Passing On & Putting To Rest: Understanding Bereavement in the Context of Interactive Technologies

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ABSTRACT

While it can be a delicate and emotionally-laden topic, new technological trends compel us to confront a range of problems and issues about death and bereavement. This area presents complex challenges and the associated literature is extensive. In this paper we offer a way of slicing through several perspectives in the social sciences to see clearly a set of salient issues related to bereavement. Following this, we present a theoretical lens to provide a way of conceptualizing how the HCI community could begin to approach such issues. We then report field evidence from 11 in-depth interviews conducted with bereaved participants and apply the proposed lens to unpack key emergent problems and tensions. We conclude with a discussion on how the HCI design space might be sensitized to better support the social processes that unfold when bereavement occurs.

Author Keywords

Bereavement, understanding people, digital persistence

ACM Classification Keywords

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

General Terms

Human Factors, Design

INTRODUCTION

While it can be a delicate and emotionally-laden topic, new technological trends compel us to confront a range of problems and issues about death and bereavement. For example, deceased users' social networking web pages often persist after their passing, typically without measures in place to appropriately handle this content. There are few mechanisms to enable users to pass information to loved ones (or withhold information from them). Along with these shifts, there is a growing trend of new death-related services on the web [21, 8]. Many of these concerns point

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to the fact that we are seeing a proliferation of digital data, but little is being done to consider the means by which our digital remains will persist after we are gone and how they will be managed. Such issues of the sensitive treatment of meaningful digital artifacts seems a largely unaddressed [23], but increasingly relevant issue to HCI research.

Researching issues related to bereavement presents complex practical, theoretical and ethical challenges deserving careful framing and cautious treatment. Death is experienced in many ways; there are many artifacts associated with death as well as many rituals and many places. The literature on death is also extensive, cutting across so many academic disciplines. Historically, the HCI community has drawn on techniques and theories from other disciplines to grapple with issues of how to approach and understand complex and often sensitive contexts [e.g. 23, 25, 36]. One contribution we offer is a way of slicing through several perspectives in the social sciences to see clearly a set of salient issues related to bereavement. In this paper we adopt a sociological perspective to unpack the complications and tensions encountered across our field research with bereaved participants. Through our literature review as well as description and interpretation of field evidence, the purpose of this paper is to provide a way of conceptualizing how the field of HCI might begin to understand and address issues related to bereavement.

The goals of our paper are to (i) report rich descriptions that help construct a more empirically accurate picture of some of what bereavement entails and how it is experienced, (ii) present a theoretical lens from which we can better unpack problems and tensions experienced by participants as well as those attributed to emergent technological developments and, on that basis, (iii) sensitize the design space in ways that might better support the social processes that unfold when bereavement occurs. A particular goal might be to enable people to be more expressive throughout these processes, and perhaps even beyond them, and the paper will end with some remarks about the design possibilities this might inspire.

LITERATURE REVIEW

Death is a fundamental part of life; it is intriguing and frightening for all of us. Whether through losing a loved one or facing our own mortality, experiences of death in all

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its forms shape us in profound ways. Among other things, death can disrupt the social cohesiveness of our everyday lives, unsettling even our most familiar practices, routines and interactions. It is not surprising that there is an extensive literature exploring death from many perspectives within the social sciences. The problem of death has been a fundamental area of inquiry from the outset of anthropology, sociology and psychology, though often in ways that have unsettled the theories with which these disciplines concerned themselves. Just as death unsettles everyday life, death can also unsettle academic theory.

Though early social anthropology was primarily interested in the structures of kinship, death posed a problem. Anthropologists sought to define what happens to a society, construed as a kinship structure, when an element of that kinship structure dies. Here the works of French anthropologists Hertz [14] and Durkheim [5] as well as British-based anthropologists Malinowski [22] and Radcliffe-Brown [29] are seminal. But much later Geertz [10] and others argued that the concept of kinship structures could not account for the unpredictable and dysfunctional aspects of life, with death being the canonical example. Instead of anthropology being focused solely on the mechanics of social relations, their kinship systems, anthropology came to focus on culture, with an especial emphasis on the "socially established structures of meaning" [10]:30. Notable anthropological enquiries into death and its associated rituals have since adopted the symbolic approach [3].

Sociology, meanwhile, has been concerned with death not as a biological fact, but as a social one. Sudnow's [32] classic study of the social institutionalization of death and dying emphasized the culturally and institutionally acceptable ways for people to 'pass on' [see also 12, 30]. In Sudnow's view, the autonomy, dignity and humanity of those who are dying is often replaced by institutional imperatives, such as efficiency. In this view *social death*, is more important than biological death, since the "socially relevant attributes of [a person] begin permanently to cease to be operative conditions for treating him, and when he is, essentially regarded as already dead" [32]:74.

