



STORIES FROM MY THANATOSENSITIVE DESIGN PROCESS

REFLECTIONS ON WORKING WITH THE BEREAVED



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The death of a loved one is a difficult experience we all face in our lives. Those who have experienced such loss are often referred to as bereaved, and are faced with many challenges: transitioning to new societal roles, handling financial matters, arranging services, and so on. Grief—the complex cognitive and emotional response to loss—underscores all of these activities [1]. 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 [2].

Here, I share vignettes from a three-year research and design process

wherein as part of my Ph.D. I worked closely with bereaved clients of a nonprofit community organization called Bereaved Families of Ontario (BFO). Two studies were conducted with members of BFO: a series of focus groups with bereaved parents concerning opportunities for technology to help meet their social support needs [3], and the design and deployment of a website called Besupp that allowed bereaved individuals to participate in online support groups [4].

My intention is to provide a reflective personal account of doing research with a vulnerable population. By sharing specific vignettes about my

work, I hope to reveal how my research activities left me and my participants navigating unusual situations. Indeed, as I embarked on this work, I suggested the term *thanatosensitive design* as a heading for design processes that seek to sensitively deal with these issues of death, dying, and mortality [5]. The three vignettes here provide concrete examples of the ethical, methodological, and technological challenges that are introduced by designing for and with a particularly vulnerable population.

VIGNETTE 1: THE WALKOUT

In 2009, I was conducting a series of focus groups with bereaved parents.



My contact at BFO sent out an email message on my behalf to invite former clients to participate. We agreed to hold the focus groups at BFO's facility in a room normally used by support groups, as it would provide 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 agreed to.

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 then 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. About 10 minutes into the discussion, she broke down sobbing. My BFO contact tactfully inquired if she was able to continue; she couldn't answer, and her husband responded by excusing them both and leaving.

I continued with the focus group with the remaining participants, and we concluded two 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 reassured 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 to be more explicit in my participant recruitment. Although the recruitment email explained that I was an academic researcher, there were reasons that participants might have confused the session with a support group, such as the familiar location, the presence of a facilitator, the small group size, and the evening timeslot. In subsequent communication I revealed more about the purposes of the sessions, but was still greeted with puzzlement from many participants—why would a computer scientist want to talk about grief? This experience made me realize the *importance of clearly explaining my presence and interest.*

I was very lucky to have a trained BFO facilitator to help me navigate this sensitive situation. Enlisting professionals has been a successful way of going about design work, and when one is working with vulnerable populations, *the presence*

of a professional is paramount. I ensured a trained facilitator 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 must learn, themselves, how to become "para-professionals."* Following this encounter, I enrolled in weekend seminars focused on bereavement counseling at my university. This allowed me the opportunity to practice interviewing the bereaved under the tutelage of professionals, and taught me how to respond to reactions such as crying. As the next vignette will also illustrate, *working with vulnerable people requires practice and planning for heightened emotions.*

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, was a widow in her sixties. As part of my research protocol, I 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 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 I would be calling her back shortly.

I spoke to my colleagues about the situation, and we telephoned a professional grief psychologist who helped to supervise my research. He assured me this was normal behavior in dealing with the bereaved and 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. I gave her his phone number and explained that he was happy to talk at any time. She assured me that this step wasn't necessary and that she was feeling fine. Over the next three months, Maria remained an enthusiastic participant in the study and made no further mention of harming herself.

Reflections and issues. This situation was one of the most worrisome in my research and raised the issue of *participant monitoring*. Following this incident, I needed to monitor her participation in interviews and look for warning signs through her use of my software. Unique here for HCI researchers (as opposed to psychologists, for example) is the fact that the technology under evaluation might give us opportunities to more closely monitor the well-being of our participants. This introduces benefit, but also obligation.

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"* [6]. In dealing with vulnerable individuals, it is common to empathize with their situations and react to them with one's own concerns and experiences. Because of the emotional intensity, I subsequently scheduled breaks for myself to recover and prepare between interviews.

VIGNETTE 3: REOPENING OLD WOUNDS

As mentioned earlier, 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 two years ago.

From reviewing the system logs, I could see that Sara had logged into the website only a handful of times, less than other people in her support group. I asked Sara to talk about her usage, and she responded:

"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 an online support group—found her continued participation to be difficult. It was clear she was logging in only 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 sentiments.

Reflections and issues. Sara's interview response helped to explain the small number of logins to the website and raised some design considerations, which are reported elsewhere [4]. Reflecting on this encounter, however, raises the issue of continued participation. Sara discussed how hard it was for her to revisit her loss, but it was not my place to tell her to quit the study, either—only to be clear that it was an option. On the one hand, she might have been 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 so far had been helpful for her. In all of this, the ultimate decision must be made by the participant. But this suggests that with vulnerable populations, *there may be times when 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 in which working with a vulnerable population differs from more traditional user research and that these concrete examples prompt discussion around larger questions for the HCI community:

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

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

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

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

I pose these questions to those working with populations of all sorts in order to stir up discussion and help us move toward best practices as a field. Sharing and discussing these issues—even if they are uncomfortable, even if they make *us* feel vulnerable—are increasingly important as we build and study technologies meant to help people in their hour of need.

ENDNOTES

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