Stories from my Thanatosensitive Design Process: Reflections on Working with the Bereaved

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Abstract
Following the loss of a loved one, bereaved individuals often find themselves struggling to deal with a new set of circumstances. Technology designers have the potential to develop systems that allow the bereaved to make sense of their grief and identify appropriate coping mechanisms. In this position paper I reflect on my experiences working with a community bereavement support organization in order to design, develop, and deploy a support group website. I share vignettes from my 3 years of fieldwork performed in partnership with a non-profit peer support organization. I use these examples to raise questions about how to perform research and design with the bereaved and conclude with a set of topics that warrant consideration for HCI work with vulnerable individuals.

Author Keywords
Death, bereavement, thanatosensitive design, reflexivity, social support.

Introduction
The death of a loved one is a difficult experience that we all face in our lives. Those who have experienced such a loss are often referred to as bereaved [9], and are faced with many challenges: transitioning to new
societal roles, the loss of income, handling financial accounts, arranging funeral and memorial services, and so on. Grief – the complex cognitive and emotional response to loss – underscores all of these activities [9]. One way some people cope with grief is by seeking out social support from peers who have also endured a loss; a common format for exchanging this kind of support is via a support group [3, 4]. Like many other kinds of community groups, bereavement support groups have taken root online in various forms [8].

In this paper, I share vignettes from my 3-year research and design process wherein I worked closely with bereaved clients of a non-profit community organization called Bereaved Families of Ontario (BFO), located in Toronto, Canada. This partnership provided a setting for the research comprising my Ph.D. thesis at the University of Toronto¹. Two studies were conducted with members of BFO: (1) a series of focus groups with bereaved parents concerning opportunities for technology to help meet their social support needs [6], and (2) the design and deployment study of a website called Besupp that allows bereaved individuals to participate in online support groups [7].

In this workshop contribution, my intention is to provide a personal account of “doing research” with a vulnerable population. In providing this reflexive first-person account, I hope to reveal how my research activities generated professional and emotional vulnerability that left me and my participants navigating unusual situations. Indeed, as I embarked on this thesis, I suggested the term “thanatosensitive design” as a heading for design processes that seek to sensitively deal with the issues of death, dying, and mortality [5]. It is my hope that the three vignettes outlined below can provide concrete examples of the ethical, methodological, and technological challenges that are introduced by working in this space.

Vignette 1: The Walkout

In 2009, I was conducting a series of focus groups with past BFO clients in order to learn more about how they provided and received social support. My contact at BFO sent out an email on my behalf to invite clients to participate in the research. We determined it would be best to hold the focus groups at BFO’s facility in one of the rooms normally used by support groups, as it provided a place where participants would feel safe. Knowing that I had never been part of a bereavement support group, my contact offered to sit in on the session, which I gratefully accepted.

Six participants responded and arrived for a focus group that took place on a Tuesday evening. Consent forms were distributed and completed, I introduced myself and the purpose of the study, and I started with my set of questions. As the discussion began, participants shared openly about their losses. I noticed that one participant, who was accompanied by her husband, was becoming increasingly emotional: her eyes welled up and her face flushed as she reached for the box of tissues on the table. About ten minutes into the discussion, her emotions overcame her and she broke down sobbing. My BFO contact tactfully inquired if she was able to continue; she was too emotional to answer, and her husband responded by excusing them both and driving home.

¹ All research activities described in this paper were approved by the University of Toronto Research Ethics Board.
I continued with the focus group with the remaining participants, and we concluded approximately 2 hours later. I was concerned about the walkout, and I asked my BFO contact about the participants who had left. She mentioned that their son had died just a few weeks ago and that she was surprised when they responded to the recruitment email. At the same time, she assured me by saying that this happened regularly in the support groups she had facilitated in the past, and that we handled it appropriately. The remainder of my focus groups proceeded without incident.

Reflections and Issues
This experience taught me a few important things about working with vulnerable populations. First, I needed to be much clearer in my participant recruitment. Although the recruitment email explained that I was a researcher affiliated with a university and that this was an academic study, there were reasons that participants might have confused the session with a support group: the familiar location, the presence of a facilitator, the email originating from a BFO volunteer, the small group size, the evening timeslot. In subsequent recruitment I tried to be much clearer about the purposes of the sessions, but was still greeted with puzzlement from many participants – why would someone from a computer science department want to talk to a bereaved person about their grief? This experience made me realize the importance of clearly explaining my presence and interest in this topic.