The fields of psychology and psychiatry have taken quite a contrastive view. Kubler-Ross [19], for example, produced what is regarded as a seminal study on dying patients in hospitals, which placed emphasis on the emotional processes associated with individuals coming to terms with their own deaths. This study almost entirely excluded the institutional processes surrounding death. Nevertheless, it ultimately resulted in a widely adopted framework for categorizing the stages through which a person comes to grips with their own mortality. Later, Kubler-Ross developed a related categorization scheme for those who grieve, suggesting a set of stages for experiencing the loss of a loved one [20]. Kubler-Ross' research has had a lasting significance to this day, in that her work was an inspiration

for the hospice care movement. Hospice care has moved the scene of dying from institutionalized halls of hospitals into the home where the focus became meaning-making and social connection, and personal autonomy [12].

Situated within this historical context, there is a current revival of interest in death and dying in all the social sciences [e.g. 6, 11-13, 20, 24, 30]. Recent research suggests death-related practices in Western societies are increasingly becoming more individualized, privatized and secular [12]. There has been ongoing interest in the role of material objects in supporting processes of remembrance and memorialisation of departed loves ones in both private and public spaces [13]. Also there has been a related concern on the home, in particular, as a key material infrastructure used to help cope with loss [24]. More broadly, there is a rapidly growing literature on the important role of objects, and the ways in which they are spatially organized in the home and elsewhere [e.g. 18, 27], how they play out in signifying human relationships with the living [2] as well as stand as proxy for the dead [13].

Related Work in HCI

With this increasing presence of digital artifacts and systems in everyday life, the nature of human interactions with objects is shifting-people now commonly mediate between material things and digital technologies. It is hardly surprising then that research related to death has very recently begun to emerge within HCI in quite a vital way. Dow et al. [4] describe use of the cemetery as a place to experiment with locative narrative-based interactions between the deceased and living, for example. There also exists an interest in the emergent uses of the internet to honour and memorialise departed loved ones from various spiritual and cultural perspectives in the work of Bell [1] and others [8]. There is also research on supporting grieving processes [34]. Uriu et al. describe the design of culturallysensitive interactions with digital photographs aimed at "archiving dead's memories" and creating modern graves or family shrines [33]:151. Kirk & Banks [17] bring up the issue of digital persistence in their articulation of a more enduring form of technology-a technology heirloomdesigned with the intent to gain sentimental value as it is passed down and inherited across multiple generations. Foong [8] describes an early values-oriented design process aimed at creating technologies to support end-of-life decision making. Massimi & Charise [23] draw on theoretical perspectives in critical humanism to critique problematic intersections of death and computing, arguing issues of mortality, death and dying ought to be considered throughout the technology design process.

AN APPROACH FOR HCI

These works represent important steps towards addressing issues of death within HCI. Overall, one might say that many of these works tend to focus on the rituals and spaces of death and associated paraphernalia, or they concern themselves with the emotional turmoil that death naturally fosters. These are natural and important areas of interest. However, as we will describe, our field evidence suggests that one of the theoretical emphases mentioned above could be used to help focus attention on other issues, and these might be rich resources for design inspiration. This is the sociological view that distinguishes death per se from *social death* [32]:74. In this view, social death does not have to do with death of the body, but rather with the death of relationships that the deceased one has with other people. This view emphasizes the difference between *death* and *bereavement*.

From this perspective, in interviewing the bereaved, not only did a number of research questions pose themselves (such as: How do relationships between the bereaved and departed loved ones unfold and shift over time? What forms do they take on and how are they managed?), we also had a way of explaining and exploring how people oriented to leaving legacies and memorials about themselves since these acts were not to be understood as only psychological; they were perhaps more significantly social acts. This view also let us approach practices that might have seemed otherwise quite peculiar, even inexplicable. As we shall see, many of those we interviewed thought nothing of using digital means to communicate with the dead. But for them, this was a way of dealing with the social act of death, not its biological manifestation.

FIELD STUDY METHOD

Data for the study was gathered in the following manner. A total of 11 participants (6 men and 5 women) were recruited through advertisements in online bereavement forums, bereavement community email lists, and through a local bereavement counselor. All participants came from the South Eastern region of the United Kingdom. The resulting pool of participants had all experienced bereavement of a close friend, spouse and/or family member at some point within the past 1-6 years. However, all participants had also experienced some form of bereavement that dated earlier than this timeframe. In some cases, participants had experienced multiple losses of loved ones in the past 6 year period. The breakdown was as follows: loss of spouse (P3, P8, P9, P10), close family member (P1, P2, P5, P6, P7, P10) and/or close friend (P2, P4, P6, P7, P11). While experiences of grief resulting from bereavement are complex and can be unpredictable, it is accepted that under normal circumstances, after 6-12 months the average person is able to re-establish a sense physical and emotional equilibrium [20]. Thus, our timeframe was selected to allow participants enough time to re-establish everyday routines and behaviors, while at the same time the experience of bereavement was likely not a distant memory.

It is important to note that recent research has indicated that even under normal circumstances of death, individuals can experience complicated grief disorder (CGD), which can indefinitely prolong experiences of grief, causing imbalances in autobiographical and biographical memory [11]. Participants experiencing CGD could dramatically skew field data. We administered APA questionnaires adapted with metrics proposed by Prigerson et al. [28] to screen participants for CGD and related disorders associated with bereavement prior to conducting interviews to ensure they were not included in our sample.

