
Dying, Death, and Mortality: Towards Thanatosensitivity in HCI

Michael Massimi

Department of Computer Science
University of Toronto
Toronto, Ontario, Canada
mikem@dgp.toronto.edu

Andrea Charise

Department of English
University of Toronto
Toronto, Ontario, Canada
andrea.charise@utoronto.ca

Abstract

What happens to human-computer “interaction” when the human user is no longer alive? This exploratory paper uses insights from the critical humanist tradition to argue for the urgent need to consider the facts of mortality, dying, and death in HCI research. Using an interdisciplinary approach, we critically reflect upon how the intersection of death and computing is currently navigated and illustrate the conceptual and practical complexities presented by mortality, dying, and death in HCI. Finally, we introduce the concept of *thanatosensitivity* to describe an approach that actively integrates the facts of mortality, dying, and death into HCI research and design.

Keywords

Death, dying, mortality, critical humanism, thanatosensitivity.

ACM Classification Keywords

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

Introduction

On July 21, 2008, a professor in computer graphics emailed our department to notify us that Bert Herzog, a leader in this field, had passed away. Following the

notice was a brief personal aside: "It's an odd feeling seeing a recent e-mail in your inbox from someone who is no longer here to receive the reply."

For the first time in history, people are dying and leaving behind large amounts of personal information stored in computers and on networked systems. As a result of the widespread use of personal computing devices, age-old biological, social and cultural events concerning death are being newly mediated by contemporary technological contexts. As our opening anecdote illustrates, modern computing technologies inescapably intersect with the facts of human mortality, dying, and death. However, these technologies are not yet designed to effectively acknowledge –or engage with– the inevitable death of their user.

While this particular technological phenomenon is unprecedented, several attendant issues are not unique to computing and the digital age. The question of how technologies and users interact has been a subject of humanist critique since Plato's *Phaedrus* (c. 370 BC) [2]. Before diving into empirical or design-oriented research, we wish to offer the community an exploration of humanist insight into the relationship between death and technology, which may then be applied to human-computer interaction (HCI).

But first, an important disclaimer: given the paucity of research in this area, it is not our intention (nor are we able at this early stage) to develop in full the wide-ranging consequences –and opportunities– implied by this topic for the HCI research and design communities. Rather, the objectives of this paper are:

- 1) to convince HCI researchers and designers of the importance of death, dying, and mortality to their work,
- 2) to introduce the concept of *thanatosensitivity* to describe HCI research and design that actively considers and integrates mortality, dying, and death into research and practice,
- 3) identify several potential areas of HCI research and design situated at this intersection of death and technology which may be thought of as thanatosensitive systems, and
- 4) assert the pressing need for increased scholarship in this area.

Distinguishing Mortality, Dying, and Death

For the purposes of this paper, we define *mortality* as "[t]he condition of being mortal or subject to death" [15]. We refer to *death* as "the act or fact of dying; the end of life" [15]. Thus mortality is an intrinsic and ongoing state over the entire lifespan of all persons. Death, on the other hand, is a singular and temporally-constrained occurrence. We designate the state of *dying* as an intermediate term, wherein the individual is in a state of physiological decline (*e.g.*, morbid illness, advanced age) facing imminent, but not necessarily immediate, death.

Since the design and research issues implied by mortality, dying, and death may be quite different, distinguishing between these concepts is essential. Being subject to death (mortality) can guide activities throughout a person's life: what decisions to make, how to spend limited time, and how to prepare for death "in the large." In contrast, the occurrence of

death has implications beyond the individual's lifespan and personal control, effecting a series of subsequent events in his or her social circle and involving media otherwise left untouched (*e.g.*, intimately personal effects such as clothing, diaries, or even mobile phones). Under certain circumstances, dying may comprise a sequence of events that provide enough time to enable an individual and their social circle to prepare for the imminent onset of death. Of course, there are numerous practical and conceptual difficulties associated with defining states of living, death, and dying [17]. Nevertheless, differentiating between each term helps to imply a distinct set of activities and issues pertinent to computing research and design.

