Matters of Life and Death: Locating the End of Life in Lifespan-Oriented HCI Research

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ABSTRACT
Examining developmental periods of the human lifespan has been a useful tradition for focusing HCI research (*e.g.,* technologies for children or the elderly). In this paper, we identify the *end of life* as another period of the human lifespan that merits consideration by technology designers and researchers. This paper maps out current and future research in HCI at the end of life by first describing how this area raises questions concerning materiality and artifacts, social identities, temporality and methodologies. Having provided a description of the richness of this area, we then frame it against HCI traditions and practices in an orientation we term the *lifespan-oriented approach.* This paper maps early efforts in end of life research, structures and suggests areas for continued work, and situates the end of life among existing areas of HCI research.

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Death, dying, bereavement, lifespan, materiality, temporality, storytelling, ethics.

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General Terms
Design, Human Factors.

INTRODUCTION
Technology is increasingly part of the way we experience death, but to date, the topic has not been well-established in the HCI literature, even though the end of life acts as a crucible, transforming longstanding HCI issues in novel and interesting ways. While the HCI community has not addressed this topic in depth, there are numerous software companies, end of life service providers, and popular press articles that demonstrate the various ways that technology interacts with the end of life.

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Software developers and end users alike increasingly apply technology to meet end of life needs. Technology helps us remember the dead through social networking and photo sharing sites such as Facebook and Flickr, and through a staggering array of memorial websites, such as Forever Missed [1]. Funeral homes and cemeteries augment traditional ceremonies with virtual condolence books and PowerPoint slide decks of photos of the deceased (see one such example at Ward Funeral Homes [2]). Technology helps us tell life stories in the face of fatal illness, and draws us closer to distant friends and family [24]. It guides hospital clinicians in drawing out advance directives [27], and enables therapists to counsel the bereaved through the Internet [26]. Sites like My Wonderful Life [3] can even provide preemptive options for planning your own funeral.

Concurrently, technology can complicate our experience of death. We may struggle to develop a will that accurately reflects the ever-shifting state of our digital assets (or use web sites like Entrustet [4] or Legacy Locker [5] to make this process easier). We may question why we were chosen to inherit certain digital possessions, reacting with confusion or resentment [53]. We may receive lingering misattributed emails or phone calls from the now deceased [46], or find disturbing system-generated recommendations to "reconnect" with dead friends on Facebook [67].

What remains certain is that technology is intersecting with the end of life in new and unexpected ways. As we have outlined above, it has the capability to ease suffering, or to disturb our sensitivities through its strangeness and irreverence. All the while, people are appropriating a wide range of publicly-available technologies – from blogs to electronic photo frames – to react to the eventuality, actuality, and aftermath of death.

Collectively, these trends help illustrate that issues related to the end of life are increasingly relevant, yet generally overlooked within the HCI community. The contributions of this paper are twofold. We begin by showing how HCI research addressing the end of life shares a *lifespan-oriented* approach that, in some ways, is similar – and can be productively linked – to work with the elderly or with children. Further, this approach precipitates a mapping of relevant stakeholder groups. Having framed the end of life among the lifespan-oriented approach in HCI research, we

then set out to provide a critical review of research at the end of life to date. We begin by arguing that the end of life has a crucible effect – thinking about technology as applied to this domain adds new depth to existing HCI issues and introduces new directions for research. We map out thematic areas that can be useful tools for framing past, current, and future HCI research in this domain. We then conclude with a forward-looking discussion about opportunities for the HCI community to impact and potentially improve the complications associated with one's death and the social processes that unfold after a death occurs for all stakeholders involved.

THE END OF LIFE AS LIFESPAN-ORIENTED HCI

One way in which HCI research is commonly motivated and presented is through studying technology usage by people in a particular period of the human lifespan. For example, the interaction between children and computers is very different from the interaction that occurs when senior citizens are the primary user group. This approach to research, which we term *lifespan-oriented,* has proven to be beneficial to the HCI community by helping to identify prominent issues associated with a period in the lifespan. Childhood, for example, inspired and informed the HCI community regarding playfulness, creativity, and imagination [25, 28, 40]. Similarly, work with senior citizens foregrounds issues of accessibility [51], privacy and autonomy [15], health [12, 56], and cognitive decline [21]. Focusing on one part of the human lifespan at a time not only improves the quality of interaction for those in the developmental period in question, but as a secondary benefit, provides portable sets of design implications, artifacts, and methods that can improve interaction for users of all ages. It further helps researchers working in a particular space to share results, coordinate research efforts, and identify important problem spaces. By contextualizing a research project within a particular period of individual development, researchers may be better able to generalize to other people also at that stage of life. It holds fixed or mitigates differences in variables such as age, cognitive/physical capabilities, and interpersonal relationships. Applications targeted at users in a particular developmental stage may see higher rates of adoption due to a better fit with the desires and goals associated with that stage (*e.g.,* applications for teenagers [64]).

