Dealing with Death in Design: Developing Systems for the Bereaved

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ABSTRACT

Increasingly, systems are being developed and used in ways that involve end of life issues such as death, dying, and bereavement. Yet design considerations and guidelines for technologists working in this sensitive area are not well-established. We therefore report on exploratory fieldwork consisting of focus groups, observations, and consultation with bereavement experts aimed at understanding how technology might be designed to support bereaved parents. From this fieldwork, we derive a set of considerations useful for researchers and designers developing systems that deal specifically with bereavement, and with the end of life more broadly. These considerations focus on *interpersonal communication*, *new ways of being in the world*, and *materiality*. We conclude with a distillation of these considerations into practical design guidelines for working in this area.

Author Keywords

Bereavement, death, dying, social support, design, memory, thanatosensitive design.

ACM Classification Keywords

H5.m. Information interfaces and presentation (*e.g.*, HCI): Miscellaneous.

General Terms

Design, Human Factors.

INTRODUCTION

HCI research has a tradition of addressing distinct parts of the human lifespan, from childhood to old age. One part of the lifespan which is now emerging as a domain for interaction research and design is that of the *end of life* [26]. The end of life is a compelling domain for research for many reasons. It challenges ideas of user agency (*e.g.,* what

if the user has died?). It draws together various strands of HCI research such as storytelling, personal information management, privacy, and lifelogging into an integrated experience with heightened stakes. It offers an opportunity to help people at an important time in their lives. Indeed, web sites have been deployed which can help users plan their own funerals [1], safeguard and distribute possessions [2,3], and publically mourn and remember the deceased [4,40].

But despite these initial examples of applying technology to end of life issues, working in this area can be intimidating. Encountering death is never an easy experience; and of course, this holds true for HCI designers and researchers. There is arguably no other human experience which challenges and engages us on a more fundamental level than death. Although death affects all of us on such a profound level, it retains a sense of taboo. Sociologists have repeatedly characterized Western culture as "death-denying" in numerous arenas from medical care to daily living [8,14,18,34]. While some critics argue that the frequent portrayal of death in the media runs counter to this characterization [7], end of life technology designers and researchers likely still have few authentic resources to draw upon beyond their personal, anecdotal experiences.

The goal of this paper is to provide HCI researchers and designers working on end of life issues with sensibilities for working with the bereaved. Based primarily on a series of focus groups with bereaved parents and our experiences participating in professional seminars and conferences on bereavement, we 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 our fieldwork, these considerations can help us better understand, interact with, and meet the needs of the bereaved. We conclude the paper with a discussion of how these considerations can translate into practical design guidelines. These guidelines may help HCI researchers and designers move into this space for future work, and develop a set of best practices for thanatosensitive design – that is, the creation of systems that actively engage with death as part of their concept [25].

RELATED WORK

While the end of life is a relatively new area for HCI, there has been some relevant work. In recent work in HCI on bereavement, Odom *et al.* provide a lens focusing on the death of a family member, showing how relationships with the deceased do not necessarily end once a person has died [29]. Based on interviews with 11 families, they describe how relationships change and become mediated by new rituals and inherited objects, and offer considerations for designing technologies that respect and engage this relationship. Massimi and Baecker offer a set of problem spaces derived from a survey and interview study conducted with bereaved family members [24]. They highlight a broad set of concerns – from the need for social support to inheritance of digital data – that reveal potential avenues for technology application and innovation for bereaved families. Massimi and Charise suggest that the HCI community address death in design through a humanistic approach called "thanatosensitive design," looking towards multiple forms of knowledge such as literature and film, in addition to empirical fieldwork, as ways of learning how to design systems that engage with death [25].

Design-oriented work has focused primarily on memorials and how they can be used as aids for remembering ancestry or the deceased. Uriu and Okude describe the design of ThanatoFenestra, a shrine developed to support Buddhist ancestor worship. The shrine displays and changes photographs of the deceased based on the flickering of a candle [35]. Kirk and Banks describe the concept of designing technology heirlooms [20] – devices crafted to respect and invoke social relationships and memories across generations through "deep storage" [21]. Van den Hoven *et al.* demonstrate design concepts such as handheld "memory stones" and tilting photo frames which are intended for bereaved people to help them communicate their grief in an abstracted way [37]. These examples demonstrate the interesting ways in which the HCI community has begun to move towards designing for the bereaved. At the same time, these projects rely heavily upon the designers' own experiences; they include very little fieldwork obtained from talking to the bereaved or professionals working in death education or care.

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 [13]. Wyche, Magnus, and Grinter, in their account of Charismatic Pentecostals in Brazil, address religious understandings of the 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 [42]. Dimond, Poole, and Yardi also describe how death, among other forms of life disruption, impacts the ability for families to maintain home networks [11].

