful to the be-

reaved can come in many heterogeneous forms, which vary in their ability to be digitized. Organizing important objects occurs over time, and in sedimentary layers. Taking care of these items is a symbolic way to honour the relationship. Designers should expect digital mementos to be of many different forms, to accumulate over time, and to be revisited.

6. *Display and Control of Mourning Symbols*: Part of dealing with a loss is controlling one's outward appearance. Systems should be designed to be ignored or hidden away so that the bereaved can focus on other parts of their lives, and project a non-grieving appearance to others when they so desire. Systems that broadcast a bereaved person's status should be developed carefully, so that the bereaved have fine-grained control over what is being displayed to others.

This thesis also documents the design, development, and deployment of a website called Besupp that embodies these considerations (Chapter 5/Phase 3). From the deployment study, additional findings concerning technology's role in social support and remembrance are revealed:

- *Value of Digital Mementos for Reminiscing*: While participants saw value in having an online Memory Box, reminiscing using online digital mementos was uncommon for several reasons: (1) digital mementos were often replicas of existing physical assets, (2) participants were concerned about the security and stability of online storage, (3) participants were not emotionally ready to view or interact with digital mementos, and (4) digitizing mementos involved too much technical expertise or overhead. System designers should ensure that systems for reminiscence support or complement existing physical assets, and allow for many ways to import/export mementos among other systems (e.g., Facebook).

- *Value of Digital Mementos for Social Support*: In an online peer-support setting, digital mementos such as photos and stories were primarily valued for their ability

to help participants get to know one another. There were two main barriers to using digital mementos in an online setting. First, participants felt that mementos drew too much attention to the loss, rather than coping with grief. Second, digital mementos were not seen to be helpful because other people in the group did not know the deceased. Sharing digital mementos with friends and family online is likely to be more successful than sharing with peers. Sharing digital mementos in peer support settings may be more successful if it is part of a more structured group activity.

- *Design of Online Peer-Support Systems*: Online peer-support systems for the bereaved should give users the opportunity to "vent" and express emotion at any time. At the same time, conversation must be consistent and frequent in order to derive value from the exchanges; this may be accomplished by allowing larger groups or imposing more structure on the support group (e.g., a moderator directing conversation). Online groups help the bereaved to normalize their grief by seeing that other people have similar experiences. Further, they allow people who are further along in their grief journeys to offer the benefit of their experience to those with fresher losses. System designers should create mechanisms for encouraging continued participation, empower moderators to direct activities, and anticipate users with a range of experiences and time since loss.

- *Attitudes towards Technology during Bereavement*: More generally, the Besupp deployment showed that using technology for social support in bereavement was at odds with existing notions of the purposes and environments for technology use. Users may associate technology with the workplace and productivity, and avoid usage because of the concentration of grief-related emotions in a single place. System designers should investigate form factors that feel less like existing modes of interaction, and perhaps allow for more general discussions to occur beyond those

related to grief.

- *Timing of Interventions*: When deploying systems for use by the bereaved, designers should consider how the system would operate as part of a user's ongoing, temporally-dependent emotional journey. Systems must accomodate the needs of those who are very close to the time of a loss, those who have found a "new normal," and those somewhere in between. These needs may vary based on the time of day, time of year, time since loss, and by the occurrence of particular life events.

Taken as a whole, this thesis calls attention to the role of computing at the end of the human lifespan, and provides an early exploration into this space through three empirical studies. These studies approach this topic using different methods in order to identify key problems and considerations for HCI designers and researchers, and progress from an early understanding of the space towards actual software design, development, and usage. This approach, which I term thanatosensitive design, suggests a way of designing systems that are sensitive to end of life issues, but more importantly, raises questions for HCI and computer science regarding computing's continued and growing presence throughout, and beyond, our lifetimes.

Appendix A

Phase 1 Web Survey

Part 1: About the participant

- What is your age? [number, open ended]
- What is your gender? [male/female]
- What is your current occupation? [text, open ended]
- What country do you currently live in? [text, open ended]
- How familiar are you with the following technologies? [Scale for each of the below: Completely unfamiliar, somewhat familiar, familiar, very familiar]
    - Email
    - Web browsing
    - Mobile phone (calling)
    - Mobile phone (text messaging)
- Has a member of your family died in the past 5 years? [yes/no]
- How long ago did this person die? [Less than 1 year, 1-2 years, 2-3 years, 3-4 years, 4-5 years, more than 5 years ago]

Part 2: About the deceased

- What was the gender of the deceased? [male/female]
- What was your relationship to the deceased? [drop down: grandparent, grandchild, child, uncle/aunt, sibling, other [open ended]]
- What was the occupation of the deceased? [text, open ended]
- How many years did you know the deceased before they died? [number, open ended]
- What was the age at which the deceased died? [number, open ended]
- How familiar was the deceased with technology? [completely unfamiliar, somewhat familiar, familiar, very familiar]
- Is there anything else that you would like to share about the deceased? [text, open ended]

Part 3: Technology inheritance

- What technologies did the deceased own? [checkbox]
    - Personal computer
    - Mobile phone
    - Email account
    - Online banking account
    - Social networking account
    - iPod/music player
    - Digital camera
    - Blog
    - Online photo sharing account

    - Instant messaging account
    - Video game system
    - Personal TV device
    - Other ___
- What happened to each of these items? [For each technology above, one of: unknown, thrown away, inherited by a family or friend, donated to charity, other (describe)]
- When the person died, did you digitize any physical items? [yes/no]
    - If yes, what did you digitize? [text, open ended]
- Is there anything else you could share about how the deceased's technologies were distributed following their death? [text, open ended]

Part 4: Using technology to remember

- Did you ever use technology to help you remember the deceased? [Yes/No]
- Which of the following have you used to help you remember the deceased? [Checkbox for each item]
    - Photos
    - Music
    - Sound files (e.g. voices)
    - Journal or documents written by the deceased
    - Videos of the deceased
    - Other (specify)
- Please rate how strongly you agree with each of the following statements. [Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree]
    - I treasure mementos of loved ones who pass away.
    - Having reminders of my deceased loved ones is important to me.
    - Bringing up memories of deceased loved ones is unpleasant for me.
    - I prefer having physical mementos to remember deceased loved ones rather than intangible ones.
    - Using a computer to remember a loved one can be just as meaningful as using physical items.
    - I feel like I should think about my dead loved ones more frequently than I do.
    - I resent it when other people bring up dead loved ones in conversation.
    - It's hard to find time to reminisce.
    - I would welcome more opportunities to think about deceased loved ones.
- In what other ways do you use technology to help you remember your loved one? [open ended]

Part 5: Digital traces

- Prior to this questionnaire, have you ever considered what would happen to your digital assets once you pass away? [Yes/no]

    - If yes, how frequently? [Very infrequently, infrequently, sometimes, frequently, very frequently]
- Please rate how strongly you agree with the following statements [Strongly disagree, disagree, neither agree nor disagree, agree, strongly agree]
    - I am concerned about how my possessions will be handled when I die.
    - I have documents on my computer I would not want my family to see when I die.
    - I have documents on my computer which I would not want my friends or acquaintances to see when I die.
- What percentage of files on your computer would you not want released upon your death? [number, open ended]
- What percentage of files on your computer would you want released, but only to very specific individuals? [number, open ended]
- What percentage of files on your computer would you want released to family only? [number, open ended]
- What percentage of files on your computer would you want released to friends? [number, open ended]
- What, if any, preparations have you made to handle your digital possessions after you die? [text, open ended]
- What other thoughts do you have with regards to your digital estate and what will happen to it after you die? [text, open ended]

Follow-up

- Would you like to participate in a follow-up interview with a researcher? [Yes/No]
    - If yes, what is your email address or phone number? [text, open ended]

Appendix B

Phase 1 Follow-Up Interview

Participant name:
Web survey number:

Hello, thank you for agreeing to participate in this interview. In this interview I will be asking you a series of potentially sensitive questions regarding how people in your family handled the possessions of loved ones who have passed away. In particular we are interested in how computational devices, such as computers or mobile phones, were handled. If you would like to stop at any time, either in full or to just take a break, you are more than welcome to do so.

If you're ready, let's begin.