In retrospect, I was very lucky to have a trained BFO facilitator present to help me navigate this sensitive situation. Enlisting professionals has been a successful way of going about design work (e.g., [1]) and when one is working with vulnerable populations, the presence of a professional is paramount. To this end, I adjusted my protocol to ensure that a trained facilitator or psychologist was on-call when I was performing my research in order to help guide me through these kinds of situations.

In addition to working alongside professionals, researchers working with vulnerable people can benefit from professional development programs that focus on improving interpersonal and clinical skills. Following this encounter, I enrolled in weekend seminars focused on bereavement counseling that were offered by the Faculty of Social Work at my University. In particular, this allowed me the opportunity to practice interviewing the bereaved under the tutelage of professionals, and taught me how to sensitively respond to emotional reactions such as crying. As the next vignette will also illustrate, working with vulnerable people requires practice and planning for heightened emotions.

This vignette also raises some procedural questions. What is the appropriate response for handling situations where a subset of participants drop out? I couldn’t abort the focus group entirely, as 4 participants were still interested and had graciously taken the time to volunteer. In my situation, I continued on and did not follow up with the two participants, and relied on the expertise of the BFO facilitator. Was this the right course of action, or should there have been additional steps taken on my part?

Vignette 2: A Cry for Help?
In the final stage of my thesis I was conducting interviews with bereaved participants who had volunteered to use a website I developed. One
participant, Maria\textsuperscript{2}, was a widow in her 60s. I first met her at a group interview with other participants, and she was enthusiastic about being a part of the research study. As part of my research protocol, I then conducted one-on-one interviews with each participant in order to gather information about their prior experiences with technology, bereavement, and social support. I phoned Maria on a weekday afternoon to conduct this interview, which lasted about an hour. The enduring nature of grief was a topic she raised repeatedly in her interview, and she provided me with insightful comments about technology’s role in this regard.

Near the end of the interview, Maria’s comments became more worrying. She described how her grief engulfed her, and that she sometimes felt like she could no longer go on living. At this point I became concerned about Maria’s safety. I had prepared for this eventuality, and kept her on the phone for a few more minutes and shifted the conversation to her experiences using websites – a less loaded topic. Before hanging up, I told her that I would be calling her back shortly.

I spoke to my thesis supervisor about the situation, and we immediately telephoned the professional grief psychologist who helped to supervise my research. I related her exact wording to him, and he assured me that this was normal behavior in dealing with the bereaved. He pointed out that because her wording was vague, and because her loss was over 10 years ago, that he felt confident Maria was not in danger of self-harm. I then called Maria back, and told her that I had consulted with my colleague about her statement. She assured me she would be fine, and I gave her my colleague’s phone number as a precaution. Over the next three months, Maria remained an enthusiastic participant in the study and made no further mention of suicidal ideation.

\textit{Reflections and Issues}

This situation was one of the most worrisome in my research with the bereaved and raises an issue of participant monitoring. In this case, Maria was able to continue to participate in the study successfully. Following this incident, however, I needed to monitor her participation in interviews and through her use of my software to look for warning signs. \textit{What responsibility do we – during research, design, development, and deployment – have to protect vulnerable individuals from threats their safety?}

While I had taken some bereavement counseling courses and spoken to the grief psychologist on my committee about this contingency, reacting to this situation as it unfolded was enormously stressful for all involved. This alerted me to the importance of self-care and avoidance of “compassion fatigue”\textsuperscript{2}. In dealing with vulnerable individuals, it is common to empathize with their situations and react to them with one’s own concerns and experiences. While in many interview or laboratory studies it may be reasonable to run 8 participants in a single workday, the same is not necessarily true when working with vulnerable populations. Because of the emotional intensity, I was sure to schedule enough time for myself to recover and prepare between interviews.

\textsuperscript{2} All names used in this paper are pseudonyms.
Vignette 3: Re-opening Old Wounds

As mentioned above, my research involved the development of a prototype website that allowed participants to gather in online bereavement support groups. Participants in my study used this website for 10 weeks, with interviews occurring at the beginning, middle, and end of this time period. Halfway through the study, I conducted an interview with Sara, a young woman who lost a sibling 2 years ago. She had completed a support group at BFO 1 year before beginning with in the study.