Our sample also represented people at many different life stages and in many different occupations. The ages of participants were as follows: (mid-20s [P4, P11], mid-30s [P1, P7, P9], mid-40s [P5, P6], mid-50s [P2, P10], mid-60s [P3, P8]). Occupations included a historian, a teacher, a computer security professional, a graphic designer, a civil servant, and a homemaker. No participants reported strong religious or spiritual affiliations. All interviews were conducted in participants' homes and lasted between 1.5 to 2.5 hours. A semi-structured interview approach was used, in which the researcher posed questions designed to prompt discussion rather than obtain specific answers.

Some questions were designed to elicit a range of *retrospective* reflections on their experiences of bereavement and the many issues that came along with it. For example: *How long has it been since you have lost your loved one? How often do you think about him or her? Do you still feel as if they are with you? What did they leave?* Additionally, interview questions aimed to elicit *prospective* speculations on participants' own mortality and how they envisioned that their legacy would live on, which included: *Do you think about how your own legacy will live on? What digital or physical things do you think will come to represent you? What kind of stories do they evoke?*

We also conducted a tour of the home, in which in situ discussions emerged about domestic objects and spaces that during the interview. All interviews were audio taped, which resulted in nearly 18 hours of recordings; photographs were additionally taken to document objects and spaces discussed during the interview. We listened to recordings and transcribed relevant segments, which were organized into themes. Weekly meetings were held with the research team to discuss and corroborate emergent themes; we coded the textual documents using these themes.

In what follows, we present several examples taken from field observations with participants, which we feel capture the core themes emerging across our interviews. Many instances of interactions with digital technologies did emerge in our fieldwork and, indeed, they highlight important issues. However, we also present many instances that owe explicitly to physical objects because, as we will discuss, our observations of how objects were used-and how complications arose—present insights into complications arising with digital objects and how they might need to be treated. Collectively, these data are then used to outline some broader thematic findings, which form the basis for a way of conceptualizing approaches to bereavement in the context of HCI research.

FINDINGS

A consistent theme across our interviews suggested that for participants, despite the occurrence of death, relationships appeared to continue on. Consider the following quote:

"I put his mobile phone in his coffin with him, right next to his ear. He got commiserated with his mobile. I would text 'miss you' or the score when Arsenal won [football] matches or ...something about the happy times we had together. Things like that." (**P9**)

This example reflects the way in which many of our participants talked about the departed in relatively mundane ways, despite the shock and grief of bereavement, and how they also evoked a sense that the death itself was not the sum of what experiencing bereavement entails. Quotes such as this illustrate how the sociological view that death is as much a social act as it is a biological one has much merit. Even in this small sample it starts to become evident that, while these kinds of relationships might unfold gradually and in peculiar ways, they nonetheless seem to persist.

If we can indeed view this example (and others) as a kind of social exchange, this then raises a number of interesting questions. For example, how is it these relationships continue? How does exchange occur and how do they unfold over time? What are their material properties? And, how are relationships performed and enacted? In the following sections, we first describe field evidence suggesting ways in which the dead communicate to the living. We then describe observations of how the living invoke and manage relationships with the departed.

Bequeathing & Inheritance as communication from the dead to the living

A central way in which relationships manifest themselves is through the presence and use of things. We know a commonplace issue of normal social relationships is that when things are exchanged between people, the receiver is implicitly obligated to take care of them. Over time these things come to signify our relationships with each other and, indeed, can mediate the ways in which we remember, recollect and relate to our loved ones [2, 6, 13]. There is a growing literature exploring the process of *passing down* objects as not merely reflecting our relationships with loved ones, but in essence *constituting* them [see 6].

Consistent with this, our field evidence suggested a primary way the departed communicate to the bereaved is through the bequeathing of things, the act of bequeathing having certain sorts of properties. Moreover, it became clear that understanding the ways in which these properties manifest is essential as the process of passing things down invokes the social relationship. However, a key peculiarity of this relationship is that it is *asymmetric*—the bereaved are left to come to grips with the things passed to them, which leaves them, sometimes, to grapple with understanding why they were chosen to be the bearer of particular things. In what follows we will describe themes that emerged during our interviews when exploring our participants' perceptions of digital and physical artifacts bequeathed to them.

Objects of personal significance & historical legacy

Artifacts bequeathed to our participants came in diverse forms and related to their lives in various ways. For example, we observed many instances of objects of personal significance bequeathed to participants that emphasized idiosyncratic aspects of personal relationships with the departed. A small sample of these objects included: an old pipe (P6), collections of figurines (P5), a sword (P1), musical instruments (P7), a pocket watch (P2), For example, P11 describes the personal significance of a bullet bequeathed to him by his late best friend, "We had been in the military together and we'd say that expression 'somewhere out there there's a bullet with my name on it.' The idea [is] if you've got it, it'd be a lucky charm. ...I couldn't make it to the funeral, but a few weeks later his Mum found me and said [he] wanted me to have it. It's a dud bullet that he carved my name onto. ...we had been really close friends in the military and I think it was his way of saying he'll watch over me. ...I'm not sure who I would give this to, you know it has its own meaning for me ... it's a way of keeping him in my heart"

In contrast, *objects of historical legacy* were regarded as heirlooms in the classic sense and ownership had been retained within the family for many decades (in some cases over a century). These objects owed to the broader family line, rather than the life of the loved one that had recently bequeathed them. A brief sample includes: early photos of long deceased family members (**P8**), paintings illustrating family crests (**P3**, **P7**) and genealogical tree (**P7**), marriage certificates (**P1**, **P5**), and family bibles (**P5**, **P10**, **P8**).