Why Utilize a Humanistic Approach?

The fact of death presents a number of important questions for computing, but the interested designer or researcher may have trouble selecting an appropriate epistemological and methodological stance to address this issue. Unlike many areas of HCI research, studies of death and mortality are rarely amenable to laboratory study. Some HCI researchers have responded to this problem by applying ethnomethodology to account for human practice "in the wild" [3]. For the study of mortality or death, even this step may be premature due to the lack of a clearly defined area of practice (*e.g.*, hospital, home, institutional residence, public spaces, or even culture). Fieldwork in this area also incurs considerable ethical and cultural concerns.

In the absence of traditional social science methods for understanding technology's intersection with human experience, research in HCI has turned productively to the arts, design, and cultural theory to inform our

understanding of technology's role in day-to-day life (whether it be with intent to "improve" this experience or not). Cultural probes, for instance, have been employed to "subvert" the traditional data collection methods used by social scientists [1]. Despite the successes of this approach, even this "build it and see what happens" method seems to carry too high an emotional risk for participants when investigating an issue as culturally-sensitive as death. To ask participants to test a new prototype or answer interview questions while they are grieving can be ethically, logistically, and technologically difficult.

While we do not imply that gathering empirical data is unnecessary or inappropriate, we suggest to the HCI community that we **first examine the humanities as a non-invasive strategy** for better understanding the conceptual and practical issues surrounding death, computing, and human experience. Looking outside of technical disciplines toward the humanities as a source of inspiration, elucidation, and evaluation has been previously suggested when examining other "slippery" concepts such as emotion and aesthetics [9]. Like these other domains, humanistic investigations of mortality, dying, and death can yield useful conceptual and practical material for researchers and practitioners alike. It is our hope that readers will, upon completion of this paper, gain an improved understanding of humanistic writings on mortality, death, and dying, and subsequently, recognition of the need to improve technological responses to the inevitable end of each individual's life.

Death and Technology in the Humanities

Scholarly research in the humanities provides remarkable insight into the conceptual parameters of

technology's relationship to death. Mortality is a universal aspect of the human condition, and studies in language, literature, and philosophy have addressed the social significance and conceptualization of death for more than two millennia. Employing the critical humanist tradition as a preliminary theoretical approach places current issues in HCI research within a much-needed historical perspective, thus enabling identification of conceptual and practical issues common to both contemporary technologies and their precedents. Moreover, key themes pertaining to the intersection of death and technology previously identified by prevalent avenues of humanistic criticism articulate effectively several open areas of HCI research. For the purposes of this paper, we limit our discussion of humanistic treatments of death and technology to selected examples from comparably recent history.

It is often helpful to begin with an example. In the late 19th century, Sigmund Freud's (1856-1939) investigations into the nature of the human mind and behavior prompted a new conceptual vocabulary that recognized death not simply as the concluding event of life, but as a force structuring the nature of life itself. While not the first to ponder mortality, Freud argued that human life is defined not only by the desire for "life" (*eros*), but also a "death drive" that encompasses the fact of death, destruction, and non-existence. In short, he suggests, "[t]he aim of all life is death" [8]. As a scholar concerned with understanding the human condition at the basic psychological level, it is remarkable that Freud would consider death to bear such influence upon human behaviour, especially when practices concerning death are so frequently unusual, hidden, and constrained to the sidelines of day-to-day

life. A century later, such pioneers might find it strange that this fundamental issue has gone unaddressed in a world where many agree that computing is reaching into all aspects (physical, psychological, etc.) of Western life.

Despite the subsequent development of psychiatry and the rejection of some of his clinical findings, Freud's insights have continued to influence modern-day humanistic conceptions of death. Notably, 20th-century thought (including Jacques Lacan, Jacques Derrida, and Martin Heidegger) have implicitly or explicitly maintained Freud's notion of the death drive. This connotes the endurance and importance of death, dying, and mortality in the minds of contemporary philosophers and cultural commentators. In reference to the ancient Greek mythological figure of death and mortality, this ever-present orientation toward death is often referred to as *thanatos*. One application of this concept is the literary genre known as *thanatography*, the "writing of death" or record of one's dying. Other technologies (e.g., photography, journals) demonstrate a similar impetus via their capacity to "to select, store, and process relevant data" (369) [12] for, about, or by their subjects. These capacities persist in modern capture and access applications (such as blogs, digital cameras, and so on).