The lifespan has traditionally been taken up in HCI in an individual developmental context (with the notable exception of multi-lifespan design, which refers to systems applied over multiple generations to enduring human problems such as genocide [30]). While HCI has inherited many of the methodological and theoretical underpinnings of cognitive psychology [19], developmental psychology has also influenced a number of HCI research studies [69]. The developmental perspective makes explicit the idea that the passage of time influences the ways in which we think, feel, and use technology "from conception to death" [10]; this contrasts dominant user models and HCI discourse wherein the "user" is presumed to be static and eternal.

While the developmental orientation has had a reasonably well-accepted presence in the HCI literature, the end of life has remained conspicuously unexplored. Indeed, developmental psychologists have long considered the (natural) end of life to be a separate period of the lifespan from other parts of older adulthood [11]. If we think about an individual's lifespan in relation to his or her own death, then there are four distinct stakeholder groups through which he or she passes, starting from a vague awareness of one's own mortality, through to one's own death. The developmental perspective suggests an awareness of past and future stages of life as part of every other stage. Additionally, throughout the lifespan, the individual will be bereaved as family and friends die. In what follows, we explore each of these four stakeholder groups in turn.

The Living: Issues of mortality and death have been fundamental areas of concern across the humanities and social sciences for centuries [58]. While these discussions are well beyond the scope of this paper, one thing that is certain is that mortality is a key component of how people perceive themselves and how they choose to live their lives. While issues of what it means to be "mortal" are complicated, to say the least, there are a set of more tractable issues related to this condition that may very well have a computational or interactional component. One example is the issue of estate planning – software currently exists that is intended to help the user determine how to distribute assets upon his or her death. This activity (drafting a will) is commonly undertaken in middle-age, or when a significant life event (such as the birth of a child) prevails upon the individual that these plans must be made. In general, however, the issues of mortality are confined and rarely addressed publically [39, 63].

Dying: Individuals who have a clear prognosis or circumstances that indicate an imminent death have a unique set of concerns. With a limited timeframe for action bearing down upon the individual, spiritual and interpersonal issues frequently rise to the fore, such as simplifying daily activity, asking for forgiveness, waiting for forgiveness, and relinquishing dreams [35, 44]. The dying may also possess a limited ability to interact with other people or technologies due to unmet biological and emotional needs, such as: pain, cleanliness, problems breathing, fatigue, depression, anxiety, and loneliness [57]. These conditions may be exacerbated by psychosocial or environmental factors, such as being isolated from friends and family as a result of hospitalization or confinement to a retirement home [23]. How the dying appropriate technology is ill-understood, but it appears communication habits could be potentially influenced, and better supported, through technological means.

Dead: Interest in "life after death" has been a foundational concept of human history and meaning-making (*e.g.,*

Lazarus and Jesus's rebirth in the Bible, the Phoenix in ancient mythologies). Personal technologies that are now widely available make it possible for actions to be effected beyond the biological lifespan – for example, automation and recording systems may make the possibility of "telepresence after death" a reality [45]. The concerns and wishes of the deceased as a conceptual category may also be worth consideration for determining how data should be stored or destroyed, and how user profiles might change following death (*e.g.,* Facebook) [67]; however very few examples exist to date that take into account the needs and values of users beyond their own lives. The deceased are implicated as a stakeholder group insofar that the living use technology to continue to remember (or forget) them.