1. Please think of a specific person in your family who has died in the past 5 years. What relationship was this person to you?
2. When did they pass away?
3. Who was in charge of organizing this person's possessions after they passed away?
4. Did this person have any personal computing devices, such as a computer or mobile phone?
5. Did this person specify any end-of-life wishes regarding the handling of their digital files, photos, or online accounts?
    a. If they did not specify, how do you imagine they would have wanted this data to be handled?
6. What problems did you encounter when trying to distribute the possessions?
7. What types of possessions were the most cherished? (to whom?)
8. What types of possessions were the most problematic to sort out?
9. Were there any disagreements about what to do with any of the possessions? How were these disagreements resolved?
10. Did handling these possessions and data result in any new understanding of this person?
11. Did you meet or interact with any this person's friends or colleagues as a result of the handling of this data?
12. Do you have any other thoughts about how technology interacted with the death of your loved one?

Appendix C

Phase 2 Focus Group Scripts

Communication/social support:

- **Intro to section:** "One of the things we're interested in talking about today is how you and other members of your family communicate about your loved one and your loss."
- What kinds of technologies have people used to talk to other members of your family?
- What about people outside of your family? Who else is it useful to talk to?
- What kinds of things do you normally want to talk about?
- Are there times where you feel lonely, and unable to find anyone to talk to?
- Has there ever been something you want to say to someone, but couldn't find a good way to say it?
- Do you ever feel like talking about your loss is burdensome to others? How do you handle situations like that?
- Are there ever times where it's better to just be alone, or when you don't want to talk to anyone?
- What kinds of things do you think computers could do, one day, to help you talk about your loss more openly or feel more connected?

Remembrance:

- **Intro to section:** "Another way that technology can really play a role is by helping people remember. For example, a computer can be helpful to look at photos, write things down, or even look at Facebook pages or online memorials."
- What kinds of things would you say help you remember?
- What are some experiences people have using computers to remember your child? Have you found them helpful?
- Do these kinds of reminders feel welcome or unwelcome?
- What kinds of things do you think computers could helpfully do, one day, to help you remember your child?

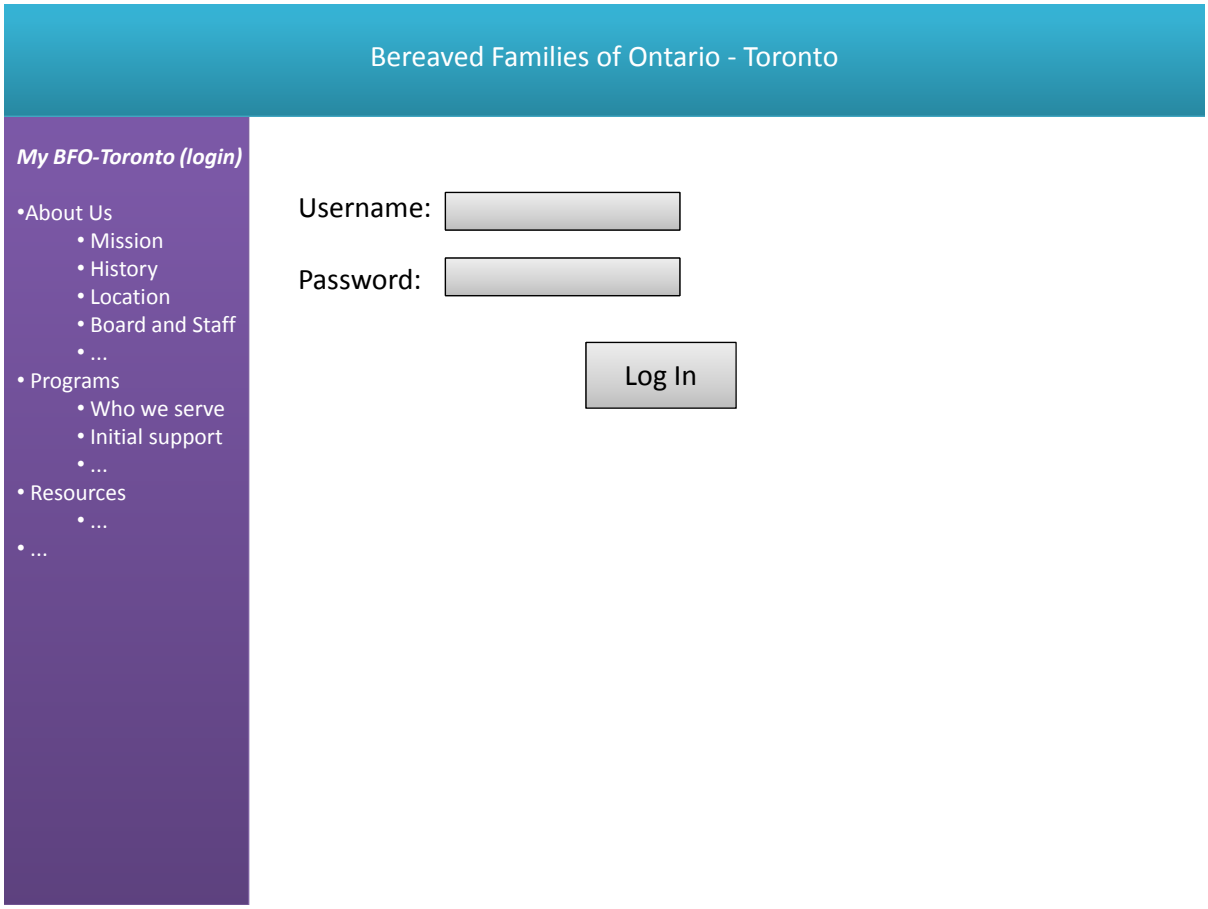
Introduce prototypes – up to 30 minutes

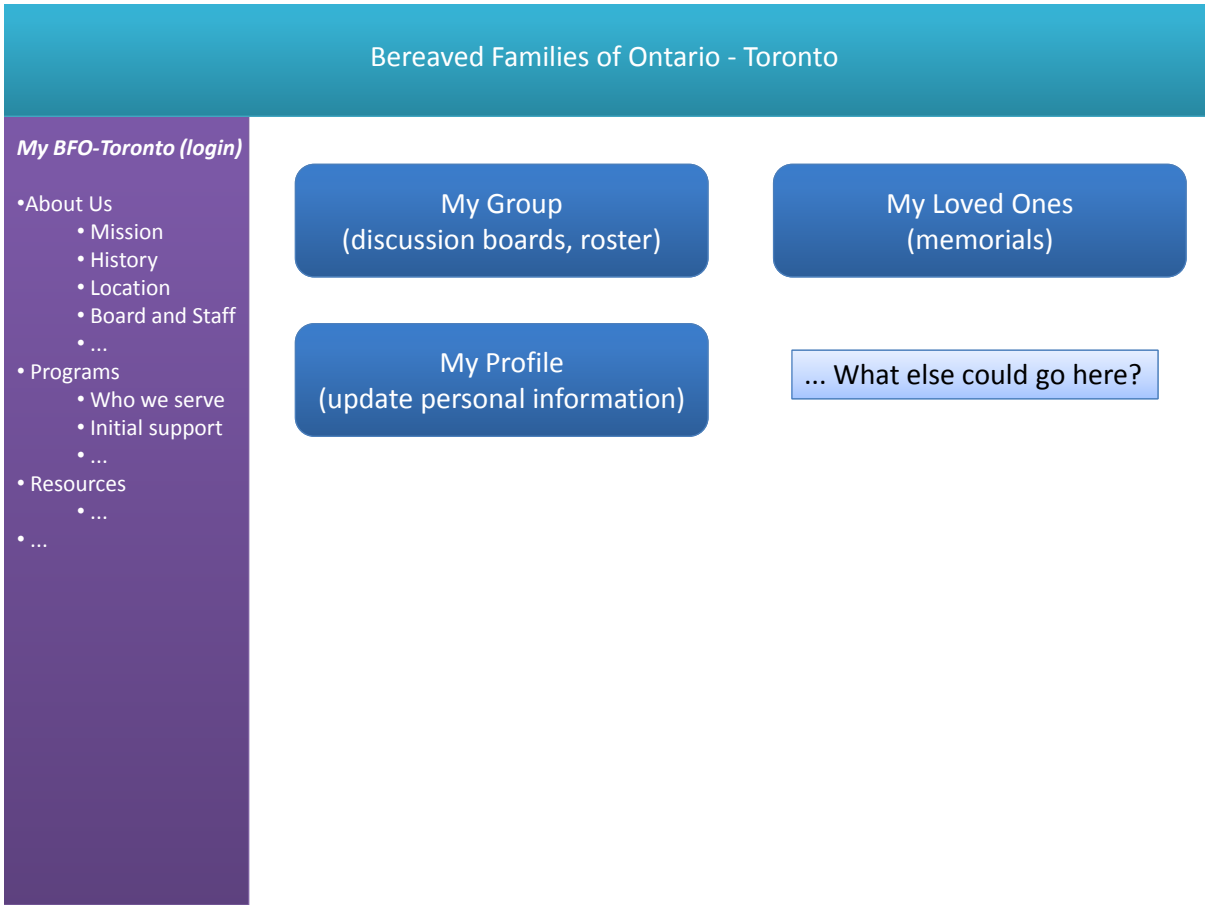
- "Now that we've talked a bit about how we talk to each other to provide support during the grieving process, I'd like to show you a few new kinds of technology that we've sketched out that might help address some of these issues."
    - 5-10 minute description of each prototype