The profound significance of *thanatos* to 20th-century humanistic thought is useful for determining how the concept of death is relevant to HCI. While the technologies are new (e.g., PCs, mobile phones), many conceptual issues associated with death have been previously unpacked, examined, and problematized by the humanities. The enormity of this subject has been abbreviated for the purposes of this short paper.

However, in the following section we seek to introduce the rich scholarship on these topics to the HCI community by arguing for the pertinence of contemporary critical thought to integrating death into HCI research and design.

Death and the Author

The theoretical approaches to the relationship of death and writing are vast [13]. To highlight potential ways in which the practical fact of death might influence research and design, we look to aspects of critical theory pertaining to the death of “the author”: the human locus of interaction with writing technologies and analogous in several key ways to HCI’s concept of a “user.”

French philosopher Michel Foucault (1926-1984) famously writes, “Writing so as not to die... is a task undoubtedly as old as the word” (53) [6]. By writing, one creates the possibility of disseminating and presenting oneself for endless acts of reading: consider the posthumous publication of journals, letters, and photographs which extends the text-producing “life” of an author beyond their mortal limits [7]. Since writing produces material artifacts, the inheritance of written materials can preserve, or, in a sense, even create life. How do texts “create” a life? In short, through the existence and utilization of a medium. An extraordinary example is that of Franz Kafka (1883-1924), German-Czech author of *The Trial* and *Metamorphosis* and now known as one of the greatest writers of the early 20th century, who was utterly unknown until his executor Max Brod published his works following his death. The physical remains of Kafka’s writings – his journals, manuscripts, and letters– in fact created the author we now call “Kafka.” Kafka never sought to publicize his

work. Without the publication of these texts, Kafka simply would not exist for literary scholars or readers. Before the invention of computing and the Internet, the actual person –the author– was *produced* by writing technologies and preserved for posterity by way of their documents. Paper, as a “device” and medium, was in essence the only means to conceptualize the author.

The high price of original handwritten literary manuscripts attests to the special relationship between a text and the physical form upon which it is written. Computing technologies alter this relationship: physical remains take the form of hard drives, not paper, and duplicating stored data is effortless, inexpensive, and possible across great distances. In this age of word-processing, the notion of an “original” no longer exists, as documents are likely altered hundreds of times prior to their (ostensibly) final form. Contemporary users of technology are increasingly the authors of huge amounts of data (documents, emails, photos, and so on). Who or what is “doing the authoring” may also be questioned: we are as likely to “co-author” a document with a piece of software (*e.g.*, templates and forms) as we are another person, or even groups of strangers (*e.g.*, Wikipedia). These authored multimedia artifacts may be of significance – emotional, financial, artistic, intellectual, or otherwise – to a range of interested parties after death. Today, we are as likely to inherit a loved one’s collection of hard drives, USB keys, SD cards, and email accounts as we are collections of papers, journals, and photographs.

This type of digital medium creates a permanence of the author-reader relationship of which we may not be aware. What about those who don’t wish to “live” forever, or who want their relationships with technology

(and future readers) to die with them? Like the inheritance of half-completed manuscripts, the idea of inheriting digital materials raises complex issues. Foucault's essay, "What is an Author?" is suggestive of such challenges in the HCI context [7]. For the author, death signifies the finalization of his or her "body" of work (the *oeuvre*). But do all of an author's works deserve to belong in this category? To make his point, Foucault asks whether the "complete works" of the prominent 19th century German philosopher Friedrich Nietzsche (1844-1900) should include his laundry lists. A contemporary analogy may ask whether his "complete works" should include cached files, most-recently-used program listings, or browser history.

