

Mobile Technologies for Grief Support: Prototyping an Application to Support the Bereaved

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Abstract

The experience of grief and death is an inevitable part of life. Grief, a natural response to death, can be a challenging and emotionally taxing journey. Bereaved individuals often feel lost in a fog of grief, unaware of the resources that are available to them or are unsure which resources could be the most useful. The intersection of grief and technology presents both an interesting challenge and opportunity for the HCI community to design technological tools to support the grieving process. In this paper, we present the results of our survey and interview study on the technological practices of the bereaved. We surveyed both online and local in-person support groups. We then used iterative, inductive analysis and open-coding to analyze our survey data. From this analysis, we identified four common themes: connection, research and reading, legacy, and finding a personal preference for support groups. Based on these themes, we prototyped a mobile application to support the bereaved and those close to them. This prototype creates a centralized space for resources for both the bereaved and those in their support network, and includes educational content on grief, links to local and online support groups, and a tool for sharing individual stories of grief and loss.

Introduction

Loss and grief are a part of life that nearly all individuals experience. But while they are common experiences, coping with the loss of a loved one is never an easy task. Understanding grief and loss often takes time, making it a potential challenge for people to recover and accept the death of a loved one¹. During this time, it is common for the bereaved to seek acceptance, support, compassion, and understanding². They may turn to in-person grief support groups and individual grief counselors to help process their grief. They may also go online to seek out internet support groups and other grief-related resources. Grief presents both a challenge and an opportunity for the HCI community. The better we understand the needs of the bereaved and the ways in which they cope with their losses, the more capable we will be of designing tools for individualized grieving.

In this work, we delve deeper into our current understandings of the bereaved, their needs, and their technological practices. First we present previous work in the grief and technology space. Next, we present the results of our survey and interview study. Finally, we present our prototype for a mobile grief support application.

Related Work

The HCI community has historically focused on three main areas within grief and technology research: digital memorials^{3,4}, expression of grief on social networking sites (SNSs)^{2,5,6}, and the development of grief-specific technological tools^{7,8}. Moncur et al. developed a framework for digital memorials, which she utilized to create Storyshell^{3,4}. Brubaker et al. examined how MySpace⁵ and Facebook⁶ serve people as online spaces for grief expression. He later presented the Legacy Contact for managing and stewarding the online data the deceased leave behind⁹. After several studies that sought to better understand the bereaved through an HCI lens¹⁰⁻¹², Masssini et al. created the Besupp website to allow bereaved individuals to connect in a novel online space⁷, and Dominick et al. created an internet-based tool designed to help uncomplicated grievers process their grief⁸.

While these works have illuminated our understanding of the bereaved and how to design for them, none have approached the intersection of grief and technology through a clinical lens. In this work, we aimed to better understand the technological practices of the bereaved from both a clinical and a holistic perspective. We sought to answer the following questions: (1) What kinds of technology do bereaved individuals use while grieving? (2) How is technology currently used to assist the bereaved in coping with loss? and (3) What differences in support do bereaved individuals experience in online versus in-person grief support groups?

Methods

We created a survey and interview study designed to gauge participants' technological practices, coping strategies, experience in grief support groups, and overall progression through their grief journey.

Study Recruitment

We approached the administrators of online grief support groups on sites like Facebook as well as the facilitators of in-person support groups in the local Bloomington, Indiana area. We recruited participants for our study through these group administrators and facilitators rather than directly approaching support group members in the interest of protecting the members' privacy. Upon agreeing to participate in our research, participants were provided with a consent document introducing our project and were then asked to complete a survey. This study was approved by the Institutional Review Board at Indiana University.

Survey

The survey consisted of questions adapted from three validated instruments: the Inventory of Complicated Grief (ICG)¹³, the Texas Revised Inventory of Grief (TRIG)^{14,15}, and the Coping Strategies Questionnaire (CSQ)¹⁶. In addition to these standardized instruments, we included new, technology-focused questions in the CSQ. These questions investigated practices such as blogging as a distraction, listening to music when perceiving pain, and using mobile apps to find uplifting or comforting content, among other practices. We also included open-ended questions to gauge the participant's experience in their support group, the kinds of technologies they used throughout their grieving process, and what they found useful or challenging when using technologies to cope.

Data Analysis

We used open coding¹⁷ to analyze the survey responses. Emergent themes were discussed among all the authors and iteratively refined as the coding process continued. Four themes resulted from the coding process: connection, research and reading, legacy, and finding a personal preference for support groups. We will elaborate on the findings below.