Bereaved: A final stakeholder group that also receives considerable attention in the death and dying literature is the bereaved. Loosely defined as the social network of people connected to someone who has died, bereavement research commonly focuses on understanding grief reactions, mourning, remembrance, and inheritance [62, 66]. This stakeholder group differs from the previous three because it is not an explicit developmental period of the lifespan, but rather a reaction to the death of a loved one. Further, the needs of the bereaved are more dynamic than those of the dying or dead; system usage and user needs change as time passes following a death [66]. Another differentiating feature is the possible inclusion of complicated or prolonged grief as a diagnosis in the upcoming fifth edition of the Diagnostic and Statistical Manual of Mental Disorders, recasting some grief reactions a mental health problem to be addressed, managed, and treated [55]. These issues, among others, are emerging in the HCI literature through qualitative studies involving bereaved people [46, 53].

Clearly there are other stakeholder groups that could be considered regarding system use at the end of life, such as funeral directors, clergy, medical staff, and so forth. However, these four categories emerge as the most salient stakeholders to immediately focus on for purposes of designing technology. Having provided this thumbnail of the primary stakeholder groups, we now trace the rise of end of life research in other disciplines, and subsequently map current and future opportunities for HCI research to productively engage end of life issues and stakeholders.

MAPPING OUT HCI RESEARCH IN THE END OF LIFE

Prior to describing HCI's interest in the end of life, we first briefly trace recent events in *thanatology* – the multidisciplinary study of death. Since the mid-20th century, there has been increasing interest in the end of life in medicine, social work, and psychology. Elizabeth Kübler-Ross's *On Death and Dying*, originally published in 1969, is often credited with bringing to public attention the unique experiences of dying people (and with it, the since-debunked "stage model" of denial, anger, bargaining, depression, and acceptance) [43]. Critical ethnographic analyses of hospitals and how death and dying are socially structured also appeared at this time, with notable studies from Sudnow [63] and Glaser and Strauss [34] casting light on how institutions manifested the "death-denying" tone of Western culture [39]. Fueled in part by these critical accounts, the hospice, palliative care, and supportive care movements took root and advocated dignity and compassion for those with long-term and fatal illnesses.

Despite the amount of public and academic interest in the end of life, researchers generally find it difficult to clearly articulate what is meant by "end of life," and when someone can be characterized as entering this part of their lifespan. For purposes of this paper, we refer to the end of life in the developmental, individualist sense outlined above: it is the period of a person's lifespan where there is an irreversible, downward progression in health and where biological death is imminent. While there are many problems with such a definition (it remains slippery like "childhood" or "old age"), we find that this term offers a useful conceptual handle for discussion.

The current state of research in this field is both behind the curve in terms of understanding how current technologies are appropriated, and simultaneously forward-looking insofar that new systems are being developed that interact with concepts in this space. These systems often draw upon existing topics in the HCI literature and re-apply them in this unique domain. In that sense, the end of life acts as a *crucible*: it draws into focus particular areas of HCI by destabilizing the interactional context (*e.g.*, how might a system respond if its intended user is dead?). It provides an arena in which long-accepted premises of interaction are no longer ensured, and opens up opportunities for research and design that meet human needs across the lifespan.

To demonstrate just how the end of life acts as a crucible, we map current research activities in this space, and show how they raise salient research questions and indicate potential design interventions. This mapping stems from our fieldwork and design work occurring in and across Europe, Canada, and the United States over the past 3-5 years, along with our consultation with researchers in the HCI community engaged with this topic at academic workshops and conferences [41, 48].

The mapping presented consists of four major themes that have been continual discussion topics at these workshops and conferences: materiality, identity, temporality, and research methods and ethics. We find these four themes compelling because they are so consistently found in various research projects; at the same time, they are different enough from one another to provide a conceptual indication of what HCI research at the end of life entails. Of course, there is some overlap between these themes; however, thinking about them separately presents a productive way to articulate key issues. Following this mapping, we expand on their collective implications for future HCI research and practice at the end of life.

Materiality and artifacts

A key way social relationships manifest themselves is through the presence and use of things; people commonly pass down key artifacts they deem reflective of their own lives as well as those constituting social bonds with friends and family [29]. Artifacts represent key elements of their identity as well as familial history and heritage. The study of the role of artifacts before, during and after bereavement is not new and has been a classic area of inquiry across the social sciences and humanities (*e.g.,* [37, 49]). This extensive body of work can serve as a productive platform to develop sensibilities concerning how technology may shape processes through which users pass on their things.