Appendix D

Phase 2 Focus Group Prototypes


Bereaved Families of Ontario - Toronto
My BFO-Toronto (login)
•About Us
• Mission
• History
• Location
• Board and Staff
• ...
• Programs
• Who we serve
• Initial support
• ...
• Resources
• ...
• ...
News items and announcements


Bereaved Families of Ontario - Toronto
My BFO-Toronto (login)
•About Us
• Mission
• History
• Location
• Board and Staff
• ...
• Programs
• Who we serve
• Initial support
• ...
• Resources
• ...
• ...
Username:
Password:
Log In


Bereaved Families of Ontario - Toronto
My BFO-Toronto (login)
•About Us
• Mission
• History
• Location
• Board and Staff
• ...
• Programs
• Who we serve
• Initial support
• ...
• Resources
• ...
• ...
My Group
(discussion boards, roster)
My Loved Ones
(memorials)
My Profile
(update personal information)
... What else could go here?

Bereaved Families of Ontario - Toronto

My BFO-Toronto (login)

- About Us
  - Mission
  - History
  - Location
  - Board and Staff
  - ...
- Programs
  - Who we serve
  - Initial support
  - ...
- Resources
  - ...
- ...

AMBER

All about Amber

Amber was born on April 10, 2002. She passed away after a long battle with cancer.

...

Messages and thoughts

We miss you Amber (Mary, Tuesday)

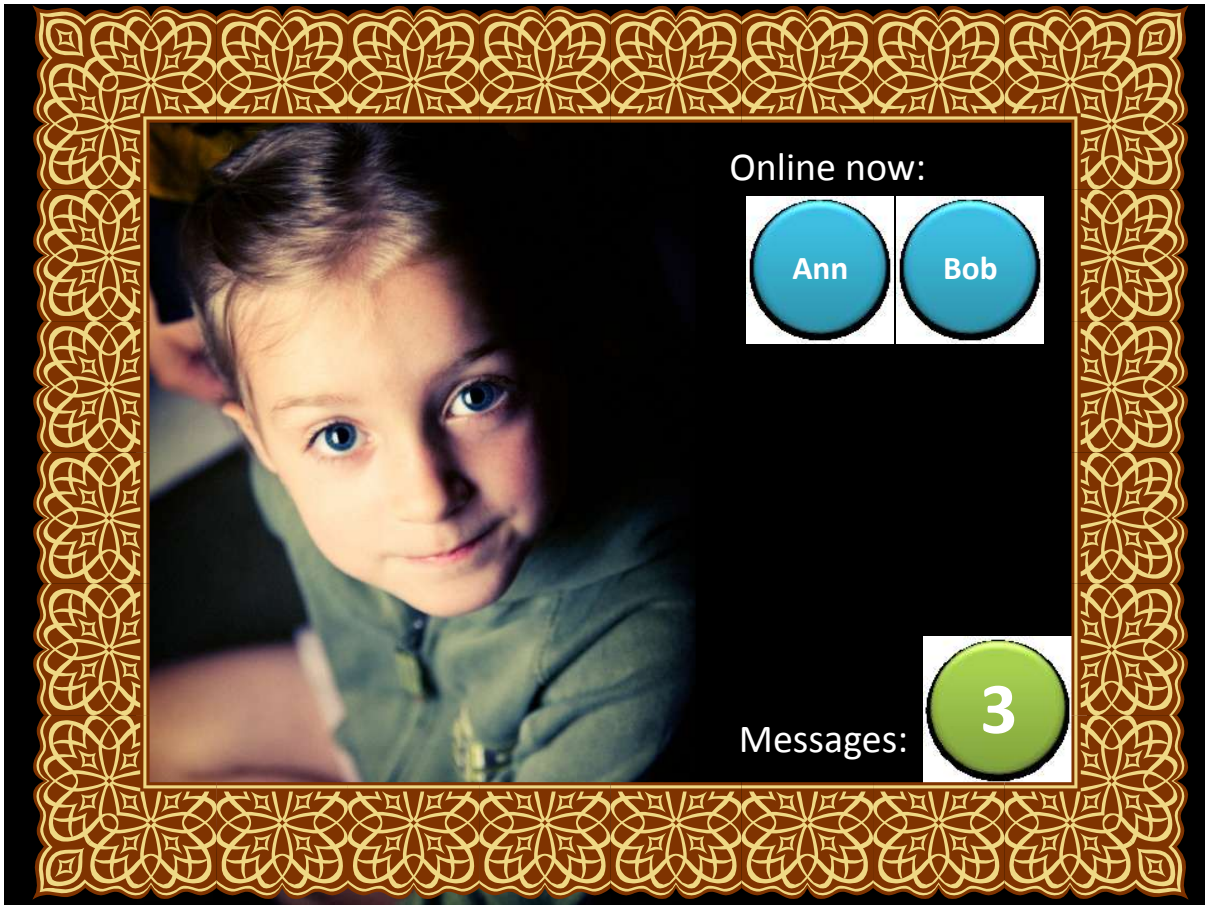
Every day is a struggle (Tony, Last month)

...

Gifts

From Mommy

From Daddy


Online now:
Ann
Bob
Messages:
3

Appendix E

Phase 3 Implementation Details

E.1 Implementation

Besupp was developed using a LAMP (Linux, Apache, MySQL, PHP) architecture and was hosted on a University of Toronto server. The domain name http://www.besupp.com was purchased in order to help participants find the site easily, and resolves to the host on the University of Toronto subnet. A mobile version of the website was mapped to http://m.besupp.com and resolved to a dedicated mobile version of Besupp located in a subdirectory on the host[1].

All pages were rendered using custom PHP (Pre-Hypertext Processor) 5.0 [www.php.net] scripts with hard-coded queries to the database. User authentication and sessioning were performed with standard PHP functions. jQuery Mobile [www.jquerymobile.com] was used to develop all pages served by the mobile version, which provided only a subset of core functionality. jQuery [www.jquery.com] and jQuery/JavaScript libraries were used to incorporate gallery views, pagination, and lightbox elements of the user interface. Custom JavaScript/AJAX (asynchronous JavaScript and XML) methods were written to permit attachments to be selected for inclusion in the Circle Chat, and for new messages to automatically refresh across multiple clients.

E.1.1 Database

A MySQL database [www.mysql.org] was employed to store all non-static information. Eleven tables were created under a single schema:

- `groups`: Stores group name, Circle Announcement text, and associated timestamps.
- `users`: Stores username, MD5-hash encrypted password, all profile information, associated Group ID, moderator flag, and timestamps for login and profile updates.
- `journal, links, photos, stories, videos`: Stores fields associated with each

[1]In the deployment study, no participant visited the mobile version of the website. It has been excluded from the analysis presented.

data type, along with the user ID of the creator, the shared/private flag, and associated timestamps.

- `groupmessages`: Stores the text for all messages sent to Circle Chat, along with the IDs of any attached links, photos, stories, or videos and associated timestamps.
- `oldprofiles`: Stores backup copies of user profiles.
- `log`: Stores all custom logging events. See Section E.1.2 below.
- `feedback`: Stores all user feedback submitted via the "Feedback" button and associated timestamps.

To create groups for the study, entries were manually added to the `groups` table. A helper script was written to manually populate the `users` table with the participants, who were manually assigned to each group.

All tables in the schema were replicated and archived at Week 5 and Week 10 for analysis purposes.