For HCI, death leaves open a range of technological applications that, when interrupted by death, become a problematic part "of" the user. At death, what defines the (dead) person in terms of their interactions with technology is out of their grasp: they no longer have a say in what "their" technologies continue to produce concerning them. To return to our example, prior to his death Kafka had expressly asked Brod not to publish his works. To justify this ethical and moral breach, in a postscript to the 1925 edition of *The Trial* Brod states that "Franz should have appointed another executor if he had been absolutely and finally determined that his instructions should stand." Similarly, Foucault expressly banned the posthumous publication of his notes and unfinished work so as to prevent any posthumous proliferation of his *oeuvre*.

In the contemporary context, we can easily imagine the proliferation of a person's technologically-mediated identities after death. The shift from material to digital technologies implies a series of attendant issues

(privacy, security, archival) which concern individuals who want their unique constellation of personal data – their technological thumbprint – to die with them. If a work is sent through email, then at least two copies of the work exist, and making additional ones is trivially easy. If emailed or uploaded to a website, the sequence of bits similarly may exist indefinitely on an ISP's server without acknowledgement. These actions may all be against the wishes of the deceased. In short, systems for managing access to files beyond death do not yet exist.

Towards Thanatosensitivity in HCI

Thus far, we have demonstrated how a critical humanistic approach highlights challenges posed by the intersection of death and technology, primarily with regards to authorship. However, authorship (or "usership") is just one of many ways in which death is changing the way we interact with computers. We now introduce the concept of **thanatosensitivity**, a novel, humanistically-grounded approach to HCI research and design that recognizes and actively engages with the facts of mortality, dying, and death in the creation of interactive systems. We illustrate how thanatosensitivity can be applied *as a critical tool* that can be used in formative evaluation to identify possible design problems and identify opportunities for improvement. To further illuminate the urgent need for thanatosensitivity in HCI research and design, we also present several examples of end-users grappling with death with the technological tools available to them today. We emphasize that this paper does not seek to unpack and explain the problems that death may cause with relationship to specific computer systems or areas of research. Instead, we hope that the reader will gain an appreciation for the breadth and reach of problems

which may occur as a result of ignoring the mortality of users in interactive systems, and perhaps challenge readers to adapt their current practices to incorporate thanatosensitivity into their future work.

Applying Thanatosensitive Analysis: Personal Devices
Foucault's concern with the fate of posthumous texts prompts us to address what becomes of digital assets upon death. We amplify the importance of this question by drawing upon Mark Weiser's observation that our interaction with technology is changing in terms of scale [16]. Where groups of people once shared a single computer, now several computers are used, often exclusively, by a single person. Futurists predict that even more personal, wearable, and implantable devices will become widespread in the coming years [10]. As devices become more personal and individualized they become more difficult for others to decipher or employ in the event of mortality, dying, or death.

One compelling example, perhaps adhered to by some readers already, is the recent suggestion by American and British ambulatory care units to program into one's mobile phone a contact named "ICE" (standing for "in case of emergency") so that rescuers can easily identify and call an emergency contact when the phone's owner is possibly dying [4]. The need for this type of preparation crystallizes how difficult it has become to unravel the data stored in highly personalized devices.

Some of this complication has been brought about as a result of computer security measures. A 2001 news story describes how Yahoo! denied the family of a deceased US marine access to his email, preventing them from accessing urgent information sent to the

account owner but necessary for handling the aftermath of his death [11]. As this webmail-based example suggests, this problem is likely to compound with initiatives which seek to place vast amounts of personal information on the web (a philosophy espoused by technology leaders including Google and Microsoft). Passwords do not enable access in the event of emergency or death. A similar, but even more problematic, counterpart to password is biometrics: systems which use biological markers unique to an individual (e.g., retinal scans, thumbprints) and routinely assume a *living* body for access. As more data becomes tied to passwords, remote hosting, and biometrics, access to data following death become increasingly problematic. Is access physically possible? Should all files be accessible after death, or only a few? For whom? Who oversees these details at the time of death? Do users understand the posthumous implications of using biometrics versus passwords? These concerns are predicted by Kafka's situation described earlier. Consider that if Kafka had password-protected his works, neither he as an author nor his extraordinary books would exist today.