Changing material properties

A key issue in general for the HCI community is the changing materiality of the things that we own and increasingly interact with [38]. As people continue to acquire, create, and archive collections of digital artifacts similarly representative of their lives and those of their friends and family, a range of new issues are emerging. It is clear many artifacts traditionally physical are also becoming virtual. For example, photographs previously taken in small numbers and printed on paper, are now taken in large numbers, some of which may never be physically reproduced (perhaps even viewed) during the original owners' lifetime. While there are well-established processes for dealing with—and inevitably dispossessing—the wealth of material artifacts often left behind in the wake of a loved one's death, it remains unclear how these processes will unfold in the context of the digital. For example, prior research [46, 53] has described a range of troubling experiences that occurred for the bereaved when they inherited computers full of their departed loved ones' personal files. These cases highlighted how complications unfolded as the bereaved were burdened by a sense of obligation to sort through archives of personal files, while having no established mechanism to do so. It was frequently the case that they hid these machines out of sight; simultaneously being unable able to dispose of them or effectively investigate their contents. In general, idiosyncratic file naming and structuring conventions, among other things, complicated these participants' efforts to construct a cohesive sense of what they had been left behind. How might new tools be designed to enable users to better contextualize their digital belongings for particular groups and pass them to receivers in more elegant and meaningful ways? Similar to other recent works questioning a life-logging perspective (*e.g.,* [61]), there seem to be significant opportunities for future research to investigate how interactive systems might be designed to enable people to craft and bequeath distilled sets of digital objects meaningful to particular individuals or groups. Nonetheless, while the quantity of digital content can be burdensome, it may also open new opportunities for reminiscence and reflection. For example, the artful re-presentation of large stores of digital photos might create new relationships to content as rich experiences archived within them are experienced in spontaneous and serendipitous ways.

Additionally, key issues such as materialization and presence must be taken into account when considering how digital elements of departed loved ones might be leveraged to create assemblies embodying significant aspects of their lives or moments shared with them. Physical artifacts are often put on display in the home to honor a person's life in meaningful and persistent ways. Digital objects and collections clearly do not have the same enduring presence, but nonetheless could provide dynamic and expressive tributes. Moreover, a key quality of digital artifacts is their ability to be inscribed with diverse types of metadata, which could provide rich opportunities to thoughtfully contextualize collections of virtual possessions passed down as well as help alleviate miscommunications in exchanges of bequeathed items. Previous research [31] has illustrated the value of converging streams of commonly available online content, such as weather information, historical events, etc., onto digital artifacts to evoke meaningful experiences. We imagine both personally ascribed layers of metadata could be combined with various 'ready-made' streams to contextualize artifacts being passed down in much more fluid and rich ways; indeed, these new interactive assemblies may also serve as rich resources for reflection on and commemoration of the lives of departed loved ones.

Very recent work [65] is emerging that explores how new form factors of interactive technologies might support ritual practices of remembrance in the home. However, to date little is known about how these new types of digital artifacts might fit within actual domestic environments and intimate places. Moreover, the processes that unfold after a death are extremely heterogonous and unpredictable, making it difficult to anticipate how a user would react to these designs even years into the future. Could these kinds of technologies serve as evocative portraits of our departed loved one's lives? Or, would they become persistent, perhaps painful, reminders of those no longer with us, leaving little space to romanticize past experiences shared with them? Clearly more research is needed to understand the social, cultural and ethical boundaries of appropriateness and acceptability these emerging technologies and systems as we consider their potential place alongside us in our own lives, and perhaps in those of future generations beyond us.

Identity

In addition to reconciling the local storage and material presence of digital elements owing to departed loved one's lives, new complications are arising as practices of storing, presenting, and sharing digital artifacts expand to online places and social networking systems, such as Facebook. In what follows, we describe a small set of critical themes related to identity in this context, which are accompanied by opportunities for future HCI research.

As people expand their practices of storing and presenting digital objects (*e.g.,* photos) from local computers to personal and shared online places, new, often valued, opportunities have emerged to support and strengthen social connection among friends and loved ones. However, along with these shifts, several new unanticipated issues have resulted in complications for stakeholders as a departed loved one's social networking profile(s) – and their attendant content(s) – continue to persist after she or he has passed away. For example, prior research with bereaved participants [46, 53] has detailed how the persistence of deceased users' public online profiles led to them being transformed into ad hoc memorial sites in which, despite their social orientation to the departed, anyone in the deceased users' online social network were allowed to post public statements. In several cases, bereaved parties perceived these actions to uncomfortably violate boundaries of social entitlement characterizing who ought to be considered "bereaved", and the socially and morally appropriate actions that ought to follow suit. In these cases the bereaved were often unable to gain access to the departed's account to intervene. Participants in these studies also described disturbing instances in which they received messages from a departed loved one's online profile, which typically owed to a family member using the deceased's account to communicate with their social network (*e.g.*, invitation to a memorial service), or system-driven notifications of content aimed at catalyzing "reconnection" with now departed friends and loved ones.