E.1.2 Instrumentation

On all page loads and major events, a custom PHP logging method was called. This method automatically wrote to the database the following information: the filename of the visited page, the current session's username, the timestamp for the event, an element type, an element ID, the group ID, the user's IP address, and a string indicating an associated action. The element type/ID uniquely identified a row in one of the following tables: `journal`, `links`, `photos`, `stories`, `videos`, or `groupmessages`. To supplement the custom instrumentation, an open source analytics package called Piwik was installed [www.piwik.org]. Similar to Google Analytics [analytics.google.com], this package collected additional information regarding visitors' browsers and operating systems, and

provides visualizations of visitors time on site, page requests, geographic location, host-names, and so on.

Appendix F

Phase 3 Participant Information Sheet

Besupp Participant Information Sheet

Researcher: Mike Massimi – mikem@dgp.toronto.edu, 416-XXX-XXXX (cell)

http://www.besupp.com – main website

http://m.besupp.com – mobile-phone friendly version of website

Your First Visit: Updating your Profile

1. Visit www.besupp.com
2. Log in using the supplied username and password. Your username should be your first name, and your password is the other code on the right hand side of the slip.
3. Click on your username at the top right corner of the site, near the "Log Out" button.
4. Click "Edit My Profile" to update your personal story if you wish. All of these fields are visible to everyone else in your Circle, so this is an opportunity to share a bit about yourself.
5. Click Save Changes. You can then add a profile photo if you choose by clicking on "Choose Profile Photo" on the left.
6. You can update your profile any time you like by following these same instructions.

My Memory Box

The Memory Box is the "private" side of the site. You can add 5 different types of items to your Memory Box:

- *Photos* – You can upload photos from your hard drive, or by entering a publically accessible URL from another site.
- *YouTube videos* – While you cannot upload videos directly to Besupp, you can link to YouTube videos to include them as part of your Memory Box. You can give them a title to display.
- *Stories* – Stories are text entries that you can write to describe particular memories or moments that are precious to you.
- *Links* – Your Links page is a place to store links to books, webpages, community groups, or other resources that have been helpful to you.
- *Journal entries* – Your journal is a permanently private place to record any thoughts that you like.

All of these, except for your private journal entries, can be shared with members of your Circle later as you see fit.

My Memory Box: Clicking this link will show you a fading slideshow of the contents of the photos, videos, stories, and journal entries that are stored in your Memory Box. You can use this to reminisce or review the items in your Memory Box.

My Circle

Your Circle is the "public" side of the site. Like a real support group, every circle has a moderator. On the left of each page you can see any recent announcements set by the circle moderator, along with a list of the other people in your circle. You can view their profile pages by clicking on their photos or names. Hovering over a user will show you a snippet of their background story as well.

Circle Chat: Clicking the "Circle Chat" button will take you a private chat room that is only visible to members of your circle. The chat will only show the last 7 days worth of messages. You can view the archives by clicking on the link at the

top of the page. You can also append photos, videos, stories, and links from your Memory Box to a chat message by clicking the appropriate button at the bottom.

Sharing Items

Over time, you and other members of your Circle may choose to share photos, videos, stories, or links with the group. You can share items in 2 primary ways:

1. "Toggle Sharing" – When you are on the editing page for an item in your Memory Box, clicking this will either share, or unshare, the item that you are viewing. It will then be visible in the appropriate link under the "Shared Circle Items" on the left side of the page.
2. "Attach" – When you are in the Circle Chat, you can attach photos, videos, stories, or links to your chat message. This will cause the item to become automatically shared with the Circle and an icon will appear next to your message indicating the attachment.

Shared Circle Items: Clicking this link will show you a "bulletin board" of all of the items that have been shared so far by members of your Circle. You can use this as a way to explore or review items from your Circle Members.

Unsharing Items

If you would like to hide an item from your Circle, click on the item from your Memory Box and then click "Toggle Sharing" to revert it back to a private status. The item will no longer appear in the "Shared Circle Items" listings, and will disappear from all chat messages the item was attached to.

Feedback

Because this is a research prototype, we are quite eager to hear about your experiences using Besupp. After logging in, at the top of each screen there is a "Feedback" button. Click on this button to bring up a window that gives you a chance to write down anything on your mind – it could be suggestions for improving the site, bug fixes, thoughts you have about your experience so far, or anything else that you'd like to share. This feedback is confidentially sent to Mike through an email.

Tips and Tricks

- Photos, videos, stories, and links that are shared will have a green border or shading in your Memory Box.
- You can view the Circle Chat archives by clicking on "Circle Chat" and then clicking the link in the header above the chat box.
- If you forget your password, please feel free to email to choose a new one. Please do not use a password that you use on any other site.
- If you'd like to change your Username, please email.
- Attaching an item to a chat message, or making a photo your profile picture, will automatically cause the item to become shared and visible to your entire Circle.

Thank you again for volunteering for this study.
Please do not hesitate to contact me for any reason – the more feedback, the better!

- Mike (mikem@dgp.toronto.edu)

Appendix G

Phase 3 One-on-One Design Interview Script

Designing Technologies to Support Bereaved Parents (Individual – Design Phase)

Research question: What are the major communicational or social support needs of bereaved parents? How can computer technology better meet those needs (or others)?

Section 1: Introduction/Understanding the loss

Thank you for taking the time to talk with me today. It is my hope that by learning from you, we (as computer scientists) will be in a position to better design home technologies that help meet the various and complicated needs that bereaved parents face.

1. Could you please begin by telling me about yourself?
    a. How old are you presently?
2. Are you married?
    a. When did you marry?
3. How long has it been since you lost your child?
    a. How did your child pass away?
4. How has this loss affected you?

Section 2: Social structure

5. Tell me about your family (try to understand structure of family).

Section 3: Communication topics and needs

6. With respect to your loss, what topics do you find it useful to talk about with your family?
    a. What topics do you prefer not to talk to your family about?
7. Who, outside of your family, do you find it comforting to talk to? (friends, support group members, clergy, etc.)
8. With respect to your loss, what topics do you talk to (friends/support group/etc.) about?

Section 4: Technology Use

9. How would you describe your familiarity with computers, cell phone, or other types of personal home technologies?
10. How have you used technology in response to the loss of your child?
11. In your experience, what kind of technology would have been most valuable to you when you first lost your child?
    a. What kind of technology would be most useful to you now?

Appendix H

Phase 3 CBI Instrument

The Core Bereavement Inventory was reproduced from [18].

Besupp Questionnaire

Please answer the following items by circling the response that best matches your current feelings.

1. Do you experience images of the events surrounding your loved one's death?

   Continuously *Quite a bit of the time* *A little bit of the time* *Never*

2. Do thoughts of your loved one come into your mind whether you wish it or not?

   Continuously *Quite a bit of the time* *A little bit of the time* *Never*

3. Do thoughts of your loved one make you feel distressed?

   Always *Quite a bit of the time* *A little bit of the time* *Never*

4. Do you think about your loved one?

   Continuously *Quite a bit of the time* *A little bit of the time* *Never*

5. Do images of your loved one make you feel distressed?

   Always *Quite a bit of the time* *A little bit of the time* *Never*

6. Do you find yourself preoccupied with images or memories of your loved one?

   Continuously *Quite a bit of the time* *A little bit of the time* *Never*

7. Do you find yourself thinking of reunion with your loved one?

   Always *Quite a bit of the time* *A little bit of the time* *Never*

8. Do you find yourself missing your loved one?

   A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

9. Are you reminded by familiar objects (photos, possessions, rooms, etc.) of your loved one?

   A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

10. Do you find yourself looking for your loved one in familiar places?

A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

11. Do you find yourself yearning for your loved one?

A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

12. Do you feel distress or pain if for any reason you are confronted with the reality that your loved one is not coming back?

A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

13. Do reminders of your loved one such as photos, situations, music, places, etc. cause you to feel longing for your loved one?

A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

14. Do reminders of your loved one such as photos, situations, music, places, etc. cause you to feel loneliness?

A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

15. Do reminders of your loved one such as photos, situations, music, places, etc. cause you to cry about your loved one?

A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

16. Do reminders of your loved one such as photos, situations, music, places, etc. cause you to feel sadness?

A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

17. Do reminders of your loved one such as photos, situations, music, places, etc. cause you to feel loss of enjoyment?

A lot of the time *Quite a bit of the time* *A little bit of the time* *Never*

Thank you!

Appendix I

Phase 3 MSPSS Instrument

The Multidimensional Scale of Perceived Social Support was reproduced from [123].

