

Provocations for Empathy-Centric Design in End-of-Life Planning

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Abstract

Empathy is increasingly shaping HCI research across diverse contexts. Across these contexts, empathy is often assumed to be granted and implicitly framed as immediate, reciprocal, and situated in the present. End-of-life, however, presents a distinct context in which expectations of empathy may extend beyond death, where reciprocity is no longer guaranteed. Drawing on interview studies with older adults engaged in end-of-life planning and remembrance, we offer three provocations for empathy-centric design. We discuss how empathy in end-of-life contexts is anticipatory and temporally distributed, involves substantial work, and is materially scaffolded for specific audiences through intentional artifact choices. Together, these provocations invite reconsideration of how empathy is conceptualized and designed in HCI across time, absence, and materiality.

Keywords

end-of-life planning, empathy, digital legacy, older adults, remembrance, death,

1. Introduction

Empathy is often defined as an “intuitive ability to identify with other people’s thoughts and feelings—their motivations, emotional and mental models, values, priorities, preferences, and inner conflicts” [1] or simply, going beyond “knowing the users” to understand how “it feels like” to be that individual [2, 3, 4]. Reflecting its growing importance across adjacent user-centered fields (e.g., medicine [5], education [6]), HCI and CSCW have increasingly examined empathy across diverse settings, further elaborated below.

Genç and Verma, in their scoping review, summarize how empathy in HCI/CSCW has been mobilized in multiple ways: to facilitate empathy between users, to support designers in understanding users, to foster empathic engagement with agents, and to design systems perceived as empathetic [7]. Their review highlights not only empathy’s versatility across contexts, but also how it is frequently operationalized as an immediate or *in-the-moment* phenomenon – for example, through chat-based interventions that prompt real-time perspective-taking among teams [8]. Empathy is also often framed as reciprocal, such as in work examining how users both perceive empathy from virtual assistants and extend empathy toward them [7]. Moreover, empathy is commonly situated in the present, frequently operationalized within synchronous, co-present interactional settings (e.g., through real-time sensory or behavioral cues such as gaze and heartbeat) [9, 10].

In contrast, end-of-life contexts offer a different configuration. Interactions may not be co-present, nor are they verifiable through immediate sensory or behavioral cues. When individuals plan for death, empathy becomes less an immediate, present-day *guarantee* and more a future-oriented, post-mortem *hope*. In contexts shaped by mortality, absence, and extended temporal horizons, empathy cannot be assumed to be reciprocal or verifiable. Instead, empathic understanding is oriented toward futures that may never arrive and interpretations that cannot be confirmed or contested in the absence of the other party.

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Drawing on interview studies with older adults reflecting on their end-of-life planning and remembrance, we use this context to discuss three provocations for empathy-centric design. Rather than offering solutions, these provocations aim to surface tensions around how empathy is anticipated, distributed, and materially mediated in HCI. We ask: what does empathy mean for HCI when it is deferred, temporally distributed, and materially mediated rather than immediate and present-tense?

1.1. Provocation 1: Empathy is anticipatory and temporally distributed

In end-of-life planning, empathy is often anticipatory and deferred, i.e., oriented toward an imagined future and directed at an imagined group of individuals whose empathic responses cannot be guaranteed. Moreover, the act of planning itself can involve empathizing with deceased past generations, further extending empathy across time.

When discussing preferences for how they wish to be remembered, participants in our studies often anticipated that their future generations, and at times their former workplace connections (further discussed in 1.3), would empathize with them by remembering their lives. For instance, one participant anticipated that her grandchildren would remember her as a “good example [of a person]” and the “things that we [her and her grandchildren] did together... maybe some stories.” Others anticipated how their future generations might remember the “big times in my life” or the “place I’ve worked... traveled.” These accounts suggest participants perhaps also wanted their future generations to empathize with or understand how *it must feel like* to be them, beyond *merely knowing them* [3, 2, 11]. However, this empathy from future generations is not guaranteed, as planners cannot witness, correct, or negotiate how such empathy is received once they are no longer present.