However, we also encountered objects bequeathed to participants that *did* owe explicitly to the lives of the departed and were anticipated to achieve historical legacy. A brief sample of these kinds of things included a toolset (P11), several artworks and photographs produced by family members (P10), a World War II era rucksack and various types of furniture crafted by the departed (P5). A particularly compelling and unusual example emerged in P2's discussion of her extensive collection of journals composed by her late grandmother and late mother, which collectively housed entries for nearly every day over the past 3 decades. The scope and content of these entries varied. For example, P2 reflects on how the systematic recordings of mundane information now richly evoke the past, "So many of the diaries just say things like 'Cleaned kitchen. Joy went to rehearsal all day. I did some gardening. Took a nap. ' ... just really dull, ordinary, everyday things [that] seem so boring, but now they're really important ... there's a whole of social history of our lives in there." Extraordinarily, important and tragic events are interwoven with the mundane: "[Later] diaries have the weights of my daughters when they were born ... and then there's my Grandmother's experience of her daughter dying. ...I sometimes feel emotional and sometimes amused and sometimes heartbroken when looking through them, but that's life isn't it." **P2** further reflects on being bequeathed this collection and its potential legacy within her family, "It hasn't been easy having them ...but I think they felt like it was necessary so they can remind us of the dull stuff and the good times and the hard times. ...it's their lives and in a way my life and I think they will become part of my daughters' lives." This statement in part conveys **P2**'s perception of the instructive properties latent in her grandmother's act of bequeathing these collections to her, which when paired with the broader historical factors of the documents, shaped her own interest in passing on these objects to her own daughters.

While only time will tell whether objects like the diary archives will continue to be passed down, what we want to highlight is the nature of exchange. One might say the objects of historical legacy communicated a "changing of the guard" and, with that change, came the obligation to preserve these objects as a matter of preserving one's broader familial heritage. The objects like the diaries do appear to have historical qualities, while also being imbued with deep personal meaning. Beyond the impetus of preservation, the bereaved came to understand this exchange as one with didactic properties: like in the case of **P2's** diaries, through the act of bequeathing these kinds of objects, elder family members communicate lessons about life even after their own death, and potentially for generations to come.

Bequeathing & complications of social relationships

The experience of being bequeathed objects was not always described as positive. In many cases participants conveyed uncomfortable feelings about objects they had been bequeathed, but nonetheless felt obligated to hold onto. These instances represented strange paradoxes in which participants could neither come to terms with objects nor get rid of them; as a result they were often begrudgingly stored away. It is important to note that most of the examples presented were intentionally bequeathed (specific things from a specific person). Obviously there are other ways of inheriting and often people are left with collections or an entire house full of things to sort through (which we highlight where necessary in the examples).

Tensions and miscommunications in the exchange

One key area in which problematic tensions arose had to do with the bereaved being unable to understand why they were selected to be the bearer of particular objects. These things came in various forms, ranging from a single a silver goblet (**P6**) to an entire wardrobe of clothes (**P10**). For example, **P1** describes a rock collection inherited from his grandfather, "My Grandfather collected rocks. I never knew that. I didn't collect [rocks] with him ...but for some reason he wanted me to have it... What do you do with such a thing! ... I keep it under my bed for now." Difficulties also emerged with things specifically bequeathed to participants that made reference to the departed's own death. Considering their nature, these things typically left participants contemplating why they had been selected to be their bearer. Physical things often took the form of final handwritten letters and notes (P1, P7, P9) that, at times, included strange or unexpected requests. These objects evoked strong emotional reactions and were hidden away so as to prevent chance encounters. Several digital examples emerged as well, for example P6 describes being bequeathed digital files detailing a final correspondence, "I received an email from her mother saying Susan wanted me to have [them]. It was the transcript of our last chat and a photo of her. ... They were a very odd reminder of her. I often wondered why she wanted me to have them. ... It was extremely painful every time I would see them because it would remind me of her death and our discussion about it and the hole it left behind. ...I didn't want to lose [the files], so I zipped them with a password. ... every once in a while I would check that they were still there but I wouldn't open them. ... The zip was deliberate, because it's passworded, it takes a conscious effort to find those files and look them up. So I have to want to look at it, I can't just accidentally come across it when I'm going through my holiday snaps or something." In another case, P8 had been left a digital video-will by her late husband, which remained a perplexing object: "I've only seen it twice. It's really uncomfortable for me. ...At the same time I don't have a lot of video of [him]. ...but this recording, it's not just data it's a little part of [him] ...but a strange one, I wouldn't say it's familiar ... by playing it it's almost like recalling the ghost from its rest whether it wants to or not." This digital recording was saved on a compact disc and stored in an envelope within a home office desk drawer, rather than on her hard drive to avoid encounters.