From reviewing the system logs, I could see that Sara had only logged into the website a handful of times, and less than other people in her support group. I asked Sara to talk about her usage, and in particular, the points in time when she felt the website was particularly helpful or unhelpful. To this, Sara responded thusly:

“It was very hard for me emotionally and way harder than I thought it would be after hearing everyone's story. I felt like... pretty upset about it truthfully. It was hard for me to come back... hearing all the sad stories again was really hard for me to take because I'm in a different place now... people using it seem to be getting a lot out of it but for me I'm just a bit heartbroken.”

From this response, I could see that Sara – though initially interested in participating in an online support group – found her continued participation to be emotionally difficult. It was clear she was only logging in because of the study, so I assured her that she could stop at any time without any repercussions. She decided to continue, however, and completed the remainder of the study, although with relatively little participation in the group. Her final interview reiterated the same sentiment.

Reflections and Issues

Sara’s interview response helped to explain the small number of logins to the website and raises some design considerations, which are reported elsewhere [7]. Reflecting on this encounter, however, raises the issue of participant reimbursement. In the study, participants were compensated $10 per week (up to a total of $100 for 10 weeks) that they logged in. This scheme was originally set out because one of the goals of the study was to examine change in perceived social support and grief symptomology over time, and that by promoting continued usage, this question could be adequately addressed. In light of this occurrence, I believe that vulnerable participants may benefit from nontraditional methods of compensation. Indeed, at the end of the study, more than half of the participants donated their $100 to BFO; their compensation was in “repaying” an organization that provided them with support shortly after their loss.

Sara discusses how hard it is for her to revisit her loss, but it raises an important question: is continued participation advised? On one hand, she may be able to find support and relief by availing herself of the opportunity to talk about her continuing grief on the website. On the other, avoiding the discussion could allow her to continue coping in her own way – one that has been so far helpful for her. In all of this, though, the ultimate decision to continue must be made by the participant – but this suggests that with vulnerable populations, there may be times where a researcher will need to intervene and put the interests of the participant above the interests of the study.
Conclusion
In choosing the vignettes above, I hope to have highlighted some of the ways that working with a vulnerable population is different from more traditional user research. At the workshop, I hope that these vignettes provide concrete examples that prompt discussion around larger questions for the HCI community:

1. How do we approach vulnerable populations? How do we explain to participants our motivations for conducting research in a way that makes sense?

2. How can we build relationships with professionals from other disciplines that have more experience with vulnerable populations? What can we learn from them, and how can we learn it (e.g., classes, discussion, observation)?

3. How do vulnerabilities manifest themselves in the course of interviews, focus groups, or other data collection activities? What are appropriate ethical and reasonable responses?

4. How should participants be compensated? Are there ways of showing appreciation for their participation beyond financial reimbursement?

5. What are our responsibilities to vulnerable participants who may unintentionally be at risk of emotional pain? Should we monitor this during studies? If so, how and when should we intervene?

In particular, I hope to pose these questions to those working with diverse populations in order to identify best practices for HCI researchers.

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References


Author biography

Michael Massimi is a Post-Doctoral Researcher in the Socio-Digital Systems group at Microsoft Research in Cambridge, UK. His research focuses on technology's role during life-changing events such as marriage, parenthood, and the death of a loved one. His work has explored the role of technologies for social support, communication, and memory as they relate to these transitory times. He has worked with several vulnerable populations including bereaved individuals, older adults, individuals with language disorders, patients with Alzheimer’s disease, and family members of hospice residents. He serves as the Webmaster of the International Working Group on Death, Dying, and Bereavement and was awarded the Noah Thorek award for contributions to Bereaved Families of Ontario – Toronto. He is an alum of the Health Care, Technology, and Place doctoral training program at the University of Toronto, where he earned a Ph.D. in Computer Science.

Reasons for Participation

I hope to participate in this workshop for the following reasons:

1. To learn about ongoing research efforts concerning vulnerable individuals;
2. To share experiences stemming from my work, and to identify best practices through discussion with others who have encountered similar situations;
3. To forge relationships with other researchers working in challenging settings.