Technology and the Human Lifespan: Learning from the Bereaved

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Jeanine* was a 32-year-old project manager, married and pregnant with her first child. She regularly posted Facebook updates about her pregnancy to share her excitement with friends and family, often with accompanying cell phone photos of her growing belly. After nine months of anticipation and a smooth delivery, she gave birth to a baby boy. Jeanine and her husband circulated a birth announcement by email and Facebook. After a few days, however, the doctors informed her that due to a rare disease, her newborn son was dying. Only 36 hours later, her son passed away. Heartbroken and devastated, Jeanine returned home to find an empty house and hundreds of text messages, voice mails, and emails—mixed messages of congratulations and condolences. Unable to handle making phone calls, she sat down to write a single mass email to her friends, family, and co-workers about her tragic loss—what she called "the weirdest email of my life." (*All names in this article have been changed.)

As personal technologies evolve, we continually have new opportunities to capture and share our lives. Mobile phones, Facebook, and Twitter have joined older forms of communication to form a varied technological landscape. As design-ers we often imagine "blue sky" scenarios, in which the envisioned user's life is stable and suffused with health and happiness: a kind of designer's optimism. But as the story above illustrates, these technologies remain in play during life's tragedies and across all parts of the lifespan. As technology becomes more personal and intimate, there is a need for increased acknowl-edgement and accommodation of the ups and downs that occur from birth to death.

As a key example, HCI research-ers and designers have recently begun to tackle the difficult issue of death. A subject often reluc-tantly discussed and hidden away in Western cultures, the end of life nonetheless is in part shaped by interactive technologies in unex-pected ways. Understanding all of the phenomena surrounding technology use at the end of life is a daunting task, but HCI research-ers are beginning to address some of the issues. Odom et al., for instance, report on ethnographic work focusing on how objects medi-ate the relationships between the living and the dead, and how what we design can inform and enrich social processes [1]. Brubaker and Vertesi explore the persistence of digital identities beyond death by investigating the MySpace pages of deceased users, finding signifi-cant patterns in how MySpace is used over time by the bereaved [2]. Researchers working in this space also came together at CHI 2010 in order to share early work and identify potential areas for future investigation [3], while entrepreneurs have organized an annual Digital Death Day (www. digitaldeathday.com) to bring together practitioners develop-ing software concerning death.

In this article, we briefly describe some of the work that we have con-ducted in this area, with a focus on sharing the stories of the bereaved and their experiences with technol-ogy. In so doing, we hope to illus-trate the importance of thinking about the entirety of the human lifespan when designing personal technologies.

Exploring Technology Practices by the Bereaved
In order to obtain a better under-standing of how the bereaved dealt with personal technologies follow-ing their loss, we began by conduct-ing a survey and interview study

[4]. The study asked questions along three major dimensions. First, how are personal technologies inherited? What properties make technologies possible (or impossible) to inherit? Second, how do the bereaved use technology to remember their loved ones? Finally, how do the bereaved shift their technology use as a result of the death? By asking these questions, we identified ways in which designers could begin to look into bereavement more deeply. Here, we retell some of the stories that participants shared with us and point out how they illustrate the confrontation and comforting role of technology.

Inheriting Technology:
Ambiguity and Uncertainty
In many cases, the transfer of property from the deceased to the living is determined by the wishes of the deceased and communicated by a will or by cultural traditions. Yet while digitalization offers convenient new ways to share information, it muddles the inheritance process in critical ways. First and foremost, 79 percent of our respondents noted even though they had the experience of dealing with a deceased loved one's digital estate, they had not given any thought to how to plan for the distribution of their own digital estate. Only 13 percent of respondents had actually made plans for their digital estate by, for instance, updating their will with instructions for how to access and distribute personal files. The remaining 8 percent saw their digital estate as none of their concern; they saw the task of distributing personal data after their death as someone else's problem. This identifies a growing need for better processes to distribute data following death. Indeed, Web services such as Legacy Locker (www.legacylocker.

com) offer customers the opportunity to upload their data, passwords, and other important information to their servers with the promise to distribute this information to inheritors following the user's death. However, it remains unclear whether sites like these will still be operating over the years and whether they are a reliable place to safeguard such important information.

While such services are interesting first efforts in this space, inheriting digital information differs from inheriting physical items in other, more nuanced ways, such as our ability to identify and claim digital assets. In our study, Margaret described how, as her mother's health deteriorated in old age, she and her siblings began to claim precious items in her mother's house: "She was a good artist, and they are just small paintings she did…all of them have been scooped up. Someone's got their name on the back of it." As this quote illustrates, there is a gradual social process wherein loved ones survey the estate before distributing it; digital assets, however, do not readily lend themselves to this. An inheritor cannot easily peer onto the hard drive or email account of a loved one, and cannot be sure whether they have taken stock of the entire digital estate to be inherited.

Even if we are aware of all of the potential files to be inherited, it is difficult to determine what is important to preserve, what should be examined more closely, and what can be safely deleted. In our interviews, Lisa described how difficult it was to maintain her mother's privacy as she went through her hard drive: "There are close things that are awkward and odd to see as you go through, and you don't know if there is something later that you

should see. It's tough. At least with [physical] diaries, you can recognize that they are a diary, and act accordingly." As we develop more forms of digital representation, it will become necessary to develop new social processes concerning inheritance and new software solutions that make these processes possible and visible.