Findings

Participant Demographic

73 individuals completed our survey. Survey respondents were 18 years of age or older, most of whom had lost their loved one within the last five years. The majority were white (88%) females (96%) between 45 and 54 years of age (29%). 92% of respondents were members of online grief support groups and 47% had experience in with an in-person counselor or group.

Online v. In-Person Support

Among the factors that online group participants mentioned when describing their like of online groups were 24/7 availability, anonymity, the lack of pressure to participate, and lack of judgment. Over half of online group participants indicated they found their group helpful. However, some (15%) did find the groups overwhelming or depressing, often because of the deluge of posts from other grievers. Of those participants who had experience in in-person groups or counseling, several valued the immediate, face-to-face interaction. However, those who did not prefer in-person groups often provided much stronger responses as to why (compared to their responses about their online group experiences). Reasons for disliking these groups included feeling overwhelmed at physically seeing others' pain in person, feeling talked over, and feeling unable to relate to groups that were not tailored to their specific kinds of grief.

Connection

Our participants communicated the importance of connection in a variety of contexts. 36% of participants spoke of a time when they connected with others who had had similar grief experiences; this occurred in both in-person and online groups. Talking to these similar others often helped participants to normalize or validate their own grief.

Besides connecting with the living, many participants (47%) attempted to contact the deceased at some point after the death. Writing to the deceased in some form (including social media posts) was the most common form of contact.

Research and Reading

Conducting their own research related to grief and reading often served as important components of our participants' grief experiences. 27% indicated they read some form of media, including articles and books on grief, stories about others' experiences, and even quotes and poetry.

Legacy

Participants frequently engaged in practices meant to enable their deceased loved one's legacy to live on. These practices included posting about their loved one, tagging them on social media, writing about them, and participating in social events designed to raise awareness of the nature of the death. For example, many of our interview participants were survivors of suicide loss and mentioned their involvement in the Out of the Darkness walk.

Discussion

The themes of connection, research and reading, legacy, and differences in online versus offline support collectively demonstrate that grief is a very personal journey. Individual grieving styles and practices vary from person to person, making a "one-size-fits-all" approach to grief inappropriate. With this knowledge, we created a prototype of a mobile application for grief support that provides a space for the user to make personalized decisions in their approach to grieving. Here, we present this application and its five key sections: "How Are You Feeling?", "Support Groups", "Fast Facts", "Share Your Story", and "Support a Griever".

Grief Application

How Are You Feeling?

After losing a loved one, individuals experience a range of emotions. The overwhelming range of emotions can often lead to feelings of apathy or numbness. To encourage our potential users to inadvertently be aware of their feelings, we have designed a rating scale for the bereaved to use when they first open the mobile application. The user is prompted with the question, "How are you feeling today?" By asking our user how they are feeling, we hope the bereaved will become more mindful of their emotions. This feature relates to the mental health of bereaved users. If they are conscious about how they are feeling, and actively not seeing any change over time, it may urge them to seek professional help.

Support Groups

The importance of support groups in our participant's responses was a factor that could not be ignored. Having the support of others can help alleviate the pain of losing a loved one. Moreover, support from griever who also experienced the same type of death can be comforting and can open the door for connecting with others. Our participants noted that belonging to a support group where they could share their story, listen to others and give and receive advice about coping with the loss of a loved one was extremely beneficial. While online readings were able to support people in understanding certain aspects of grief, interacting with actual people either in online or in-person groups provided a strong sense of support to the griever who participated in our study.

We included a "Support Groups" feature in our application because our participants expressed feeling out of place, or guilty in certain support groups because the type of loss was not the same. With this feature, our users are given the freedom to search for online and in-person support groups that they can identify with, without feeling pressured. We provide a list of in-person groups based on the zip code a user enters, as well as a list of online support groups tailored to their type of loss. Many of our participants had a strong preference towards either online or in-person support groups, which is why we decided to provide users with the resources to identify the group(s) that best support them. Groups where people have experienced similar losses were beneficial in creating strong connections among group members as they could better relate to each other.