Besupp Questionnaire

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Mark column 1 if you **Very Strongly Disagree**

Mark column 2 if you **Strongly Disagree**

Mark column 3 if you **Mildly Disagree**

Mark column 4 if you are **Neutral**

Mark column 5 if you **Mildly Agree**

Mark column 6 if you **Strongly Agree**

Mark column 7 if you **Very Strongly Agree**

		1	2	3	4	5	6	7
1.	There is a special person who is around when I am in need.							
2.	There is a special person with whom I can share my joys and sorrows.							
3.	My family really tries to help me.							
4.	I get the emotional help and support I need from my family.							
5.	I have a special person who is a real source of comfort to me.							
6.	My friends really try to help me.							
7.	I can count on my friends when things go wrong.							
8.	I can talk about my problems with my family.							
9.	I have friends with whom I can share my joys and sorrows.							
10.	There is a special person in my life who cares about my feelings.							
11.	My family is willing to help me make decisions.							
12.	I can talk about my problems with my friends.							

Appendix J

Phase 3 Group Introduction Script

Session 1: Introduction

Thank you for coming today and for choosing to volunteer in the study. First, I'll give you a brief description of how the study will run, and then ask you to please sign these informed consent forms.

To introduce myself, my name is Mike Massimi. I'm a Ph.D. student in the Department of Computer Science at the University of Toronto. My thesis research is looking at how we can develop technologies that can help bereaved people with their access to social support. Last year I ran a few focus groups with people from BFO to learn a bit more about what kinds of support they valued.

Based on those focus groups, we have created a website called Besupp. The purpose of this website is to offer people who attend support groups, like the ones offered at Bereaved Families of Ontario, an online, virtual space that enables them to continue to communicate, share, listen, and reflect. Now, we're running a study to determine how Besupp can help people with social support.

As part of the study, you will be asked to use Besupp in order to participate in an online support group for the next 8 weeks. Everyone here today attended meetings at BFO in the past, but from different years. You'll also have a trained moderator using the site, just like you had a moderator when you attended sessions at BFO. On the site, you can chat with each other and share photos, videos, stories, and links. You can use the site as frequently as you like.

Because this is a research study, there are some things you should know.

1. After the 8 weeks are over, the site will be taken down. At that point in time, we will be working with BFO to determine whether or not the site should be offered to support groups in the future.

2. Anything posted to the site will be saved on our servers here at U of T, and will be analyzed as part of the study. I am the only person who will have access to the raw data. Any analysis or reports will have all identifying information removed. Besupp is a closed registration system – this means that only the people in this room will be able to see anything that you choose to share on the site. Random people from the internet cannot "stop by" and create an account.

3. To help me understand how you are using the site, I kindly ask that you participate in 3 individual sessions. The first will occur in the next week, the second will be in about a month, and the third will be at the end of the study in about 2 months. These can be done in person or over the phone. In between sessions, I'd also ask that you send me any ideas, thoughts, or feedback that you have. You can do this through the site itself, or by emailing or calling me. The more feedback I receive from you, the better!

4. You will be compensated $10 for each week that you actively participate in the study, up to $80 for all 8 weeks. You are free to stop at any time for any reason. You will receive the compensation at the end of the study.

Appendix K

Phase 3 Individual Interview - Week 1

Besupp Individual Session 1

Participant:

Date:

Demographics

Age:

Technology comfort:
(Scale from 1 – 4 : Not at all, Somewhat, Moderately, Very Comfortable)

Facebook:

Smart phone:

Home computer:

Occupation:

Date of death:

Important dates in the next 2 months?:

(Confirm telephone/email addresses)

Interview

1. Could you tell me about your grief journey thus far?
2. How did you come to your first support group?
3. What do you hope to gain from being part of support group? What would you like to discuss with a support group?
4. How would you describe your experiences dealing with friends and family since your loss occurred?
5. Who do you currently talk to when you feel like you need support? Why?
6. Are there particular times of day or triggers where you wish you had someone to talk to?
    a. What kinds of things do you wish to talk about at these times?
7. Do you have a "Memory Box" or something similar? What do you keep in it?
8. What are the possessions, places, music, etc. you find most meaningful?
9. What stories do you find are the most important to tell?
10. When you are feeling in need of support, do you like to perform any particular activities? What might they be?
11. Why did you decide to enrol in this study?
12. What do you hope to get out of using Besupp for the next 2 months?
13. Any other thoughts or questions for me?

Appendix L

Phase 3 Individual Interview - Week 5

Besupp Individual Session 2

Participant ID:

Date/time:

Introduction

1. How has your experience with Besupp been so far?
2. Have you used the mobile version?
3. How would you compare your support group experience so far with Besupp to your previous face to face support group experiences?

Memory Box
(log in and check alongside)

4. How would you describe the experience of creating this online Memory Box?
5. What have you added to your Memory Box so far?
    a. For each item: Why did you add this item?
    b. For each item: Why did you choose to share/not share it?
6. Were there any items that you considered adding to the Memory Box, but chose not to? Why did you choose not to add them?
7. Do you find the Memory Box to be a helpful way to remember your loved one?
8. How did you use the Memory Box in conjunction with other tools, such as Facebook or Flickr?
9. Are there any items in your Memory Box that you unshared? Why?
10. What are your overall impressions of the photos feature of the Memory Box?
11. What are your overall impressions of the stories feature of the Memory Box?
12. What are your overall impressions of the videos feature of the Memory Box?
13. What are your overall impressions of the journal feature of the Memory Box?

Circle

14. How would you describe your experience sharing and viewing with your Circle so far?
15. Compared to the first week of the study, would you say that you are communicating with members of your Circle more frequently, less frequently, or the same amount?
16. Compared to one month ago, would you say that you are communicating with your friends and family more frequently, less frequently, or the same amount?
17. Do the things you discuss in the Circle chat differ from a face to face support group? If so, how?
18. Do the things you discuss in the Circle chat differ from the things you talk to friends and family about? If so, how?
19. What has your experience been like with respect to the timing and organization of messages in the Circle chat? Have you used the chat archives?
20. What has it been like to view the photos and stories that people in your Circle have shared? Have any been particularly helpful or meaningful?

Appendix M

Phase 3 Individual Interview - Week 10

Besupp Individual Session 3 – Final

Participant:

Date:

Completed questionnaires online? _____

Introduction

1. How has your experience with Besupp been since the last time we talked?

Memory Box
(log in and check alongside)

2. Have you added anything to your Memory Box since the last time we talked?
3. What have you added to your Memory Box since then?
    a. For each item: Why did you add this item?
    b. For each item: Why did you choose to share/not share it?
4. Were there new items that you considered adding to the Memory Box, but chose not to? Why did you choose not to add them?
5. Are there any items in your Memory Box that you unshared? Why?
6. Overall, do you think that the Memory Box is a good way to memorialize and remember your loved one?
7. Overall, do you think that the process of creating a digital Memory Box is a helpful way to work through your grief? For other grieving people?
8. Do you have any thoughts about the [photos, stories, videos, links, journal] features of the Memory Box?
9. Did the Memory Box help you share your grief with your Circle? If so, how? If not, why not?
10. In a next version of Besupp, would you keep the Memory Box?
    a. If so, what would you change?
    b. If not, why?

Circle

11. What has your experience with the Circle been like since the last time we talked?
12. Compared to the last time we talked, would you say that you are communicating with members of your Circle more frequently, less frequently, or the same amount?
13. Compared to the last time we talked, would you say that you are communicating with your friends and family more frequently, less frequently, or the same amount?
14. Have you noticed any changes in the topics that are being discussed in the Circle chat since the last time we talked? Are there any topics you wish were discussed?
15. Have there been any new [photos, stories, videos, links] that people have shared that you found particularly interesting or helpful?
16. Do you think that having the ability to share [photos, stories, videos, links] contributed to the support group experience?

Bibliography

[1] Aho, A. L., Tarkka, M., Astedt-Kurki, P., and Kaunonen, M. Fathers' experience of social support after the death of a child. *American Journal of Men's Health 3*, 2 (2009), 93–103.

[2] Aipperspach, R., Hooker, B., and Woodruff, A. The heterogeneous home. In *Proc. Ubicomp 2008* (Seoul, Korea, 2008), ACM, pp. 222–231.

[3] Allumbaugh, D., and Hoyt, W. Effectiveness of grief therapy: A meta-analysis. *Journal of Counseling Psychology 46*, 3 (1999), 370.