Applying Thanatosensitive Analysis in Research

We have demonstrated how thanatosensitivity changes the set of problems encountered by a particular set of commonplace technological tools, including word-processing software, the Internet, and mobile phones. However, thanatosensitive analysis may also be applied more broadly to entire cutting-edge research agendas to question underlying assumptions and suggest avenues for new research questions and projects. We offer one example by applying thanatosensitivity to a familiar concept: that of a future where "smart homes" containing sensors, displays, and actuators provide an

alternative to institutionalization for seniors [5]. These types of technologies promise to restore autonomy, dignity, and cognitive ability to older adults in need of help. Like other researchers in this area, we are optimistic about how these technologies may improve quality of life for their users. However, realistically speaking, little research to date has addressed problems associated with the mortality and death of the occupant. What becomes of such instrumentation upon death? In addition to studies on how to deploy such technologies, should we be considering how to repurpose or “undeploy” these technologies from an unoccupied home? Attendant discussions about privacy must also ask what happens to sensor readings once the individual dies: should they be deleted or saved? Would these types of systems place additional emotional or practical burdens on the family of the deceased? These design issues are currently neglected but brought into focus as a result of a thanatosensitive reflection upon this research area.

Beyond “aging in place”, similar issues emerge across many HCI research areas. We illustrate this breadth by listing just a few subfields of HCI, and research questions uncovered by a cursory thanatosensitive analysis.

- *User-centered design*: Are users considering about their own deaths when they respond to questions about how they would like software designed? Are they concerned about the mortality of others? What insight can they offer into thanatosensitive issues? How do we design for groups of people who will outlive one another or be at different stages of life?
- *User modeling*: Do formal cognitive or sociotechnical models account for the death of actors in these systems? How are actors differentially represented in

states of living or dying? Can death even be adequately represented by formal models in the first place? Is this type of representation useful in the design of long-term systems or not?

- *Intelligent agents*: Can we design intelligent personal agents that operate at a level which permits a person to undertake actions past their natural death? When “reaching beyond the grave” what should these types of agents do? How do we create the data types and algorithms necessary to allow this functionality to occur? Is this a morally and ethically sound proposition, or the realm of science fiction?
- *Research methodology*: How do we sensitively, ethically, and morally address issues of death and mortality in fieldwork? When is it appropriate to raise issues of this nature, and when is it not? How, and should, we handle data gathered from people who die during or after a study? What are the standards for sound research when conducting these types of studies? Do traditional methodologies work, and how should we adapt them?
- *Privacy*: Death changes what constitutes “private” information. What constitutes “inheritable” data? What types of devices/data are considered private in the event of death, and which are not? To whom should responsibility fall for maintaining privacy past death? What kinds of technology-centric work is required in order for people to maintain privacy posthumously?

Answers to any of these questions lie outside the scope of this paper. We hope, however, that this preliminary list suggests the breadth and number of questions able to be raised in consideration of only a few subfields of HCI. We encourage experts in all subfields of HCI to reflect on death, dying, and mortality, and how these issues intersect with their work. We now briefly touch upon some current research and practices which illustrate this intersection.

Thanatosensitive Research and Practice Today

While there exist numerous unanswered research questions surrounding thanatosensitive design, some early work in digital storytelling, photo sharing, and archiving has revealed the emotional importance of inheriting digital assets upon death [14]. These systems may help us gain insight into the identities of our ancestors (similar to reading your grandmother's diary...or blog).

Despite the lack of research, some commercial and personal practices surrounding death do exist. For instance, the website Asset Lock (www.assetlock.com) automatically emails instructions and files to designated people in the event that the account owner dies. However, most consumer software packages are not so explicitly designed for death; instead, people repurpose existing software. Examples include the practice of leaving eulogistic comments on MySpace and Facebook profiles of dead users, turning these sites into ad-hoc memorials, or funeral ceremonies in online gaming communities such as World of Warcraft. Like physical places and religious/cultural practices, these virtual environments allow participants a place to mourn and reflect. These are legitimate reappropriations of technologies by end-users, but do not explicitly address, at a design-level, thanatosensitive issues.