UNDERSTANDING BEREAVEMENT

Before presenting our design considerations, it is important to understand the research context. The goal of our research was primarily to better understand bereavement, and in particular, to do so from a technology design perspective. Based on prior work [24], we were interested in designing systems that provided social support. At the same time, we remained open to new possibilities and technological opportunities concerning bereavement more broadly – concerning, for example, issues of, remembrance, temporality, and emotion – because these topics influence, and are influenced by, the social setting in which grieving takes place. It is for this reason that in the considerations that follow, social support may be noticed as an underlying theme. Even so, the considerations presented are important for working with the bereaved regardless of domain. We briefly discuss social support tradeoffs to situate ourselves before describing how and where we studied it in the context of bereavement.

Research Domain: Social Support

The bereaved value social support and obtain it from a variety of sources [19,30]. 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. Support group members may be a better source for long-term support, but are only available at a set number of weekly meetings. Therapists are similarly difficult to access and can be a costly option. Internet support groups are much more 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 that these environments are trustworthy and credible. This array of options demonstrates how time plays an important role in selecting, accessing, and using various forms of support. In our fieldwork, we sought to better clarify this understanding of social support, and at the same time, learn about the "doing" and "being" of bereavement more generally.

Research Settings and Participants

Death is clearly a complex and immense topic, and unfolds in innumerable ways for people across the globe. In our investigation, we focused on bereavement in the secular context of the United States, Canada, and Western Europe. While of course cultural and religious elements are present in this (and any) study of death, we selected this context due to the widespread availability of computing resources and because we, as researchers, identify most strongly with this context. Positioning ourselves in this way allows us to better understand, reflect upon, and present the processes we observed, and permits us to center inquiry around lived experience with technology.

Middle-aged bereaved parents, in particular, were selected at the suggestion of a professional psychologist involved with several community groups in Ontario, Canada. We also chose to work with bereaved parents for two additional reasons: first, losing a child is so traumatic that parents are highly motivated to seek out support, and second, they represent a group familiar with technology and are therefore able to reflect on their own computing experiences.

Three focus groups took place at two different non-profit, secular community organizations: the COPING Centre in Cambridge, Ontario, and the Toronto branch of the province-wide organization called the Bereaved Families of Ontario. These focus groups involved a total of 24 bereaved parents who had completed a support group at one of these two organizations in the past 5 years[1]. Staff members from these organizations co-facilitated each focus group. These community organizations are of a peer-to-peer volunteer format; the group format does not involve a psychologist, therapist, social worker, or other type of professional.

To complement this first-person perspective with the perspective of bereavement experts, we participated in a 5-day bi-annual professional retreat in Germany organized by the International Working Group on Death, Dying, and Bereavement. Informal interviews were conducted with prominent international researchers and practitioners working in psychology, psychiatry, palliative/hospice medicine, nursing, sociology, social work, religion, the arts, family counseling, funeral services, and so on. These were accompanied by opportunistic observational field work in cemeteries in the United States and Germany, funeral homes in Canada and Germany, and a Buddhist shrine in Canada.

Throughout the design process, we kept notes about our experiences engaging with the bereaved, visiting field sites, and talking with professionals in the death, dying, and bereavement community. In our conceptual design, we draw upon many aspects of the process described by Wright and McCarthy where we draw upon shared narratives, dialogues with bereaved others, and our own human experiences [41]. Based on our notes, discussions, and lived experiences as designers, we present a set of considerations for working with the bereaved.

DESIGN CONSIDERATIONS
The considerations are grouped into three themes: *interpersonal communication, a new way of being,* and *materiality*. We find these themes house many of the design-oriented findings we uncovered from our fieldwork and research, and give purchase to a larger set of considerations that may fall within these spaces.

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[1] Quotes in this paper are attributed to particular focus group sessions as FG1, FG2, or FG3.

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. Men and women grieve differently, with men frequently demonstrating an instrumental style of grief which is focused on "doing," and women adopting an intuitive style which is more focused on "being." 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 [31].

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 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 a gulf of misunderstanding surrounding the loss. 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, 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. We describe here two considerations which designers should be aware of when designing systems for the bereaved, and in particular, communication systems.

Circles of Sympathy: Managing Communication Availability
In our fieldwork and research, we have found that bereaved parents frequently constricted their communicational availability and frequency. This might seem strange; in their emotionally devastated state, we often think that these vulnerable people may need substantial help and sympathy. While our participants and research demonstrates 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 behavior to more tightly control *who* can contact them and *when* they are receptive to communication.

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 [27]). For the bereaved parents at the grief support centers we observed, 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.

"At [this organization], it's nice to be with people that have lost a baby." – 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.

"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

As a result, the bereaved parent may find themselves in a position where they are consoling the consoler, rather than the other way around. This added to the emotional stress associated with communicating with outsiders. Bereaved parents also described how conversation with outsiders was generally unhelpful – one study found that 80% of statements meant to support the bereaved are ultimately "unhelpful" [10]. 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" [36]. 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 "fathers experienced social isolation but also deliberately isolated themselves from human relationships" [6]. 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

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 our 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 we have 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 bereaved parent became open and available, ready to talk about their loss, the rest of the world seemed to have closed off, much to their chagrin.

"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

To sum up this consideration, while we often think of communication from the extended network as being desirable, reflecting on this design process 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.