[4] Aronson, J. A pragmatic view of thematic analysis. In *The Qualitative Report* (1994), vol. 2.

[5] Association, C. H. P. C. Hospice palliative care in Canada, 2004.

[6] Balabanović, M., Chu, L., and Wolff, G. Storytelling with digital photographs. In *Proc. CHI 2000* (2000), ACM, pp. 564–571.

[7] Balk, D., Wogrin, C., Thornton, G., and Meagher, D. *Handbook of Thanatology: The Essential Body of Knowledge for the Study of Death, Dying, and Bereavement*. Association for Death Education and Counseling, The Thanatology Association, 2007.

[8] BANKS, R., AND SELLEN, A. Shoebox: mixing storage and display of digital images in the home. In *Proc. TEI 2009* (Cambridge, United Kingdom, 2009), ACM, pp. 35–40.

[9] BARTALOS, M. K. *Speaking of Death: America's New Sense of Mortality*. Praeger, Nov. 2008.

[10] BAUR, D., SEIFFERT, F., SEDLMAIR, M., AND BORING, S. The streams of our lives: Visualizing listening histories in context. *Visualization and Computer Graphics, IEEE Transactions on 16*, 6 (2010), 1119 –1128.

[11] BENDER, J., O'GRADY, L., AND JADAD, A. Supporting cancer patients through the continuum of care: A view from the age of social networks and computer-mediated communication. *Curr Oncol 15*, s2 (2008), s42–s47.

[12] BENDER, J. L. *The Web of Care: A Multi-Method Study Examining the Role of Online Communities as a Source of Peer-to-peer Supportive Care for Breast Cancer Survivors*. PhD thesis, University of Toronto, 2011.

[13] BERKMAN, L., AND SYME, S. Social networks, host resistance, and mortality: a nine-year follow-up study of alameda county residents. *American Journal of Epidemiology 109*, 2 (1979), 186–204.

[14] BONANNO, G., AND BOERNER, K. The stage theory of grief. *JAMA: The Journal of the American Medical Association 297*, 24 (2007), 2693.

[15] BONANNO, G. A., AND KALTMAN, S. The varieties of grief experience. *Clinical Psychology Review 21*, 5 (July 2001), 705–734.

[16] BRUBAKER, J., AND HAYES, G. We will never forget you [online]: An empirical investigation of post-mortem MySpace comments. In *Proc. CSCW 2011* (2011), ACM, pp. 123–132.

[17] BUCKLE, J. L., AND FLEMING, S. *Parenting after the Death of a Child: A Practitioner's Guide*, 1 ed. Routledge, Aug. 2010.

[18] BURNETT, P., MIDDLETON, W., RAPHAEL, B., AND MARTINEK, N. Measuring core bereavement phenomena. *Psychological Medicine 27*, 1 (Jan. 1997), 49–57.

[19] CARROLL, B., AND LANDRY, K. Logging on and letting out: Using online social networks to grieve and to mourn. *Bulletin of Science, Technology & Society 30*, 5 (2010), 341–349.

[20] COHEN, S., UNDERWOOD, L., AND GOTTLIEB, B. *Social Support Measurement and Intervention: A Guide for Health and Social Scientists*. Oxford University Press, USA, 2000.

[21] COHEN, S., AND WILLS, T. A. Stress, social support, and the buffering hypothesis. *Psychological Bulletin 98*, 2 (Sept. 1985), 310–357.

[22] COLA, J. Find what happens to your email and social networking accounts when you die? http://www.makeuseof.com/tag/what-happens-to-your-email-and-social-networking-sites-when-you-die/, Nov. 2009.

[23] CONSOLVO, S., EVERITT, K., SMITH, I., AND LANDAY, J. Design requirements for technologies that encourage physical activity. In *Proc. CHI 2006* (2006), ACM, pp. 457–466.

[24] DAMIANAKIS, T., CRETE-NISHIHATA, M., SMITH, K. L., BAECKER, R. M., AND MARZIALI, E. The psychosocial impacts of multimedia biographies on persons with cognitive impairments. *The Gerontologist 50*, 1 (2010), 23–35.

[25] DAVIDOWITZ, M., AND MYRICK, R. D. Responding to the bereaved: An analysis of "helping" statements. *Death Education 8*, 1 (1984), 1–10.

[26] DIMOND, J. P., POOLE, E. S., AND YARDI, S. The effects of life disruptions on home technology routines. In *Proc. GROUP 2010* (Sanibel Island, Florida, USA, 2010), ACM, pp. 85–88.

[27] DOKA, K. J. Disenfranchised grief. In *Disenfranchised Grief: Recognizing Hidden Sorrow.* Lexington, MA, England: Lexington Books/D. C. Heath and Com, 1989, pp. 3–11.

[28] DOMINICK, S. A., IRVINE, B. A., BEAUCHAMP, N., SEELEY, J. R., NOLEN-HOEKSEMA, S., DOKA, K. J., AND BONNANO, G. A. An internet tool to normalize grief. *Omega 60*, 1 (2009), 71–87.

[29] DOW, S., LEE, J., OEZBEK, C., MACLNTYRE, B., BOLTER, J. D., AND GANDY, M. Exploring spatial narratives and mixed reality experiences in oakland cemetery. In *Proc. CHI 2005* (Valencia, Spain, 2005), ACM, pp. 51–60.

[30] DURRANT, A., ROWLAND, D., KIRK, D. S., BENFORD, S., FISCHER, J. E., AND MCAULEY, D. Automics: Souvenir generating photoware for theme parks. In *Proc. CHI 2011* (New York, NY, USA, 2011), CHI '11, ACM, pp. 1767–1776.

[31] ERICKSON, T., SMITH, D. N., KELLOGG, W. A., LAFF, M., RICHARDS, J. T., AND BRADNER, E. Socially translucent systems: social proxies, persistent conversation, and the design of Babble. In *Proc. CHI 1999* (New York, NY, USA, 1999), CHI '99, ACM, pp. 72–79.

[32] FEIGELMAN, W., GORMAN, B., BEAL, K., AND JORDAN, J. Internet support groups for suicide survivors: A new mode for gaining bereavement assistance. *OMEGA–Journal of Death and Dying 57*, 3 (2008), 217–243.

[33] FLEMING, S., AND ROBINSON, P. Grief and cognitive–behavioral therapy: The reconstruction of meaning. In *Handbook of Bereavement Research: Consequences,*

Coping, and Care. Washington, DC, US: American Psychological Association, 2001, pp. 647–669.

[34] FOONG, P. S., AND KERA, D. Applying reflective design to digital memorials. In *Proc. SIMTECH 2008* (Cambridge, United Kingdom, 2008).

[35] FORTE, A., HILL, M., PAZDER, R., AND FEUDTNER, C. Bereavement care interventions: A systematic review. *BMC Palliative Care 3*, 1 (2004), 3.

[36] FREUD, S. Mourning and melancholia. *Journal of Nervous and Mental Disease 56*, 5 (Nov. 1922), 543–545.

[37] FRIEDMAN, B., AND NATHAN, L. P. Multi-lifespan information system design: a research initiative for the HCI community. In *Proc. CHI 2010* (Atlanta, Georgia, USA, 2010), ACM, pp. 2243–2246.

[38] FROHLICH, D., KUCHINSKY, A., PERING, C., DON, A., AND ARISS, S. Requirements for photoware. In *Proc. CSCW 2002* (New York, NY, USA, 2002), CSCW '02, ACM, pp. 166–175.

[39] GETTY, E., COBB, J., GABELER, M., NELSON, C., WENG, E., AND HANCOCK, J. I said your name in an empty room: grieving and continuing bonds on facebook. In *Proc. CHI 2011* (New York, NY, USA, 2011), CHI '11, ACM, pp. 997–1000.

[40] GLASER, B. G., AND STRAUSS, A. *Awareness of Dying.* Aldine Transaction, Dec. 1965.

[41] GOFFMAN, E. *The Presentation of Self in Everyday Life.* Penguin psychology. Penguin, 1990.

[42] HALLAM, E., AND HOCKEY, J. *Death, Memory and Material Culture*, first ed. Berg Publishers, Dec. 2001.

[43] HALVERSON, C. A., ERICKSON, T., AND SUSSMAN, J. What counts as success? punctuated patterns of use in a persistent chat environment. In *Proc. GROUP 2003* (New York, NY, USA, 2003), GROUP '03, ACM, pp. 180–189.