To be clear, each of the cases comprising these data are diverse and by no means represent an exhaustive set of death-related complications emerging with social networking systems. What we want to draw attention to is how they are linked by a common underlying problem: in the physical realm rituals have occurred to mark the passing of loved ones, whereas online they persist in a *liminal* space [33], neither alive nor treated as dead, but lingering on not unlike any other user in the system. In this same selection, bereaved participants reported a range of responses when asked to reflect on how they desired their digital possessions stored online to be treated after they are gone. In some cases, participants wanted to have control over their account(s) and content(s), often explicitly desiring to grant (or restrict) access to different archives of digital artifacts to specific people. Whereas, others desired to immediately cede total control to their loved ones. Additionally, while prior work has indicated the crucial role "letting go" of artifacts plays in moving past painful life experiences and evolving aspects of one's self [49, 52], it is unclear how one might dispossess digital artifacts shared in online places, such as Facebook, which owe to the life of the departed. While recent changes have occurred in Facebook to enable deceased users' accounts to be 'pushed' into memorials [67], there are still no clear mechanisms in place to facilitate the transfer of account ownership (and attendant digital possessions) to the bereaved.

The complications across these instances typically owe to the often unanticipated persistence of departed loved one's digital identities. They collectively suggest a suite of tools could be designed and incorporated into existing social networking sites to encourage users to prospectively consider the lifespan(s) and destination(s) of their online accounts and contents, and who(m) ought to have rites to them. There may be similar opportunities in supporting user delineation of future ownership permissions by fluidly integrating this kind of functionality into privacy tools as they become more sophisticated and integrated facets of social networking systems. More research is needed to understand the extent to which new interventions would be effective in making the processes of passing on (or destroying) online content more transparent. Additionally, research is required to understand to what degree these kinds of interventions are valued, and, importantly, when they themselves may become socially inappropriate or unacceptable. We can imagine, even if subtle, prompts to prospectively reflect on the longevity of one's digital possessions beyond life may not be desirable. Further, it is important to consider if tools and systems for bequeathing one's digital possessions would provide expressive outlets to celebrate unique social bonds between specific people. Or, would they create nagging obligations to continually curate and manage digital things as the social relationships implicated in them grow and change?

Finally, as the HCI community continues to expand to non-Western contexts, new questions arise in terms of how technology and systems are affecting – and potentially complicating – the social, cultural and religious aspects of groups that have well-established practices for dealing with death. For example, how do members of a group that believe in reincarnation come to terms with the persistence of a deceased member's social networking profile? Very little research to date within the HCI community explicitly addresses these concerns. However, emerging work at the intersection of spirituality and computing [13] suggests a key area that can be built on in the future as techno-spiritual, social, cultural and death-related issues increasingly converge in contexts around the world.

Temporality

Concepts of time and pacing are useful for evaluating our experiences of moving towards and beyond death. They sensitize us to differing aspects of the experience highlighting avenues for further research. Taking such a temporal lens to an aspect of experience is familiar territory for HCI and is something that has recently been explored in a growing literature on "trajectories" of experience [14]. In taking this approach we consider four focal points along a trajectory towards and beyond death.

Orienting to a future death

For most people death occurs as a result of either old age or long term illness and as such its inevitability is something that most people consider at some point in their lifespan.

Consequently, there is value in understanding how people prepare for death and in designing supportive technologies. For some, especially the terminally ill, the use of social networking sites, online support groups and remote counseling has become a valuable (perhaps controversial) resource in developing preparedness for death [22]. There has been little pragmatic research however, into the efficacious design of such resources.

An alternative aspect of preparedness is more material in its concerns. As other sections of this paper discuss, there is a growing need to manage the digital resources and ephemera of one's life and herein there is much scope for the development of tools to support the adequate archiving and triaging of digital resources. This digital settling of affairs concerns not only the design of tools to literally bequeath digital artifacts, negotiating the complex social imperatives of bequeathing and inheritance practices, but also the design of tools for managing one's digital legacy – for making testament of one's intentions with regards such ephemeral things as the correct use and appropriation of various social networking sites, post-mortem.

