Thanatosensitively Designed Technologies for Bereavement Support

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Abstract

Computing supports a number of activities across the lifespan, from interactive games for children to smart homes for seniors. However, one part of the lifespan which is often overlooked by application designers is the end of life – a period marked by issues of mortality, dying, and death. My thesis takes up this area as its object of study, and does so specifically by examining the bereaved as a target population. I argue that most modern technologies are not designed with proper acknowledgement of the eventual death of their users, and that this oversight results in a series of circumstances which complicate affairs for bereaved family members. Based on evidence from a survey and interview study, I identify opportunities for technology designers to support bereavement activities through a process called "thanatosensitive design." My thesis seeks to contribute methodological insights for designing for the end of the lifespan, a novel system which connects bereaved individuals together, and account of how this system mediates social support.

Keywords

Thanatosensitive design, bereavement, dying, death, domestic technologies, ubiquitous computing.

ACM Classification Keywords

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

General Terms

Design, Human Factors.

Introduction

My research goal is to develop the concept of *thanatosensitive design (TSD)* [1]: the multidisciplinary study, design, and evaluation of computing technologies which actively engage with issues of human mortality, dying, and death [5]. There is little doubt that computing pervades many aspects of modern life, and continues to improve the quality of life for people across the world. Yet technology seems to offer little support at this critical time period in the human lifespan. This comes despite the fact that increasingly, death has a computational component. Computer owners pass away and leave behind hard drives of data, funeral homes create online memorials for the deceased, and "digital natives" are telling their life stories through computers and mobile phones more than ever. This thesis seeks to understand how to design for the end of the lifespan, and explore the impact of domestic ubicomp systems for supporting the bereaved.

Related Work

In conceptualizing TSD, the technological perspective joins the psychological and sociological traditions as a complementary, but unique, way of understanding and alleviating human concerns surrounding death. Indeed,

Stage	Study	Status
1	Web survey and interview study	Completed
2	Elaborating the TSD methodology	Proposed
3	System deployment	Proposed

Table 1. Studies comprising the thesis.

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[1] *Thanatos* is the Ancient Greek personification of death, and a term often used to refer to the Freudian "death drive."

technological design work in this research area has already begun to emerge, with notable efforts including the creation of technological heirlooms [2] and commemorative digital artifacts [7].

When considering bereavement activities, the home is implicated as an important site of technology use for remembering, mourning, and honoring the dead [3]. The home also plays a key role in religious observation (*e.g.*, the Jewish tradition of "sitting shiva"). Based on the home's centrality at the end of life, it stands to reason that domestic ubicomp technologies could sensitively support the bereavement process as they have other diverse family activities, including scheduling [6] and religious observation [8].

Thesis Structure and Progress on Stage 1

My thesis is comprised of three stages (Table 1). The first stage (recently completed) consisted of a web survey and interview study intended to provide a better understanding of how the bereaved inherit, use, and reflect upon personal technologies. The results identified a number of ways that personal technologies complicated, improved, or changed the way that bereaved families handled a loved one's death. These were summarized in a list of ten empirically-grounded opportunities for technological innovation and design.

I have selected one of these opportunities, which I call "*The Support Problem*," to examine in further detail in the remaining two stages of my thesis. This problem identifies the need for bereaved people to provide social support for one another despite distance, and over a sustained period of time. While memorial services and funerals are important times to provide short-term co-located support, there is an on-going need to provide

Figure 1. Example of a private space in the home for remembering the dead through photos (reproduced from [3]).

further support across time and distance. The goal of technologies which address this problem is to better connect bereaved people and provide prolonged, consistent social support following the death of a loved one. At the same time, it is unclear how to design this type of technology without negatively impacting the grieving process, and how to introduce these kinds of technologies as options for the bereaved. For this reason, the goal of Stage 2 is to better articulate and respond to the methodological challenges in TSD, while Stage 3 examines how a new technology for the home changes social support during bereavement.

Stage 2: Elaborating the TSD Methodology

How to sensitively design technologies for the bereaved or dying is a question which remains to be answered. During this stage of my thesis, I propose to analyze, adapt, and refine design activities in order to provide guidelines for conducting TSD. I intend to generate a list of design methods and conduct a critical analysis of their suitability for working with this highly sensitive population; this will be an opportunity to ensure that tools like focus groups, participatory design workshops, questionnaires, interviews, observations, and contextual inquiries are able to be used in a way which upholds the dignity of participants. These new methods will be piloted and adapted with the help of bereaved individuals and grief professionals to ensure the guidelines are both effective and respectful. Lessons learned from attempting these methods can help establish procedural and conceptual "best practices" for conducting TSD in other settings. Specific research questions include:

- What does a TSD process entail? What are the stages of this process? What kinds of activities are

involved at each stage? How do these activities translate into design implications?
- How can we adapt existing data-gathering techniques to be sensitive to the needs of a grieving population? How do these techniques compare and contrast with less sensitive topics and populations?

Stage 3: Evaluating a Domestic Ubicomp System for Bereavement Support

During Stage 2, the content of the design activities will focus on the development of a system for mutual bereavement support. While the design will change as Stage 2 progresses, a preliminary design inspiration comes from the practice of creating and maintaining dedicated spaces in the home for honoring and remembering the dead (Figure 1).

The system under consideration will be a novel in-home device for remembering the dead and providing social support to other grieving individuals. The system will be a small tabletop or wall-mounted touch screen ambient display with a small "altar" area beneath it. I propose this format because my prior work suggested highly personal ambient displays created new opportunities for conversation and sharing identities among family members [4]. Media will be shared between systems, creating a support environment for bereaved individuals. Users will be able to place a sentimental object (*e.g.,* a piece of jewelry) on the altar. The system will detect this object, photograph it and incorporate it into the collage of materials presented on the screen. Other people using the sytem at remote locations will see that a new item has been added and will be able to respond in kind or in alternative modalities (*e.g.,* voice or text messages). This tangible input method leverages a sociological perspective which highlights the role of material objects

in mediating relationships with the dead (such as the jewelry mentioned above) [1].

To evaluate the system, a field study is proposed. Participants will be recruited, with the assistance of a coordinator, from a bereavement support group in the Toronto area called the COPING Centre. All participants will be part of the same regular support group. Members of the group will be asked to use the system in their homes for an 8-12 week period. The effect of the system on these participants, and the ways in which it changes their behavior, will be understood through interviews, questionnaires, observations, and home visits. Qualitative analysis techniques (i.e., grounded theory) will be applied to the collected materials. Specific research questions in Stage 3 include:

- Does this technology meet the goal of providing social support? If so, what does this social support entail, and what kinds of interactions are most valuable to the bereaved?
- Does the system help participants communicate aspects of their loved one's death in new or different ways? Does the physicality and unobtrusive nature of the system allow for new domestic practices?

Conclusion
My thesis proposes to establish and elaborate thanatosensitive design (TSD) as a technique for creating novel systems which can provide support for bereaved individuals. In the course of my thesis, I have three specific goals: to contribute a better understanding of how bereaved people use technology (Stage 1), to develop methods for the TSD process (Stage 2), and to build and deploy a domestic ubicomp system for supporting providing social support (Stage

3). Results from these studies stand to impact the range of services that computing might provide for the bereaved, and contribute to a better understanding of how these services can be designed in a manner that is respectful, dignified, and compassionate.

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