[44] HELMES, J., CAO, X., LINDLEY, S. E., AND SELLEN, A. Developing the story: designing an interactive storytelling application. In *Proc. ACM International Conference on Interactive Tabletops and Surfaces* (Banff, Alberta, Canada, 2009), ACM, pp. 49–52.

[45] HÖÖK, K., STÅHL, A., SUNDSTRÖM, P., AND LAAKSOLAAHTI, J. Interactional empowerment. In *Proc. CHI 2008* (Florence, Italy, 2008), ACM, pp. 647–656.

[46] HOWARTH, G. *Death and Dying: A Sociological Introduction*, 1 ed. Polity, Dec. 2006.

[47] JACOBSON, D. Types and timing of social support. *Journal of Health and Social Behavior 27* (1986), 250–264.

[48] KASTENBAUM, R., AND COSTA, P. T. Psychological perspectives on death. *Annual Review of Psychology 28*, 1 (1977), 225–249.

[49] KAUNONEN, M., TARKKA, M., PAUNONEN, M., AND LAIPPALA, P. Grief and social support after the death of a spouse. *Journal of Advanced Nursing 30*, 6 (1999), 1304–1311.

[50] KIRK, D., AND BANKS, R. On the design of technology heirlooms. In *Proc. International Workshop on Social Interaction and Mundane Technologies (SimTech) 2008* (Cambridge, United Kingdom, 2008).

[51] KIRK, D. S., AND SELLEN, A. On human remains: Values and practice in the home archiving of cherished objects. *ACM Trans. Comput.-Hum. Interact. 17*, 3 (2010), 1–43.

[52] KLASS. *Continuing Bonds: New Understandings Of Grief*, 1 ed. Taylor & Francis, Feb. 1996.

[53] KOSEM, J., AND KIRK, D. Spomenik: Monument. In *CHI 2010 Workshop on HCI at the End of Life* (2010).

[54] KRUEGER, R., AND CASEY, M. *Focus groups: A practical guide for applied research*. Sage, 2009.

[55] KÜBLER-ROSS, E. *On death and dying*. Routledge, London, 1989.

[56] LANDRY, B. Storytelling with digital photographs: supporting the practice, understanding the benefit. In *Proc. CHI 2008 Extended Abstracts* (2008), ACM, pp. 2657–2660.

[57] LEHMAN, D. R., ELLARD, J. H., AND WORTMAN, C. B. Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *Journal of Consulting and Clinical Psychology 54*, 4 (1986), 438–446.

[58] LEONARDI, C., MENNECOZZI, C., NOT, E., PIANESI, F., ZANCANARO, M., GENNAI, F., AND CRISTOFORETTI, A. Knocking on elders' door: Investigating the functional and emotional geography of their domestic space. In *Proc. CHI 2009* (Boston, MA, USA, 2009), ACM, pp. 1703–1712.

[59] LEVY, L., AND DERBY, J. Bereavement support groups: Who joins; who does not; and why. *American Journal of Community Psychology 20*, 5 (1992), 649–662.

[60] LEVY, L., DERBY, J., AND MARTINKOWSKI, K. Effects of membership in bereavement support groups on adaptation to conjugal bereavement. *American Journal of Community Psychology 21*, 3 (1993), 361–381.

[61] LINDLEY, S. E., DURRANT, A., KIRK, D., AND TAYLOR, A. S. Collocated social practices surrounding photos. *International Journal of Human-Computer Studies 67*, 12 (Dec. 2009), 995–1004.

[62] LINDLEY, S. E., HARPER, R., AND SELLEN, A. Desiring to be in touch in a changing communications landscape: attitudes of older adults. In *Proc. CHI 2009* (Boston, MA, USA, 2009), ACM, pp. 1693–1702.

[63] LIU, L., HIRANO, S., TENTORI, M., CHENG, K., GEORGE, S., PARK, S., AND HAYES, G. Improving communication and social support for caregivers of high-risk infants through mobile technologies. In *Proc. CSCW 2011* (2011), ACM, pp. 475–484.

[64] LOCASTO, M. E., MASSIMI, M., AND DEPASQUALE, P. Security and privacy considerations in digital death. In *Proc. New Security Paradigms Workshop 2011* (2011).

[65] MACIEJEWSKI, P., ZHANG, B., BLOCK, S., AND PRIGERSON, H. An empirical examination of the stage theory of grief. *JAMA: The Journal of the American Medical Association 297*, 7 (2007), 716.

[66] MARTIN, T. L., AND DOKA, K. J. *Men Don't Cry - Women Do: Transcending Gender Stereotypes of Grief*. Psychology Press, 2000.

[67] MASSIMI, M., AND BAECKER, R. M. A death in the family: opportunities for designing technologies for the bereaved. In *Proc. CHI 2010* (Atlanta, Georgia, USA, 2010), ACM, pp. 1821–1830.

[68] MASSIMI, M., AND BAECKER, R. M. Dealing with death in design: developing systems for the bereaved. In *Proceedings of the 2011 annual conference on Human factors in computing systems* (New York, NY, USA, 2011), CHI '11, ACM, pp. 1001–1010.

[69] MASSIMI, M., BERRY, E., BROWNE, G., SMYTH, G., WATSON, P., AND BAECKER, R. M. An exploratory case study of the impact of ambient biographical displays on identity in a patient with alzheimer's disease. *Neuropsychological Rehabilitation 18*, 5-6 (Dec. 2008), 742–765. PMID: 18609021.

[70] MASSIMI, M., BERRY, E., BROWNE, G., SMYTH, G., WATSON, P., AND BAECKER, R. M. An exploratory case study of the impact of ambient biographical displays on identity in a patient with alzheimers disease. *Neuropsychological Rehabilitation 18*, 5-6 (2008), 742–765.

[71] MASSIMI, M., AND CHARISE, A. Dying, death, and mortality: towards thanatosensitivity in HCI. In *Proc. CHI 2009 Extended Abstracts* (Boston, MA, USA, 2009), ACM, pp. 2459–2468.

[72] MASSIMI, M., DIMOND, J., AND LE DANTEC, C. Finding a new normal: The role of technology in life disruptions. In *Proc. CSCW 2012, to appear* (2012), ACM.

[73] MASSIMI, M., ODOM, W., BANKS, R., AND KIRK, D. Matters of life and death: locating the end of life in lifespan-oriented HCI research. In *Proceedings of the 2011 annual conference on Human factors in computing systems* (New York, NY, USA, 2011), CHI '11, ACM, pp. 987–996.

[74] MASSIMI, M., ODOM, W., KIRK, D., AND BANKS, R. Hci at the end of life: understanding death, dying, and the digital. In *Proceedings of the 28th of the international conference extended abstracts on Human factors in computing systems* (New York, NY, USA, 2010), CHI EA '10, ACM, pp. 4477–4480.

[75] MONCUR, W. Providing affective information to family and friends based on social networks. In *Proc. CHI 2007 Extended Abstracts* (San Jose, CA, USA, 2007), ACM, pp. 2219–2224.

[76] MORI, J. Memorialising day-to-day content: bushfire affected communities. In *Proceedings of the 22nd Conference of the Computer-Human Interaction Special Interest Group of Australia on Computer-Human Interaction* (New York, NY, USA, 2010), OZCHI '10, ACM, pp. 435–437.

[77] NADEAU, J. W. Meaning-Making in bereaved families: Assessment, intervention, and future research. In *Handbook of Bereavement Research and Practice: Advances in Theory and Intervention*. American Psychological Association (APA), 2008, pp. 511–530.

[78] NAGER, E., AND VRIES, B. Memorializing on the world wide web: Patterns of grief and attachment in adult daughters of deceased mothers. *OMEGA–Journal of Death and Dying 49*, 1 (2004), 43–56.

[79] NEUBERGER. *Dying Well: A Guide to Enabling A Good Death*, 2 ed. Radcliffe Medical Press, Aug. 2004.

[80] NEUSTAEDTER, C., BRUSH, A. J. B., AND GREENBERG, S. A digital family calendar in the home: lessons from field trials of LINC. In *Proceedings of Graphics Interface 2007* (Montreal, Canada, 2007), ACM, pp. 199–20.

[81] NEUSTAEDTER, C., BRUSH, A. J. B., AND GREENBERG, S. The calendar is crucial: Coordination and awareness through the family calendar. *ACM Trans. Comput.-Hum. Interact. 16*, 1 (2009), 1–48.