Beyond a future-oriented anticipation of empathy, planners also empathize with past generations as they plan for death, while simultaneously anticipating that future generations will empathize with those past generations as well. During the interviews, although we primed participants to reflect on how they themselves wished to be remembered after death, their reflections often extended to the lives of their parents and ancestors, revealing deep empathic engagement with past generations. For example, the participant who mentioned wanting to preserve the “big times in my life,” later, upon deeper reflection, brought up her “dad’s World War II memories” and her grandfather’s immigration story of arriving in “a little town in Louisiana,” where “even though he was Jewish, he played Santa.” She wished to preserve her grandfather’s immigration story, which was captured in a “newspaper article,” so that future generations could empathize with their ancestors’ lives. Another participant, anticipating that her grandchildren would want to empathize with her own parents’ lives, preferred to preserve the “cards and correspondence [between her parents]” that had been passed down to her.

Together, our participant accounts show how empathy, in an end-of-life planning context, perhaps stretches across time—linking past and future generations—rather than occurring immediately during a shared moment of interaction, and often not guaranteed. Designing for empathy in such contexts complicates how we understand empathy in design and raises questions about how empathy can be meaningfully designed when it is not only anticipatory but also fundamentally unverifiable (e.g., the planner may not be alive to confirm whether their intended empathic response is realized, for instance, through the sensory or behavioral cues of future descendants).

1.2. Provocation 2: Empathy is work—not just feeling

Rather than functioning solely as an “intuitive ability” to identify with other people’s feelings [1, 11], empathy in planning for death is *work*, including emotional, curatorial, interpretive, and infrastructural work distributed across people and technologies.

Past digital legacy research has identified how planning for end-of-life can be emotionally burdensome, not only for planners but also for bereaved family members [12, 13, 14]. In line with these findings, participants in our studies, often empathizing with their future bereaved, perceived that their death could impose emotional burdens on their family members. This perceived burden shaped some of their end-of-life data planning decisions. For instance, one participant noted that her data (e.g., messages, photos,

social media) could become an “emotional issue” for her son, as inherited data might act as triggers for grief, and therefore preferred to delete some of her data. Moreover, for planners themselves, confronting their own mortality in order to initiate end-of-life planning can also be emotionally burdensome [12].

To navigate this emotional work, participants engaged in intentional curation of their artifacts for remembrance, resulting in additional labor in the form of curatorial work. As noted in the earlier subsection, curating artifacts involves considerations of remembrance, including *what* and *who* is to be remembered, such as selecting a “newspaper article” to preserve a grandfather’s immigration story. Beyond simply choosing the right artifacts for the right reasons, participants also sought to scaffold their anticipatory empathy by conveying their motivations, values, and inner conflicts [1]. To do so, they preferred to add contextual information to their artifacts. For example, one participant explained that her earring would require an interpretive scaffold to convey the “remembrance of the moment... where I got it, and who I was with,” so that future generations could fully understand its “sentimental value.” Overall, participants anticipated that their family members would engage in interpretive labor to make sense of the meanings and values embedded in these artifacts.

Yet, the success of such empathic response hinges on another form of work: infrastructural work. By infrastructural work, we refer to the often invisible labor required to sustain technological systems over time so that artifacts remain accessible and interpretable for future generations, including the maintenance of storage platforms, data formats, and organizational arrangements that outlive the planner. In their accounts, participants pointed to a range of infrastructural concerns, including the obsolescence of storage platforms and formats, as well as the permanence of technology companies, drawing on their own lived experiences. These concerns shape whether empathy can be realized by future audiences (i.e. those who remember them after their death). For example, one participant, recalling how floppy disks, CDs, and DVDs became obsolete during her lifetime, asked, “How do you know they’re gonna have the cloud tomorrow? I don’t know.” Another participant, skeptical about the longevity of third-party services such as Ancestry.com, remarked, “companies come and go, ownership comes and goes... they may be in a totally different business by the time you die than what you started out with.” Together, these accounts raise important questions about who is responsible for this infrastructural work. Empathy-centric design risks obscuring this labor, potentially shifting the burden onto bereaved family members who are already navigating grief and loss. More broadly, this raises further questions about who is ultimately expected to perform the work of empathy building in end-of-life planning technologies, and how this labor is distributed by design.