These instances highlight some of the tensions arising from the asymmetric nature of the relationship. Participants felt obligated to hold onto particular objects, despite at times not having a clear understanding of why they did so. The act of bequeathing without explaining obligates the receiver to interact with an object that they cannot rationalize in light of previous patterns of communication, making it unexpected. The ambiguity of this unexpected communication is discomforting and, as our participants described, can result in lingering ambivalent feelings over the intended meaning.

The burden of unfiltered contents and collections

Another significant thematic area has to do with complications arising from participants being unable to manage and make sense of collections of objects bequeathed to them. While the things we encountered took on both physical and digital forms, they were typically groups of objects that contained things of perceived importance as well as miscellany; a sample included: huge archive of paper documents (**P3**), a computer (hard drive) (P7, P11), and mobile phones cluttered with personal and work-related text messages (P4, P8). For example, P10 describes the experience of sorting through a large box her late mother bequeathed to her, "It's full of all kinds [of things] from her life ... photographs from random periods, old train tickets, postcards she never wrote, it's endless really. I feel guilty for not going through it more ...it's a bit overwhelming. ...I'd like to think I will someday, but it will probably sit out in the shed."

P11 describes the experience of dealing with a computer left to him by his late best friend, "[he] wanted me to have it, the files and all. And, it ended up being horrendous. ...I tried to go through the directories to figure out where things roughly were, but it was disorganized and most of the time made no sense. ... I mean I know there's music and photo files, but there are more important things. ... I came across some text files that were sort of unfinished diary entries ... they were pretty personal ... I feel like he would not have wanted anyone else to see them. That was actually unsettling. They were in a folder with his financial expenses and stuff like that. ... I still haven't copied the hard drive so I don't use the computer." P7 had yet to make progress dealing with the computer he inherited from his late friend, "I simply don't know what to do with it. I feel like can't go through it, there could be anything on there. ...but I don't want to wipe it. I considered just pulling out the hard drive and putting it in a box and getting rid of the tower."

These examples highlight the bereaved perceived the collections to be important and felt obligated to deal with them, while simultaneously becoming burdened as they attempted to cohesively come to terms with a wealth of unfiltered information. In **P11** and **P7's** cases, the digital seemed to amplify this problem, causing serious trepidation over whether unexpected encounters might arise in future interactions with their respective hard drives.

Across our interviews participants recognized this very issue as they expressed concerns about steadily growing amounts of digital information they wish to pass on, while having no established mechanism to do so. Similar to the photographs and journals inherited by our participants, they themselves conveyed strong interest in passing several kinds of digital objects, such as personal narratives or diaries (P1, P2, P3, P6, P7, P10, P11), archives of blog posts or other digital content posted on social media websites (P1, P2, P4, P11), digital photos and collections (P1, P2, P4, P6, P7, P11), digital artworks (P6, P11), and digital music collections (P1, P4, P7, P11). For example, P2 compares her own archives of twitter and blog data to her extensive collections of family diaries, "I use twitter in a kind of anecdotal way...to document different things from buying a prop for the next rehearsal to more mundane things I do. ...it's all kind of similar stuff really to my family diaries. ... I hope to pass all [my] twitter and blog posts down and even though some of it's boring, when I look back and read diary entries and find my grandmother saying 'I cleaned the bathroom today' in 20, 30, 40, 50 years time it actually becomes interesting. ...I think there's a lot of potential for my children to look back on this stuff. ...And I'd be delighted if their [children are] reading them. How exactly I'll get that information is another story. Who knows where it really even is!"

Issues also arose over how to pass down digital versions of personal writings; for example P10 remarks: "I definitely would like them to be passed on to my children ... but I don't know if anyone else would understand how to find them [on my hard drive]. My god, they might not understand my system of storing them, because I don't understand it half the time." (P10). P2 and P10's reflections mark open questions over how content stored locally or on the Internet should be treated if they are to be passed down manageably-or at all. After clearing out a near household's worth of objects after the loss of her live-in boyfriend, P4 reflects on the qualities of the physical and digital, "The things we have that remind us of loved ones are the most meaningful and that is because we get rid of all the other semi-meaningful things... on a computer we just tend to create huge amounts of information without sorting it out. That's why [inheriting] digital information is not as meaningful. ... There's [digital] stuff you write that's not important even to you and that wouldn't be important to anyone else, but then once you die things suddenly become more important so things would be kept that really don't need to be kept ... when you have to go through physical things and you don't have enough space for everything you have to hold onto the most valuable and let go of the least. Whereas with digital information you hold onto more and ...you end up with things that don't mean anything." In her reflection, P4 highlights salient issues at hand with respect to bequeathing digital information and, in particular, issues of equitable exchange. In contrast to handing over the entire contents of one's digital life, there may be virtues in passing down key selections-leaving space for recipients to make sense of what is left behind and perhaps inscribe another layer of value onto the legacy it evokes.