How one's remains, physical and digital, are to be treated and how one orients towards death must be informed for many people by religious or spiritual sensibilities, as we briefly alluded to above. Consequently, technology design that works in this space will presumably also need to consider how such faith-based matters intersect with technology (*e.g.,* [13, 68]).

Constructing narratives

One way in which people orient towards death and come to deal with its emotional consequences (*i.e.*, come to terms with the event itself, support the pre-grieving and eventual grieving of others, settle affairs and unburden oneself), is to form some narrative account of a life [20]. Within the trajectories literature this concept resonates with the notion of developing "historical trajectories" [14], having an account of experiences generated through data collection. Technological advances in data capture offer new means for doing this and at differing scales. For example, data capture might record an entire life (as per the My Life Bits project [32]) or just significant moments and interactions of our life, recorded through our interactions with objects [6], for example. Such data of experience can then be repurposed for the development of these accounts.

As a means for bridging from preparedness to post-mortem, creating a narrative account has significant potential value. How artifacts are shared and how they are given meaning through narration is a rich source of current research in HCI [53]. There is much potential in understanding how digital technologies can support the construction of what we might term *narratives of dying*, for people who are approaching the end of life. Design in this space requires a solid understanding of the attendant concerns of the users of such memorial technologies. Building tools to allow narratives to be recipient designed and to be delivered in contextually appropriate times and through appropriate means is an imperative but complex challenge.

In the moments (passing)

For much research on dying (even amongst our own prior works), there is often little foregrounding of the moment itself. Technology will however increasingly intersect with these moments. This area becomes problematic for discussion because of the ways in which it so readily raises issues of personal control and agency in one's own demise (or put another way, raises the issue of assisted suicide). The act of controlling one's own death of achieving it in one's desired way with dignity and control, having a good death [9, 36], even for those not directly taking their own lives, could be (and is) much managed with technology. The use of ambient and embedded (and even embodied) technologies to manage one's sensory and emotional experiences at the ultimate moment is an area of valid concern and clearly a potential human-computer interaction of much significance. Research within such spaces however, must be done in awareness of attendant moral, ethical and political sensibilities that might be raised.

Legacies and monuments

Post-mortem, extending our temporal lens on death past the moment itself, the legacy we leave behind and the ways in which we are remembered materially (including the digital) are evident concerns. The notions of monuments and memorialisation have been considered extensively in other fields, such as anthropology and cultural studies. As we move into the era of ubiquitous computing, with mobile, situated and perhaps again bodily-embedded technologies, we will increasingly leave behind a contextual data footprint. There is a suggestion that such a data footprint might be repurposed and become some form of lasting monument to persons or groups of people [42]. As discussed above, we see signs of this repurposing of the digital in practices of Facebook memorialisation; and indeed, in addition to emergent complications, the ad hoc memorilisation of departed users' social networking profiles has also provided rich resources for reflection and some collective sense of closure [18]. But with increasingly complex uses of technology such data might become increasingly personal, offering strange new records of a life which can be archived. In addition to this there is growing interest in the use of digital technologies in funerary ware and shrines to the deceased [65]. The value-centered design of future physical-digital and pervasive memorials depends upon developing a deep understanding of the human value of and response to such concepts and technologies.

Research Ethics, Methods, and Design Considerations

Death and dying are parts of life that can cause great strife, trigger significant changes in family structures, and cause people to enter an emotionally raw state. Just as additional protections are warranted when conducting research with vulnerable populations, investigating mortality, dying, death, and bereavement requires special consideration of

participants' well-being. For researchers interested in working on issues surrounding the end of life, we discuss ethical and methodological issues, which should be considered during study design and execution – an approach called *thanatosensitive design* [47].

Standards for professional conduct in this area have been developed by the Association for Death Education and Counselling. These standards govern behaviour for grief therapists, death educators, researchers, and so on [7]. While many of the tenets outlined are similar to those found in other professional associations (such as the ACM or APA), ADEC outlines unique circumstances end of life professionals face that HCI researchers rarely encounter. One tenet describes the need for professionals to present "various views of a death-related question" which respect the individual's preferences, needs, and background. Another one of their ethical standards discusses the need to refer clients to an appropriate professional if the individual shows signs of dangerous behaviour (*e.g.*, if a participant shows signs of suicidal behaviour). We detail some of the potential issues that HCI researchers and designers may want to consider when working at the end of life, and organize them by potential stakeholder group.