1.3. Provocation 3: Empathy is materially scaffolded, and for specific audiences

Empathy in end-of-life planning can be plural and audience-specific, shaped by material aspects of the artifacts themselves. An individual planning for death does not merely anticipate empathy from others after death; they actively shape how such empathy might be made possible through choices about which artifacts persist, in what form, and for whom. These choices dictate how future audiences may come to understand, or remember them.

Across our interviews, we noted how participants anticipated different empathic responses from different social groups, and negotiated material forms accordingly. Below we describe the artifacts that participants carefully chose for building post-mortem empathy across generations. For close family members, *embodied presence*—presence as lived and perceived through material and technological forms [15, 16]—became central to shaping empathy after death. In particular, these artifacts captured the physical traces of how they looked and sounded (e.g., photos), temporal traces of materialized passage of body and lived experiences (e.g., collection of driver’s licenses over twenty years), and the relational traces of the intergenerational self (e.g., breadbaskets that were passed down). For instance, one participant who anticipated that his “own future descendants” would be interested in his “appearance” preferred to preserve his photographs. In this way, participants were not merely preserving memories but actively shaping how future empathic understanding might unfold. This anticipatory work varied across audiences. For more distant audiences such as former colleagues or students, participants tended to select artifacts that emphasized roles, achievements, and professional identity. For example, one

participant, a retired instructor of medicine, articulated different desired forms of empathic response across non-family audiences: he hoped to be remembered by his former students as “a good teacher,” and by broader audiences, including Ayurvedic¹ practitioners, as “one of the people who helped to introduce Ayurveda to America.” Accordingly, he chose to preserve his authored books.

Participants also considered whether artifacts should remain in physical form or be digitized, as well as where they should be stored. Physical artifacts, such as photographs and letters, were valued for evoking the era in which they were produced and for fostering intimacy through handwriting or touch, whereas digital forms were considered more durable and accessible for future generations. To illustrate, one participant noted that physical artifacts such as her “diary” embodied qualities like “handwriting” that could bring “them [past generations] closer to you,” shaping her decision to preserve her artifacts in physical form rather than digitizing them.

These findings suggest that empathy after death is neither abstract nor automatic. Rather, it is materially scaffolded through intentional negotiations of form, medium, and durability, and tailored toward specific audiences with distinct interpretive frames. Yet technologies and conversations around empathy in end-of-life and mourning contexts often risk collapsing these distinctions, aggregating diverse artifacts and audiences into singular spaces of mourning and remembrance (e.g., *collective empathy* on digital platforms through online mourning [11]). This misalignment between planners’ desires for audience-specific empathy and technologies that aggregate remembrance into singular spaces raises an open question for empathy-centric design: how might systems support multiple, materially distinct pathways to empathy without collapsing differences across audiences whom planners envision engaging in remembrance in distinct ways?

Collectively, these provocations suggest that empathy in end-of-life contexts is fragile, labor-intensive, and materially mediated, posing new challenges and opening new opportunities for empathy-centric design. As empathy-centric systems continue to be developed, it becomes vital to reconsider how empathy is conceptualized, distributed, and designed in HCI.

Declaration on Generative AI

The author(s) have not employed any Generative AI tools.

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¹Ayurveda is a traditional form of medicine that originated in India [17]. The participant described himself as having previously worked as an instructor of Ayurveda.

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