
HCI at the End of Life: Understanding Death, Dying, and the Digital

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Abstract

Death and our experience of it is a fundamental aspect of life and consequently every human culture has developed practices associated with responding to, signifying, and dealing with its implications. As our technology pervades our cultures, we find that the digital is increasingly intersecting with these practices. This raises issues which have rarely been conceptualized or articulated in the HCI and CSCW communities. It is increasingly important to design "*thanatosensitive*" technologies which support death-centric practices such as collaborative acts of remembrance, bequeathing of digital data, or group reflection on the digital residua of a life. This workshop will bring together participants interested in such technologies and their implications. Potential topics include, but are not limited to: devices for reflection and meaning-making across multiple lifespans; interdisciplinary practices surrounding mortality, dying, and death; technology heirlooms; digital rights management; and methodological approaches to researching end-of-life technology issues.

Keywords

Death, dying, mortality, end of life.

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

General Terms

Design, human factors.

Motivation

Losing a loved one can disrupt the social cohesiveness of our lives, unsettling even our most familiar practices, routines and interactions; and dealing with the experience of bereavement is often fraught with a range of very real, complex and emotional difficulties on individual and societal levels [5]. However, the ways in which people use technology in practices concerning mortality, dying, and death are areas of HCI research which have historically received little attention. This lack of scholarly research is precipitated by both practical and theoretical problems emerging in the HCI community and computer use at large. For example, families have begun to grapple with issues of how to distribute digital assets upon the death of a loved one, leading to “digital wills.” Social networking tools contain entries for people who are no longer alive, and often fail to provide a clear way of handling this situation. From early adulthood onward, people find themselves confronted with their own mortality, and use technologies to accommodate, defy, or even attempt to circumvent their own deaths, by living on through some digital legacy. Despite the underlying implications of these emergent practices, the HCI community has not begun to seriously address the intersection of death and computing technology.

This workshop comes at a time when death and dying are moving once again into the home, and can

contribute a much-needed technology-oriented perspective to the ongoing interdisciplinary discussions about death. For most of Western history, dying occurred in the bed, in the home, surrounded by family, and given structure through cultural rituals. As the great World Wars came to pass, however, Bendle [1] argues that dying became militarized – it occurred against the context of a war, and in battlefields far away from home. Following the World Wars, dying became medicalized and occurred primarily in hospitals, where institutional efficiency inhibited the individual’s subjectivity and humanity—an issue deeply explored through sociological studies on the social organization of death [10]. In the past two decades, the hospice/palliative care movement (largely influenced by Kübler-Ross’s seminal work on dying patients in hospitals [7]) moved the scene of dying back into the home and the focus became on meaning-making, social connection, self-direction, and dignity [3]. Moreover, recent research suggests death-related practices are becoming increasingly more diverse, secular and individualized [3, 4]. This occurs at a time when HCI technologies increasingly find purchase in the domestic space, and stand to contribute a great deal.

Very recently, however, some of the first work in the HCI literature has begun to appear that both acknowledges and engages with end-of-life issues. Kirk and Banks [6] describe a novel type of computational artifact – the technology heirloom – which is explicitly designed to be handed down, inherited, and cherished across multiple lifespans. This work, and recent parallel research by Odom et al. [9], articulates attendant issues beyond inheritance, including the residual “digital patina” of users, which can be treated in contrast to the dominant cultural disposition towards

replacing technologies rather than keeping them as valuable, self-defining possessions. There also exists interest in the reflective design of online memorials [2] and technologies to support both individual and group mourning [11]. Massimi and Charise [8] suggest that increased attention be paid to this area by critically examining areas of research and design which fail to elegantly or reverently acknowledge the death of the user; they coin the term *thanatosensitivity* as an approach to research and design which actively engages with issues of mortality, dying, and death throughout the process of technology development.

This early research motivates this workshop, which intends to break new ground by bringing together, for the first time, researchers and practitioners interested in the interfaces between end-of-life practices and technology. Because these issues cut across the entire span of work in human-computer interaction, practitioners and researchers in all areas of HCI can benefit from considering these issues in this forum.

Themes

Conceptualizing the design space surrounding end-of-life practice requires an interdisciplinary, open-minded, and culturally sensitive approach. This workshop will bring together researchers and practitioners to address the following themes:

- *Technology & Design*: Computationally enhanced artifacts which help groups of people to share, remember, and relate to the deceased or dying. Examples include technology heirlooms, online memorials, electronic gravestones/memorials/shrines, or traditional desktop software which addresses

mortality, death, and dying in unique or novel ways.

- *Social Practices*: Obtaining a better understanding of how technology and other artifacts are appropriated, used, discarded, or incorporated into social practices surrounding death (e.g., [4]). Topics in this theme may include ethnographic analyses of end-of-life issues, sociological models of practice, culture-specific practices, or other forms of empirical qualitative research focused on the intersection of mortality, dying, death, and technology (e.g., interviews, questionnaires, surveys).
- *Humanities and Cultural Studies*: Insights related to mortality, dying, and death as understood in fields traditionally underrepresented in HCI (including, but *certainly* not limited to: archaeology, religion, anthropology, sociology, literature, philosophy, or the arts). Understanding how to incorporate these themes into research or design practice will be a major component of this workshop.
- *Research Methodology and Evaluation*: Discussions of how to conduct thanatosensitive research (that is, research is sensitive to issues of dying, death, and mortality). Topics of interest include (but are not limited to): epistemological approaches, empirical methods, conceptual or theoretical frameworks, analysis procedures, and standards and metrics for evaluation of systems. Discussions will also include how to conduct ethical and respectful research, either with respect to a particular

methodology/setting, or more generally across contexts.

Workshop Goals

Primary goals for the workshop are as follows:

- *Identify and share common research interests in this area.* This is accomplished through participant presentations of their position papers in the morning. In the afternoon, we will make progress towards a better conceptual understanding of research in this area by creating affinity diagrams in the break-out discussion groups.
- *Draw attention to this topic as an emergent strand of research.* We seek to promote the visibility of this type of research to the HCI community in at least 3 ways. First, holding the workshop and including it in the workshops program will demonstrate its potential for growth. Second, we shall, as a group, prepare a poster to be placed on display for the rest of the conference that illustrates the concepts discussed during the workshop. Finally, we will move towards collating the position papers into a special issue of an appropriate journal for disseminating this research more widely.

Conclusion

Where, how, and when we die are all increasingly mediated by technology. This workshop offers an opportunity for researchers from a range of disciplines to meet and better understand the role and opportunities for technology in this space. It is only through sensitive, thoughtful, and ethical consideration that technologies may be introduced that could one day

help people make meaning, find solace, and grapple with mortality, dying, and death.

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