Bereaved

Working with the bereaved introduces a unique set of challenges. Immediately following a loss, the bereaved may be in heightened states of emotion or in shock; this raises ethical concerns and compromises data collection [8]. But should we design technologies for the newly-bereaved at all? While some hospital-based studies found that the bereaved would like to be offered professional services such as counselling immediately after the death of a loved one [50, 54], multi-site longitudinal studies found that intervention is often unnecessary and may even potentially interfere with an adaptive grief response [16, 60]. Given the lack of consensus surrounding bereavement counselling, it remains unclear whether or not technology-centred interventions would be appropriate for the bereaved immediately after a loss. Current best practice is to make technological support or resources available, but not necessarily included as a standard part of care. Further, the holiday season, along with important dates like birthdays, death dates, marriage anniversaries, and so on have been noted as particularly difficult times for the bereaved [17]. Additional social reconfigurations occur as time passes, with family structures shifting to adapt to the loss. Researchers should consider the richness and variety of relationships the bereaved might have to the deceased when determining who to involve in the research process; similarly, designers should create systems that address an evolving family unit.

Dying

Talking to the dying as a distinct group of individuals with a specific set of needs and lessons to teach began in earnest with Elizabeth Kübler-Ross's work interviewing dying patients [43]. Her work, like much of the work since then, has focused on individuals in hospital settings who are in palliative care or have been given a poor prognosis. In these settings, the complications of working in hospitals (*e.g.,* issues of access, consent, use of medical data) are exacerbated by the failing health and limited time of participants; fatigue, pain, or drowsiness may impinge upon participants' ability to understand questions or respond. Additionally, family and friends may be acting on behalf of the individual. While family members may act as surrogates for certain types of questions, the validity of their responses is likely to be poor [8]. Schulman-Green *et al.* suggest a set of alterations to standard interviewing techniques based on their work with dying patients and their families [59]. They note the importance of allowing the interviewee to lead the interview, and the need for additional time and patience when allowing the interviewee to respond. HCI researchers and designers can potentially innovate in this space by developing technologies that permit the dying to communicate their needs and perspectives at their own pace, rather than during a single sitting.

Dead

When designing systems, it is increasingly important to consider how the system might gracefully and respectfully present or use information associated with the deceased. The idea of using technology to prevent death entirely, or to "speak from beyond the grave" has been a motif in science fiction for decades, but has begun to actually occur in current systems. As noted, Facebook's "friend suggestion" function intimated that a dead person was interested in speaking with the user [67]. Similarly, Massimi and Baecker describe how highly personal technologies like caller ID serve to disorient and surprise the bereaved when they receive a call from a dead relative [46]. Interactive systems designers should consider how agency is attributed to the users of their systems, and how that agency might be represented when a user is actually dead.

This idea of agency ties into notions of consent and data maintenance. Researchers and designers in this space need to carefully acknowledge how data associated with a dead producer should be handled: does it die along with its owner, or remain? Is it included in analysis, or removed? How should access to the data change as a result of a death? Systems designers and researchers should have clear plans about what happens to research data if a participant dies during the study, and additionally, should consider ethical approval of using of secondary sources (*e.g.,* webpages, emails) of people who have died during research.

The Living

As we increasingly store meaningful information across multiple disks, accounts, and devices, some living users have begun to plan out what should happen to their data upon their own deaths. Websites like Entrustet [4] promise to safeguard data and release it upon the death of the user. However, this type of situation raises ethical questions

surrounding ownership and replication of data, right to inherit, and the legal role of these systems in various jurisdictions. How do we design systems to allow the living to create and ensure post-death plans are executed properly?

DISCUSSION

As presented in the four themes above, the end of life offers opportunities for a wide variety of HCI research and design. By addressing this domain, we have also shown how it fits with existing lifespan-oriented approaches in its ability to act as a crucible. In this discussion, we wish to suggest broad, but tractable directions for the HCI community to make an impact on the quality of end of life situations. We first address research directions, and then design directions.

Research Directions

At the moment, there are many anecdotes, stories, and thought-provoking scenarios about technology use at the end of life, but very few rigorous studies. HCI researchers interested in the end of life can contribute in multiple ways.