In this section we explored how the act of bequeathing artifacts can be seen as a way in which the dead continue to communicate once they are gone. In the next section, we explore how the bereaved invoke and manage these asymmetric relationships.

The Doing of Bereavement

As we begin to understand problems related to bereavement as problems of a social relationship, then how do the living reciprocate the exchange? How do they invoke and manage the relationship and where might tensions arise? How do these performances change over time? In what follows we describe several instances and emergent themes from our field evidence, which suggest various ways through which these exchanges manifest and tensions arose.

Ongoing use of familiar communication systems

One emergent theme can be characterized as participants' continued use of communication systems in order to communicate with loved ones, despite their passing. Our participants described a range of activities, such as sending private messages to a departed loved one's email account (P7), posting messages on social networking website pages dedicated to the departed (P2, P4, P7, P9, P11), and continuing to call and text their loved one's mobile phone (P9). Returning again to the example of P9 who described sending voice and text messages to her departed husband via a mobile buried in his coffin, "... [I did this] so I could still stay in contact with him. I know it sounds daft, but you cling to things like that, feels important to keep in contact." However, when asked if she still tries to contact him, P9 reflected "...not as much. I still do sometimes. I want to hang onto him, but I don't do it as much." In another example, P7 reflects on sending emails to the account of his late close friend after his death, "It didn't feel abnormal at the time, I did it without considering it. ... After a while you feel like you need to move on from [doing it]. ... You don't forget them, it more a moving on if you like." In the context of these examples, one might say the tapering off of use shows the shifting nature of the social relationship. As the amount of email, text messages and calls to the departed falls, participants perhaps began to feel that they had said enough through these familiar forms of communication.

However, in newer communication systems, such as social networking websites, tensions arose that complicated the shifting nature of participants' social relationships with the departed. The core problem across these instances had to do with a lack of established mechanisms to appropriately mark a departed persons' account. For example, over the past 6 years P4 lost a close friend and her boyfriend, both of whom had Facebook accounts. P4 describes tensions of re-encountering their public pages still in operation: "the thing I don't like is that they've died but their profiles pop up at me every now and then and I'm not expecting it and it's a bit of a shock. ...I'd never forget them, but I need them to be somewhere else where I can remember [them] when I want to. ... otherwise it's affecting my life from moving on. I need to be living without being upset about those memories all of the time." Despite the fact that P4's relationship with her deceased loved ones is shifting, tensions arise as she comes across their pages within an online space conceptualized for the living. In the physical realm rituals have occurred to mark their passing, whereas online they persist in a *liminal* space [35]; neither alive nor treated as dead, but rather lingering on in ways not unlike any other user of the system. These tensions are amplified as P4 describes the disturbing instance of receiving a posthumous Facebook message from her departed boyfriend, "someone went onto his account and invited people who were friends with him to an event to remember him, but it was so shocking because it popped up saying 'John invites you to this event' and I just thought 'how

could this be happening' ...it just wasn't right." Instances also emerged that highlighted ways in which the current design of social networking sites resulted in conflicts relating to privacy and appropriateness of action. For example, **P4** discusses the media's use of quotes from a departed friend's social networking page, "Janet died in a bad bus accident abroad. It was all over the news and a reporter used quotes from her Facebook [page]. ...they put quotes of what her boyfriend had last written and what she had last posted. ...it felt like a big invasion of privacy and disrespectful to anyone that did know her." Here, a lack of measures to treat this space differently led to the projection of deeply personal information into the public realm.

Conflicts also emerged from internal actions within Facebook as issues of moral appropriateness of behavior came to the forefront as deceased users' pages became adhoc memorial sites. For example, **P11** describes problems associated with loss of access, "the main problem was that lots of our close friends weren't on Facebook when he died, so they couldn't get added as his 'friends' and see his page you know since no one could get into his account. So it stayed up there and slowly filled up with a lot of random [people leaving] clichéd messages. ...The whole thing ended up feeling insincere." **P11** reflections highlight the issues of entitlement with respect to who ought to be considered 'bereaved', and the socially and morally appropriate actions that ought to follow suit.

What we want to draw attention to in these examples is that, perhaps even beyond accessibility, tensions seem rooted in the inability to treat these online spaces differently when a person has passed away. This is not to suggest that these spaces ought to be deleted, but rather a more sophisticated layer of choice should be considered in the system design— a desire highlighted by several of our participants as they prospectively considered their own online accounts. For example, **P2's** description is an exemplary representation of statements echoed by several of our participants, "In terms of my Facebook page, if something happened to me. I wouldn't want to have any control over it. I would like it to be the decision of the people it affects. ...I would want them [family] to make their own choices. I wouldn't want to dictate what they should or shouldn't keep."