Having a "Poltergeist" Moment

Betty, a woman in her late 20s, lost her mother—a busy academic administrator—to cancer. Several months after her mother died, Betty received a phone call. When she checked the caller ID, the name that appeared was her mother's. She relates her reaction: "I got a call a couple of months from her office after she died, but it was her phone number, and I thought I was having some surreal poltergeist kind of moment…I recognized she'd passed away and thought, 'My mom's calling me,' and I froze and freaked out. I remember that it terrified me, but how excited I was at the potential to talk to her."

This story demonstrates the potential for technology to act as a stand-in for the living, often resulting in confrontational situations. Another key example mentioned in our study is how Facebook sometimes suggests users reconnect with a deceased friend. In both of these cases, a highly personalized technology (a mobile phone number, a Facebook page) plays a role in the "reanimation" of the dead in order to give the impression that the owner is still alive. As designers of interactive technologies, we must be acutely aware of how software personalization and digital identities persist beyond the natural life of the user in order to avoid such strange interactions.

Considerations for Designers

Following our initial examination of some of the ways in which bereaved people deal with technology, we have begun to focus our efforts on understanding bereavement more thoroughly, and understanding how technology designers might play a role in comforting and supporting the bereaved. To that end, we have engaged in three focus groups with grieving parents at community support group centers. We have also spoken with professionals who deal with the bereaved on a daily basis, including psychologists, psychiatrists, nurses, social workers, clergy, and so on. Based on a combined understanding of both the bereaved parents' perspective and the professional community, we have come to a number of guidelines that may be helpful to designers [5]. We share some of them here.

Grief is not a problem to be solved. Many of our informants remarked on the common Western misconception that grief is a medical condition with clear stages and an end. Even the most well-intentioned consoler may look forward to a day where the grief is over, and the bereaved return to "normal." Our participants decried this kind of characterization, noting that they never really stop grieving the loss of their children. Similarly, bereavement professionals have debunked the "stage theory" (denial, anger, bargaining, depression, and acceptance) of grief suggested by Kübler-Ross [6]. Rather, bereavement professionals and the bereaved alike see grief as a lifelong shift in worldview without "closure." For designers, this means we must avoid the mistake of trying to cure grief by offering the bereaved a prescriptive solution for their emotional state (e.g., an online treatment program with the promise of recovery).

Communication is complicated. In many cultures, the days following a death involve a large number of people. Friends and family arrive to console one another, and burial and memorial services are organized in coordination with local businesses and religious organizations. While it is true that the bereaved often find comfort and strength from their interactions with other people, there are many times where isolation, disconnection, and silence are preferred. Many of the bereaved parents we spoke to remarked on their need to "hide out" at home, shut off their phones and computers, and avoid contact with people they knew. Indeed, family and friends were often of little help because they could not relate to the experience of losing a child. Family and friends were instead valued for their material and functional support roles—doing chores, organizing affairs, or offering food. The parents we spoke with found the most support from other people who had suffered a similar loss—sharing their stories, validating their feelings, and understanding that their reaction was normal. For designers, we must recognize that technology-based communication will be purposefully avoided at times. Further, when communication does occur, the most meaningful interaction can sometimes occur with people who are not friends and family; we must support multiple social circles and perhaps connect the bereaved to one another.

What interaction might look like. In our conversations with the parents and with professionals, we sought to understand what designers might choose to focus on that would be helpful to the bereaved. One of the most important activities that technology can support is storytelling. Stories help the bereaved to accept and feel the reality of the loss. They allow people to relate to one another through shared circumstances, and offer ways to explore what-if scenarios. The HCI community has examined systems of storytelling for a number of years, and there are significant ways in which technology can be applied to help the bereaved craft, share, and read stories.

A second way in which interaction designers might support the bereaved is by engaging them in meaningful activities concerning their loss. Many participants and professionals describe the need to externalize grief. This can take many forms: Participants described creating memory books, planting trees, renovating the house, painting, sculpting, quilting, establishing a charity, and so on. Technology designers can support the bereaved by offering an environment for them to create meaningful external artifacts. Further, these processes can be linked to form communities of loss. A bereaved person might create a Web memorial and then join it with other memorials along a specific theme (e.g., cancer, drunk driving, or religious affiliation). The activity then not only comforts the individual but also may also help to comfort a larger community.

Conclusion

In our work to date, we have begun to understand how we might design technologies that support the bereaved and acknowledge death as part of the design intention—a process we call "thanatosensitive design." We have shown how personal technologies can bring us comfort at the end of life but at the same time become problematic or confrontational entities. By studying the bereaved, we open up the discussion of what it means for technology to be used across and beyond the user's lifespan.

Current work on HCI at the end of life is a first step toward acknowledging and engaging the multitudinous ways in which technology affects all parts of our lives—the good, the bad, the expected, and the unexpected. Similarly, it draws attention to the various stages of life—from birth to death—and the ways that personal technologies are now often incongruent with a developmental perspective. While technology does advance rapidly, we must also begin to consider how we can create personal technologies that gracefully grow—and die—with us.

ENDNOTES

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[6] Kübler-Ross, E. *On Death and Dying.* Routledge, London, 1969.

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