Storytelling, Narratives, and the Importance of Time
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. 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" [28]. 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 we conducted at support group centers, the creation and maintenance of a story is a precursor to subsequently sharing this story with supportive others. Being able to "tell the story" was seen as an important milestone in the grieving process. 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 conscious, the child is honoured and the memory "lives on." Over time, the acknowledgement and reaffirmation of the story by others helps to foster emotional closeness and the perception of support for the bereaved. A community of care springs up from the sharing of a 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

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

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 [24,40]. 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 [16].

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" [9]. 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.

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 [39]. 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 we conducted, bereaved parents praised the format of 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* [22]. 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.

Expression and Emotion – 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* [12]. 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" [33]. 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. These sentiments were echoed by participants in our 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" [36]. One way of considering these activities, for purposes of design, is as *group/prescriptive, group/creative,* and *individual/creative*. Note that these labels are simply useful devices for thinking about potential systems designs, and not representative of the entirety of activities a bereaved person might undertake.

Group/prescriptive types of grief activities are those which are shared among a larger social group and come with significant structure intact. The Chinese tradition of burning joss paper in honour of ancestors, for example, allows mourners to engage in a culturally-understood and sanctioned activity, and potentially experience a sense of community connection. Another example is a candlelight vigil, where a group of mourners all perform the same simple activity in solidarity. Religious activites like the Jewish tradition of "sitting shiva" are also similarly prescriptive and group-oriented. 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's grief. However, these types of activities involve significant individual creative processes in parallel and unison. One excellent example is the Mothers Against Drunk Driving (MADD) memorial quilt (*e.g.,* [5]) – each bereaved parent creates their own unique square of the quilt, which is then stitched together to form the whole. 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 [33].

Individual/creative activities share the same emphasis on creativity and "working out" grief through 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. One example provided by a participant in our focus groups is a father who, in his grief,

tore down the backyard shed and rebuilt it. Another example is a mother who writes extensively in her journal following her loss. 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.

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 [23]. In addition, artists and other creative people may find the creation of a new work to be a fulfilling way to honor and remember the deceased. Figure 1 shows an art installation observed during our 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.

Examining these different ways of "doing," technology designers can find unique perspectives on how they might design their 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 [17]. 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" [36]. Technologies could potentially fulfill a role similar to these rituals, or alter the way that existing home rituals occur.

Materiality
Thus far we have shown how the bereaved face complicated social and psychological worlds of which system designers and researchers should be aware. We now turn to the physical world, and examine more closely how special objects and places – the material "stuff" of life – is drawn into these psychological and social practices.

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" [38]. He describes encountering in his psychiatric practice a number of grieving individuals who formed troubling relationships with particular objects – perhaps a deceased lover's shirt, a 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.

Figure 1.
"Reisegepäck I" by Ulrike Oerter.

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 [15]. Recently, Odom et al. described how inheriting possessions functioned as a social act, influencing acts of communication, remembrance, and ritual performance [29].

While the literature demonstrates the importance of materiality in the lives of the bereaved, we would like to draw attention to the mechanics of working with these objects. In our observational fieldwork in cemeteries and funeral homes, we noted three thematic ways in which the bereaved related to their possessions: heterogeneity, sediment, and upkeep. These notions re-emerged during our 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, we saw how 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 together the memory of the deceased. One example from our focus groups came from a woman whose infant was stillborn; she described how she scrounged

together the small amount of materials that testified to his life into a box:

*"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 *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 [32].

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 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, bearing in mind these material processes can help create meaningful experiences for the bereaved. A system sensitive to these kinds of experience 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.

Display and Control of Mourning Symbols

We have shown how materials play a role in social and psychological processes that the bereaved encounter – a final consideration is towards 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 [12]. 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.

"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" need to be crafted in a way that allow the bereaved the opportunity to ignore or conceal the mourning symbol.

GUIDELINES

In presenting the considerations above, we have aimed to convey the richness to be found in designing systems with the bereaved in mind. From this account, we distill a set of practical guidelines that can be readily "picked up and used" by designers. Some of these guidelines may also be relevant for end of life situations besides bereavement – for example, systems which support the dying.

1. **Grief is not a problem to be solved.** 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.

2. **Communication is complicated**. 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.

3. **Family and friends are not as helpful as one may think**. 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, consider extra-familial sources of support 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. **Relationships don't die.** When a loved one dies, the relationship does not evaporate. Rather, a new asymmetry is introduced which changes the way that the relationship is conducted. Systems should acknowledge the reality of the relationship and the loss. In so doing, they can support the new form of relationship between the deceased and the bereaved.

6. **Make making meaningful.** 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.

7. **Allow many things over time.** 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.

8. **Control mourning symbols.** 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 mourning symbols are extremely private, while others are meant to be publicly viewed. When designing systems to be used by the bereaved, consider how the system could be easily ignored or omitted from daily interactions.

9. **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.

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 paper, we have reflected on our exploratory fieldwork examining the "doing" and "being" of bereavement from a technology design perspective. Our 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. We have provided a set of considerations for researchers and designers working with the bereaved, and distilled these into potentially useful guidelines for the design of future systems. 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.

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