Despite these problems our participants also pointed toward potentially novel aspects of these systems, particularly in instances where new online space was specifically demarcated for remembrance. For example, **P2** compares attending her friend's funeral and later visiting an online memorial website, "*I went to Al's funeral, which was ok but I didn't have a chance to talk to many people. So, it was a shared experience in the sense that we were all there, but there was no kind of interaction for me. But, this [memorial] website was more interactive in the sense that I could write what I wanted to say and other people could read it and I could read what they had to say. ... I found that valuable ...to be aware of all the different dimensions of* *relationships this person had with others.*" This example and others suggest rich opportunities for creating socially constructed narratives reflective of the relationships formed throughout a person's life, if adequate measures are taken to mark and negotiate online space owing to the departed.

Collectively, these examples highlight key complications and opportunities owing to newer technologies with respect to the appropriate treatment of changing social circumstances. Next, we expand on how participants manage shifting social relationships on their own terms.

Rituals and techniques for managing the relationship

The diverse ways in which our participants managed relationships with departed loved ones was largely reflected in the management of physical and digital artifacts. As noted, we observed a range of digital and physical things that caused troubling moments when encountered. Whether through encrypting digital files deep within the directory structure (P6), removing digital files from an often used hard drive and storing them on external media elsewhere in the home (P8), or filing funeral paraphernalia in the confines of desk drawers (P3, P4, P7, P10, P11), great care was taken to simultaneously preserve and deeply hideaway these things. For example, P6 reflects his encrypted files, "It's the technological equivalent to putting them in the back cupboard. You put [them] away because you need to ...you have to ...you know they're there ...but they get covered up ...life keeps moving on." As illustrated, these objects are visceral markers of the departed's death; they are hidden and sedimented as a way of moving past the biological moment of death, signifying an important act in the transition of the relationship.

Our participants also reported diverse uses of artifacts in ritualized ways to engage in periods of reflection on the departed. A key quality of these artifacts was their ability to be invoked and then be put away or simply fade into the background. A sample of non-digital artifacts included candles (P1), a windup clock (P5), photo album (P3, P9, **P10**, **P11**), and trinkets held in a jacket that belonged to the departed (P2). A particularly compelling example was a statue sculpted by **P3's** late wife, which was now on display on his mantelpiece and beginning to show early signs of decomposition, "it was my decision to move it out in the garden for a while, which means that it will rot ... [it is] about finding its final resting place." One might say P3's management of the statue evocatively reflects the shifting nature of his relationship with his wife. P3 describes the statue's peripheral nature, "so I would say that I still have it around because it brings up thoughts about my wife, but it's not overwhelming. I can see it and think about her or just as easily not do so." We also encountered several participants (P4, P8, P9, P11) in possession of digital archives of text messages received prior to a loved one's passing. P8 reported possessing over 200 text messages sent from her departed husband, which highlighted many momentous and mundane aspects of their relationship.

These messages are saved on a flash memory card, which is stored separately in an ornate box only taken out during the ritual. "Now and then I bring them out. ...[I] see things he's written to me, like 'I hope today went ok' and I think about why he sent that and what was going on then. ...I know I can always find them, but it's also important I can put them away." P8's & P3's reflections are exemplary samples of participant responses in their emphasis on the integral role objects play in enabling the bereaved to manage aspects of their relationship with the departed. Once the ritual comes to a close, aspects of the relationship too can be put away by the bereaved on their own terms.

DISCUSSION AND IMPLICATIONS

It is clear that bereavement and the many issues that come with it are complex. A key contribution of our study is to show how we can reach a better understanding of the experience of bereavement as being strongly related to the experience—and problems—of managing a shifting, asymmetric social relationship. Our approach provides a way of understanding how the bereaved are communicated with and how aspects of these relationships continue to persist, while other are put to rest. In this, we have discussed the ways in which, physical, and increasingly digital, objects play significant roles in these processes.

What then can we say about the design of digital technologies with this deeper understanding in mind? On the one hand, we have shown how digital systems raise issues of ownership, access and persistence, which together create new issues and complications for the bereaved. Equally, the fact that people can inherit vast quantities of unfiltered, unmanaged data makes the inheritance of digital materials different from the inheritance of physical objects. With respect to all of these issues, the bereaved attempt to reconcile with the social relationships they are trying to manage. At the same time, we have seen how digital technologies open up new possibilities for continuing these relationships, for engaging in rituals, for creating new kinds of treasured content, and for celebrating the lives of the people no longer with us.

Considering the paucity of HCI research in this area to date, we propose two key concerns aimed at sensitizing the design space and inspiring thought on how future technologies could better take into account the range of experiences and social processes that unfold when bereavement occurs. The first concern is the moral endurance of an archive-the importance of designing technologies that support more nuanced practices of owning, storing and managing materials, in ways that enable appropriate relinquishment beyond the life of the owner. What we aim to emphasize here is not the explicit endurance of archive materials per se, rather the delicate social arrangements that enable the custodian of the archive to allow some elements to dissipate from memory, while others retain a longer lasting valence through attention and care-even if that attention and care has no material

properties and is merely social acts of looking and holding and looking again. A second interest is *richer forms of contextualization*—the capacity to implicitly or explicitly ascribe explanation or descriptive contextual attributes to convey why an object is significant to the owner and why it may be of significance to the receiver(s). In what follows we draw on these concerns to outline several considerations arising from this study suggesting areas for future research.