Achieving a better understanding of how technology is currently used at the end of life. This understanding helps provide technologists and end of life professionals alike with a foundation for improving end of life experiences. As we discussed before, this could be "in the moments" of death, looking at issues of materiality following death, or crafting a narrative to cope with one's own mortality. A variety of methodologies – both qualitative and quantitative – could be applied to better characterize users of end of life systems. Example research questions include: What percentage of the population uses technology for memorialization purposes? For inheritance purposes? What are the factors that predict use or avoidance of technology? How do religious, cultural, and personal differences account for technology use? How do types, and settings, of death influence the way that technology is used?

Applying and extending existing HCI theories, principles, and technologies to this domain. Many current theories and principles in HCI could be extended to consider the eventuality of death. For example, distributed cognition has been a useful tool for describing how knowledge in organizations is stored, communicated, and reproduced; but how is the death, or removal, of an actor in such a system accounted for? What are the best principles for systems that successfully withstand the test of time such that they are able to be enjoyed by multiple generations of users? What are the ethical dimensions of various technologies for achieving the various goals at the end of life?

Scholarly discourse and interdisciplinarity. The field of thanatology has been long-established, but to date, has had little input from technology experts. Cultivating a stronger technology-oriented presence in this field of study can help us find partnerships, resources, and common ground with people from a wide variety of disciplines. Thanatologists working in the arts and humanities may already adopt technology as part of their practice, but lack the expertise to adapt the technology to handle the delicate social and processes associated with death. At the same time, the thanatology community can benefit from the unique opportunities that technology can provide in terms of data collection, intervention, and application.

Design Directions

The end of life has been a continual topic in art and design. Interaction designers, too, may find it a significant—if not unavoidable—domain to explore. Here we suggest further opportunities for interaction designers and researchers.

Designing to empower. As the assistive devices community has shown, systems can be designed in a way that empowers the end user to achieve his or her goals despite disabilities. For the dying, this might indicate an opportunity to give the user the chance to say goodbye in a unique or meaningful way through channels that are more accessible than writing or typing. For example, there may be an opportunity in designing technologies that enable the dying to communicate their wishes in a more personal or desirable way, perhaps through conveying more expressive messages to specific individuals or groups. However, as we have discussed, it is crucial to take into account how these digital materials might be received and treated by other stakeholders, such as the bereaved, and consider ways in which they could be embodied, stored or put to rest. At the same time, interactive technologies and systems could be designed that empower all of us, as mortals, to engage in end of life planning more readily, or to make arrangements more easily. And finally, we can consider how systems might empower people who have died to maintain a digital identity that preserves their integrity and desires in this life; or, to deliver messages for loved ones into the future.

Designing to ease the transition. Systems intended for personal use rarely consider the death of the user, or even a change in the user's power of agency. Interaction and system designers may consider how their products could, be (mis)used following a death. How will data from the device be retrieved? How will this change affect the larger network structure? Who might become the new user, and how does that change the use cases for the technology or service?

Making meaning and making strange. All people seek to achieve personal understandings of what life and death mean. Interactive technologies and systems can place viewers or users into immersive emergent situations and experiences that can open the space for this kind meaning-making to unfold. For example, systems that sensitively "reanimate" the dead or transcend the barriers of death may have powerful emotional and even therapeutic effects.

CONCLUSION

In this paper, we have laid out the foundation for future work in HCI at the end of life. We have done so by first situating the end of life as part of a larger tradition of *lifespan-oriented research*. Drawing on this tradition, we described how the end of life introduces a new set of

challenges, while also helping us to reexamine long-standing HCI issues in a new light. In particular, we call to mind four stakeholder groups which have been, and will continue to be, central to work in this area: *mortals, the dying, the dead, and the bereaved.* Based on our fieldwork, examination of the literature, and experiences organizing and attending international workshops on this topic, we have suggested four thematic areas that begin to map out what research at the end of life might include: *materiality, identity, temporality, and research ethics/methods.* With these conceptual cornerstones in place, it becomes possible to construct a concrete foundation from which future work can productively leverage and grow. Finally, we have remarked on research and design directions that may be explored to achieve a better understanding of technology's role at the end of life, improved designs and interactional experiences, and, ultimately, a more meaningful, personal, and human experience for anyone as she or he inevitably encounters or experiences the end of life.

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