[82] NORTH, J. Parents of dead students use facebook to reconnect, Nov. 2007.

[83] ODOM, W., HARPER, R., SELLEN, A., KIRK, D., AND BANKS, R. Passing on & putting to rest: understanding bereavement in the context of interactive technologies. In *Proc. CHI 2010* (Atlanta, Georgia, USA, 2010), ACM, pp. 1831–1840.

[84] ODOM, W., PIERCE, J., STOLTERMAN, E., AND BLEVIS, E. Understanding why we preserve some things and discard others in the context of interaction design. In *Proc. CHI 2009* (Boston, MA, USA, 2009), ACM, pp. 1053–1062.

[85] OLEKSIK, G., AND BROWN, L. M. Sonic gems: exploring the potential of audio recording as a form of sentimental memory capture. In *Proceedings of the 22nd British HCI Group Annual Conference on People and Computers: Culture, Creativity, Interaction - Volume 1* (Swinton, UK, UK, 2008), BCS-HCI '08, British Computer Society, pp. 163–172.

[86] OLIVERI, T. Grief groups on the internet. *Bereavement Care 22*, 3 (2003), 39.

[87] OLSON, G. M., AND OLSON, J. S. Distance matters. *Human-Computer Interaction 15*, 2 (2000), 139–179.

[88] PALEN, L., AND VIEWEG, S. The emergence of online widescale interaction in unexpected events: assistance, alliance \& retreat. In *Proceedings of the ACM 2008 conference on Computer supported cooperative work* (San Diego, CA, USA, 2008), ACM, pp. 117–126.

[89] PARKES, C. M. *Bereavement: Studies of Grief in Adult Life*, 2nd revised edition ed. Routledge, May 1986.

[90] PETRELLI, D., VILLAR, N., KALNIKAITE, V., DIB, L., AND WHITTAKER, S. Fm radio: family interplay with sonic mementos. In *Proceedings of the 28th international conference on Human factors in computing systems* (2010), ACM, pp. 2371–2380.

[91] PICTON, C., COOPER, B., CLOSE, D., AND TOBIN, J. Bereavement support groups: Timing of participation and reasons for joining. *Omega 43*, 3 (2001), 247–258.

[92] RANDO, T. *Treatment of complicated mourning.* Research Press Champaign, IL, 1993.

[93] RICHES, G., AND DAWSON, P. Lost children, living memories: the role of photographs in processes of grief and adjustment among bereaved parent. *Death studies 22*, 2 (1998), 121–140.

[94] ROBERTS, P. From MySpace to our space: The functions of web memorials in bereavement. *The Forum 32*, 4 (Oct. 2006), 1–4.

[95] ROBERTS, P., AND VIDAL, L. A. Perpetual care in cyberspace: A portrain of memorials on the web. *Omega: The Journal of Death and Dying 40*, 4 (2000), 521–545.

[96] SCHWAB, R. A child's death and divorce: Dispelling the myth. *Death Studies 22*, 5 (1998), 445–468.

[97] SELLEN, A., FOGG, A., AITKEN, M., HODGES, S., ROTHER, C., AND WOOD, K. Do life-logging technologies support memory for the past? an experimental study using sensecam. In *In Proc. CHI 2007, ACM Press* (2007), pp. 81–90.

[98] SHIMIZU, M., NAKATANI, M., KATO, H., AND NISHIDA, S. Communication environment for sharing fond memories. In *Proceedings of the 2004 ACM SIGCHI International Conference on Advances in computer entertainment technology* (New York, NY, USA, 2004), ACE '04, ACM, pp. 290–295.

[99] SILVERMAN, P. K. *Widow to Widow: How the Bereaved Help One Another*, 2 ed. Brunner-Routledge, Sept. 2004.

[100] SKEELS, M., UNRUH, K., POWELL, C., AND PRATT, W. Catalyzing social support for breast cancer patients. In *Proceedings of the 28th international conference on Human factors in computing systems* (2010), ACM, pp. 173–182.

[101] SOFKA, C. Adolescents, technology, and the internet: Coping with loss in the digital world. In *Adolescent encounters with death, bereavement, and coping*. Springer Pub Co, 2009, pp. 155–173.

[102] SOFKA, C. J. Social support "internetworks," caskets for sale, and more: thanatology and the information superhighway. *Death Studies 21*, 6 (Dec. 1997), 553–574. PMID: 10179827.

[103] STAUDT, C. From concealment to recognition: The discourse on death, dying, and grief. In *Speaking of Death: America's New Sense of Mortality*, M. K. Bartalos, Ed. Praeger, 2009.

[104] STONE, L. D., AND PENNEBAKER, J. W. Trauma in real time: Talking and avoiding online conversations about the death of princess diana. *Basic and Applied Social Psychology 24*, 3 (2002), 173.

[105] STROEBE, M. S. Coping with bereavement: A review of the grief work hypothesis. *Omega: Journal of Death and Dying 26*, 1 (1992), 19–42.

[106] STROEBE, M. S., HANSSON, R. O., SCHUT, H., AND STROEBE, W., Eds. *Handbook Of Bereavement Research And Practice: Advances in Theory and Intervention*, 1 ed. American Psychological Association (APA), June 2008.

[107] SUDNOW, D. *Passing on: The Social Organization of Dying*. Prentice Hall, June 1967.

[108] TURKLE, S. *Life on the Screen: Identity in the Age of the Internet*. Simon and Schuster, 1995.

[109] URIU, D., AND OKUDE, N. ThanatoFenestra: photographic family altar supporting a ritual to pray for the deceased. In *Proc. DIS 2010* (Aarhus, Denmark, 2010), ACM, pp. 422–425.

[110] VALE-TAYLOR, P. We will remember them: a mixed-method study to explore which post-funeral remembrance activities are most significant and important to bereaved people living with loss, and why those particular activities are chosen. *Palliative Medicine 23* (2009), 537 –544.

[111] VAN DEN HOVEN, E., SMEENK, W., BILSEN, H., ZIMMERMAN, R., DE WAART, S., AND VAN TURNHOUT, K. Communicating commemoration. In *International Workshop on Social Interaction and Mundane Technologies 2008* (2008).

[112] VOLKAN, V. D. The linking objects of pathological mourners. *Arch Gen Psychiatry 27*, 2 (Aug. 1972), 215–221.

[113] WAGNER, B., AND MAERCKER, A. A 1.5-year follow-up of an internet-based intervention for complicated grief. *Journal of Traumatic Stress 20*, 4 (2007), 625–629.

[114] WALTER, T. Facing death without tradition. In *Contemporary Issues in the Sociology of Death, Dying, and Disposal*, G. Howarth and P. Jupp, Eds. Macmillan, Basingstoke, 1996.

[115] WALTER, T. Disaster, modernity, and the media. In *Death and Religion in a Changing World*, K. Garces-Foley, Ed. M. E. Sharpe, Armonk, NY, 2004.

[116] WALTER, T., HOURIZI, R., MONCUR, W., AND PITSILLIDES, S. Does the internet change how we die and mourn? an overview. *OMEGA: The Journal of Death and Dying 64*, 4 (2012), 275–302.

[117] WILLIAMS, A., AND MERTEN, M. Adolescents' online social networking following the death of a peer. *Journal of Adolescent Research 24*, 1 (2009), 67.

[118] WOODRUFF, A., AUGUSTIN, S., AND FOUCAULT, B. Sabbath day home automation: "it's like mixing technology and religion". In *Proceedings of the SIGCHI*

conference on Human factors in computing systems (San Jose, California, USA, 2007), ACM, pp. 527–536.

[119] WORDEN, J. W. *Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner*, 4 ed. Springer Publishing Co., Inc., Aug. 2008.

[120] WORTHAM, J. As older users join facebook, network grapples with death, July 2010.

[121] WORTMAN, C., AND SILVER, R. The myths of coping with loss. *Journal of consulting and clinical psychology 57*, 3 (1989), 349.

[122] WYCHE, S. P., MAGNUS, C. M., AND GRINTER, R. E. Broadening ubicomp's vision: an exploratory study of charismatic pentecostals and technology use in brazil. In *Proc. UBICOMP 2009* (Orlando, Florida, USA, 2009), ACM, pp. 145–154.

[123] ZIMET, G. D., DAHLEM, N. W., ZIMET, S. G., AND FARLEY, G. K. The multidimensional scale of perceived social support. *Journal of Personality Assessment 52*, 1 (1988), 30–41.