Designing for deep storage, sedimentation & graceful decay— Despite some objects' troubling qualities, maintaining ownership was a highly significant part of putting aspects of the relationship to rest. While P6 reported encrypting digital content to avoid accidental encounters. the knowledge of how to successfully navigate this process could be beyond an average users' skill set. Beyond merely incorporating multiple points of storage, these concerns suggest deeper and more nuanced levels of choice be designed into interactive systems that enable people to demarcate particular content for deep storage and explicitly treat it differently from other data stored within the system. While issues of privacy and security clearly underlie this area, it equally seems important to consider participants' desires to know where these objects are, be assured of their safety, and perhaps even convey temporal sedimentation. More broadly, P3's treatment of his late wife's statue highlighted decay as an evocative form of remembrance. How could systems be designed in ways that enable users to allocate groups of content for deep storage, while peripherally expressing to owners the safety of these collections? What roles might metaphors of sedimentation and graceful decay play in inspiring richer experiences surrounding deep storage artifacts as they are held onto over longer periods of time? In what ways should deep storage archives endure when owners themselves pass away? Some research in HCI has explored the importance of personal [16] and home [18] archiving practices, which could be leveraged in future work, as could the notion of digital material histories [25] and the use patina as a metaphor in software design [15].

Clarifying exchanges through contextualizing content— Major tensions arose with respect to participants being unable to make sense of why they had received particular objects. These concerns appeared amplified in the digital where few tools exist to ascribe rich information that might help the bereaved understand the value assigned to them by the departed and why they were selected to be the receiver. How might the implicit or explicit ascription of personal and contextual information to digital objects help demarcate the significant from the trivial within vast personal digital archives? In what ways could developing tools to expand expressive potential in interactive technologies enable users to highlight unique personal or familial bonds characterizing social exchanges such as bequeathing and inheritance? Several researchers, such as Frohlich et al. [9] and Petrelli et al. [26], have explored the potentials of using interactive technology to attach narratives to physical and digital objects supporting sentimental value; Petrelli et al. [27] have since expanded on the virtues of metadata in this context. This collective work could be leveraged to investigate relationships with significant digital objects and the role new tools might play in encouraging people to engage with them in more expressive and, potentially, enduring ways. We imagine this space could be extended to explore how collaborative interactions might encourage reminisce among loved ones, and how these stories might be passed down and added to from generation to generation.

Emphasizing reciprocity & engagement-Despite the potential to pass on massive personal and familial archives of information, participant reflections on distinctions between the digital and the physical suggested there may be virtues in enabling people to carefully craft and deliver smaller selections of digital materials. In this way, a space could be opened that invites the receiver to make sense of these materials through interacting with-and perhaps adding to-them, which might evoke the relationship in richer and more satisfying ways. We observed the leaving behind of material and digital legacies as well as the continued used of familiar communication systems as significant social acts. How then might we design for reciprocity in more sensitive and meaningful ways? Similar to other recent works [26-27, 31], this implication seems to question a life-logging perspective. We think it germane to emphasize engaging interactions with a distilled set of artifacts, opposed to passive maintenance of a life's record.

Marking shifting status and state—We found complications of privacy, social entitlement, and even false re-animation of the departed emerged, all of which owed to a lack of established mechanisms to treat online spaces of the departed differently. How might interactive systems be designed to more easily enable designated loved ones to push the webpage of the departed into a condition signifying their change of state and status? As P2 saliently highlighted, online spaces could be leveraged to create a unique platform for personal and public expression related to the departed's life. These reflections might collectively construct an enduring social record of a person's life, perhaps even evolving with new contributions over time. To what extent could tools for richer contextualization be integrated in online systems or digital appliances? What design decisions might lead to evocative socially constructed portraits of a person's life, and in what digital and physical forms should they become instantiated and passed on? Early interest is emerging in the HCI community [e.g. 8, 17, 23, 34], which may be built on as issues related to digital persistence continue to emerge.

CONCLUSION

We have developed and articulated a lens on bereavement against a backdrop of social relationships. From this purview, we have unpacked issues arising in participants' bereavement experiences. We observed that relationships with the departed persist in diverse ways and the bereaved in turn attempt to make sense of and manage the transitory nature of these relationships. Moral endurance of an archive and richer forms of contextualization were proposed as sensitizing concerns to inspire the design of future technologies that (i) support people in the selfdetermined management of shifting, asymmetric relationships and (ii) give people tools to deal with digital materials in ways which invoke the intimate bonds of social relationships, and which promote reflection on their own legacy. While a limitation of our study is that our participants did not report religious affiliations, research on spirituality and computing [e.g. 1, 36] suggests a key area that can be built on as techno-spiritual and death-related practices increasingly converge. Ultimately, we hope this study will inspire future research into how technologies might be designed to better support people as they face choices of passing on or putting to rest social relationships, now and well into the future.

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