# Technologies for Supporting Bereaved Families

**Michael Massimi**
University of Toronto
mikem@dgp.toronto.edu

## ABSTRACT

Computing supports group activities across the lifespan, but one time period which is often overlooked is the end of life. My thesis examines this area by developing technologies for bereaved families. Based on evidence from a survey and interview study, I identify opportunities for 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 called MyShrine which connects bereaved individuals together, and an account of how MyShrine mediates how individuals provide social support.

## Author Keywords

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

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## General Terms

Design, Human Factors.

## RESEARCH QUESTIONS

Technology designers often overlook the end of the lifespan as a unique time for computing to support group activities. From organizing a funeral to remembering the deceased, the period of time following a loved one's death requires families to work together to provide social support. My thesis asks two main questions concerning this phenomenon: (a) how do we sensitively design for this period of the human lifespan, and (b) what effect might ubiquitous computing technology have on families as they grieve and remember their loved ones? I address these research questions more specifically in the next two proposed stages of my thesis. First, I provide an overview of my progress to date.

## THESIS PROGRESS

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

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

**Table 1. Studies comprising the thesis.**

the way that bereaved families handled a loved one's death. I summarized the results of this study 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 further support across time and distance. There is an opportunity for us to design technologies which 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 bereavement 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 – called MyShrine – changes social support during bereavement.

## STAGE 2: ELABORATING THE METHODOLOGY

How to sensitively design technologies for the bereaved or dying is a question which remains to be answered. Thus, during this stage of my thesis, I intend 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 [3]. As part of this, I propose to analyze, adapt, and refine design activities in order to provide guidelines and opportunities for conducting TSD. I intend to generate a list of design methods and conduct a critical analysis of their suitability

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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."

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 less intrusive and more sensitive to the needs of a grieving population? How do these techniques compare and contrast with user-centered design more generally?

## STAGE 3: FIELD STUDY OF MYSHRINE

During Stage 2, the content of the design activities will focus on the development of a system for mutual bereavement support which will be evaluated in Stage 3. A preliminary design inspiration comes from the practice of creating and maintaining dedicated spaces in the home for honoring and remembering the dead [1].

The system under consideration will be called *MyShrine*, and will be a novel in-home device for remembering the dead and providing social support to other grieving individuals. The form factor of MyShrine will be a small tabletop or wall-mounted touchscreen 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, social support, and sharing identities among family members [2]. MyShrine will allow for media to be shared between shrines, creating a social support environment for bereaved individuals. Users will be able to place a sentimental object (*e.g.,* a piece of jewelry) on the MyShrine altar. The system will detect this object, photograph it and incorporate it into the collage of materials presented on the screen. Other people using MyShrine at remote locations will see that a new item has been added and will be able to respond (*e.g.,* in kind, or in voice or text messages).

To evaluate MyShrine, a field study is proposed. Participants will be recruited, with the assistance of a coordinator, from Bereaved Families of Ontario: an ongoing bereavement mutual support group in the Toronto area. All participants will be part of the same regular support group. Members of the group will receive MyShrine to use in their homes for an 8-12 week period. The effect of MyShrine on this population, and the ways in which it changes their social support behavior, will be understood through interviews, questionnaires, observations, and home visits. Research questions include:

- Does MyShrine provide social support? If so, what does this social support entail, and what kinds of interactions are most valuable to the bereaved?
- Does MyShrine 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?

## BENEFITS OF PARTICIPATING IN THE DC

Attending the CSCW DC will provide me with the opportunity to improve my thesis structure, refine my research questions, and identify new methods for analyzing and presenting my data so that it best contributes to the CSCW community. As a computer scientist, the interdisciplinary perspectives offered by sociologists and designers attending the DC will help determine how I elaborate the TSD methodology, and what kind of system I design in Stage 3. I am also enthusiastic about better understanding how "grief work" or "bereavement work" as accomplished by families can be articulated and explained by concepts such as activity support and distributed work.

## CONTRIBUTIONS AND CONCLUSION

My thesis proposes to establish and elaborate thanatosensitive design as a technique for creating novel systems which can provide support for bereaved families. 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 the first in-home electronic domestic shrine, called MyShrine (Stage 3). The MyShrine deployment study will help technologists understand how domestic ubiquitous computing systems can help meet needs related to the end of life. These results stand to impact the range of services that computers might provide for bereaved families the future, and how these services can be designed respectfully and compassionately.

## REFERENCES

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