Conclusion

HCI research must contend with the fact that users eventually die. In this exploratory paper we introduce the concept of *thanatosensitivity* in order to explicitly account for questions of human mortality, dying, and death in relation to computer systems. We have shown the variety and richness of scholarship in the humanities which attests to the importance of the

intersection of technology and death. As a secondary epistemological and methodological contribution, we hope this work demonstrates to the HCI research community the benefit of looking beyond the "usual" social sciences (*i.e.*, psychology and sociology) to the humanities, including literature, history, and philosophy, when engaging in interdisciplinary work.

We argued that thanatosensitive analysis of system design and research agendas can suggest design improvements and new avenues for research. We do not make attempts to answer the complex questions raised by thanatosensitive analysis due to the length and involvement of providing satisfactory answers. However, the quantity and breadth of questions raised by this limited exercise clearly demonstrates that thanatosensitivity reveals fascinating paths forward for advancing both design and research. More broadly, as computing increasingly permeates lives and cultures, we hope this paper encourages the HCI community to tackle life's "big issues": mortality, dying, and death among them.

ACKNOWLEDGMENTS

We thank the CIHR-sponsored HCTP program at the University of Toronto.

REFERENCES

1. Boehner, K., Vertesi, J., Sengers, P., and Dourish, P. How HCI interprets the probes. In *Proc. CHI 2007*, ACM Press (2007), 1077-1086.
2. Bolter, J.D. *Writing Space: Computers, Hypertext, and the Remediation of Print*. Lawrence Erlbaum, 2001.
3. Button, G., and Dourish, P. Technomethodology: paradoxes and possibilities. *Proc. CHI 1996*, ACM Press (1996), 19-26.

4. Coates, S. 'ICE' Cell phone place would help rescuers. *Washington Post* (18 July 2005), A06.
5. Dishman, E. Inventing wellness systems for aging in place. *Computer* 37, 2 (2004), 34-41.
6. Foucault, M. *Language, Counter-memory, Practice: Selected Essays and Interviews*. Cornell University Press, Ithaca, New York, 1980.
7. Foucault, M. What is an author? *The Foucault Reader*. Pantheon, New York, New York, 1984.
8. Freud, S. Beyond the pleasure principle. In *Penguin Freud Library, Vol. 11*. James Strachey et al. (eds.), Penguin, Harmondsworth, 1984, 311.
9. Gaver, W. Cultural commentators: Non-native interpretations as resources for polyphonic assesment. *IJHCS* 65(4), 292-305.
10. Harper, R., Rodden, T., Rogers, Y., and Sellen, A. *Being Human: Human-Computer Interaction in the year 2020*. Microsoft Research Ltd., Cambridge, England, 2008.
11. Hu, J. Yahoo denies family access to dead marine's e-mail. *CNET News* (Dec. 21, 2004). http://news.cnet.com/Yahoo-denies-family-access-to-dead-marines-e-mail/2100-1038_3-5500057.html.
12. Kittler, F. A. *Discourse Networks 1800/1900*. Trans. Michael Metteer. Stanford University Press, Stanford CA, 1990.
13. Landy, F. *Beauty and the Enigma: And Other Essays on the Hebrew Bible*. Continuum International Publishing Group, 2001.
14. Massimi, M., Berry, E., Browne, G., Smyth, G., Watson, P., and Baecker, R.M. An exploratory case study of the impact of ambient biographical displays on identity in a patient with Alzheimer's disease. *Neuropsychological Rehabilitation* 18, 5/6 (2008), 742-765.
15. OED. Oxford English Dictionary Online. Oxford University Press. <http://dictionary.oed.com>.
16. Weiser, M. Nomadic issues in ubiquitous computing. <http://www.ubiq.com/hypertext/weiser/NomadicInteractive/>.
17. Wikler, D. Not dead, not dying? Ethical categories and persistent vegetative state. *The Hastings Center Report* 18, 1 (1988), 41-47.