Fast Facts

Grief is often an overwhelming experience for people, making it difficult to identify quality information and support groups from those that fail to provide the necessary support to those who need it. To alleviate some of this stress on

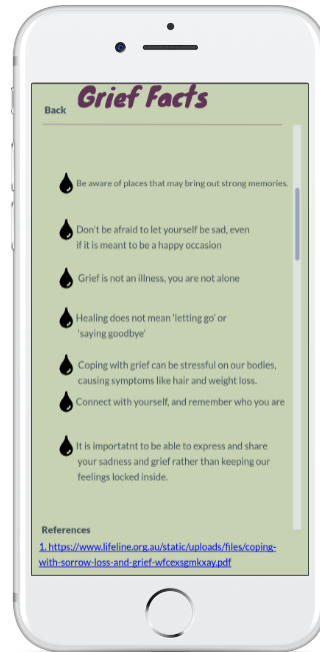


Figure 1: Fast facts for grievers to read

grievers, we created a page of grief fast facts with the intent of providing grievers with a consolidated list of common facts about grief (see Figure 1). We wanted to reduce the stress on grievers as they try to identify quality information regarding grief. Many of our participants noted that when they first began their grief journeys they wanted to know as much about grief and the loss of their loved one as they possibly could. Searching through all of the search results on a web browser can be trying and frustrating for people who are already vulnerable. The Fast Facts feature helps mitigate some of this frustration.

Share Your Story

This desire to tell the story of the loss and grief journey is expressed in a variety of ways. Due to the nature of this study and the fact that we primarily sought out participants in online support groups, the primary method of storytelling for our demographic was sharing to social media. The bereaved may share their stories in written form, such as a post on Facebook, or visual form, as a photo. In our application, we created a space for the bereaved to write their own stories and read the stories of others (see Figure 2).

Support a Griever

Wanting to support a grieving loved one but having no idea how can be a frustrating experience for everyone involved. It is difficult to watch someone go through such a difficult time, especially when there are a multitude of ways to try to support the bereaved. Moreover, misunderstandings may arise when the bereaved grieve in a way that is very different than how their support system thinks they should grieve. To help avoid situations like this, we created the "Support a Griever" section. Here, users can read about grief, some of the best things to do to support their loved one, things they should avoid, and frequently asked questions. Essentially, we wanted to create a central hub of information designed to minimize conflict and increase understanding.

We found that it was important to include resources for those who want to support a griever because many of our participants noted that their loved ones tried to support them but actually made their grief journeys more difficult. People may try to support their loved ones without actually understanding what their loved one is going through. While everyone's experience with grief is unique, if someone has not experienced grief, it is even more difficult to understand what the grieving experience is like.

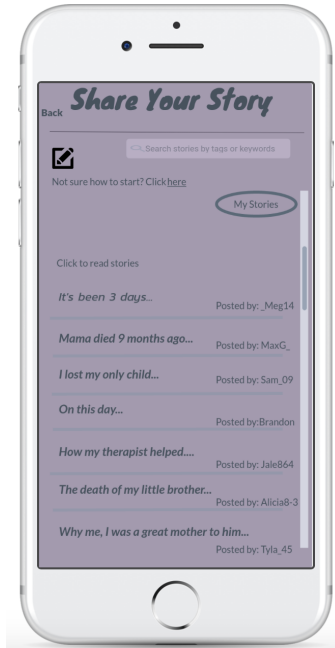


Figure 2: Share your story feature

Limitations

We believe that, due to the vulnerable nature of grief, reaching out to group coordinators (rather than directly to potential participants) was in the best interest of protecting the privacy of the bereaved. However, this placed a damper on our ability to reach a wider population of survey respondents. Additionally, our respondent demographic was highly homogeneous in terms of ethnicity, gender, and age.

Conclusion

We have presented the results of our survey and interview study on the technological practices of the bereaved, as well as our prototype of a mobile grief support application. The work provides us with a better understanding of people's experiences with grief and the role that technology plays in their grief. A tool that will allow the bereaved to remember their loved one in their own way and at their own pace could serve as a robust, individualized support resource. Moreover, the HCI community can employ its current knowledge of digital memorials, SNS's, and specialized grief support tools to build upon the concepts put forth in this prototype. Our future work will focus on implementing our prototype, with considerations for incorporating music into the application.

Acknowledgements

We would like to thank our survey respondents for sharing their stories with us. We also thank the National Science Foundation for funding this research. Grant number CNS-1560267.

References

- [1] Pin Sym Foong. Designing technology for sensitive contexts: Supporting end-of-life decision making. In *Proceedings of the 20th Australasian Conference on Computer-Human Interaction: Designing for Habitus and Habitat*, OZCHI '08, pages 172–179, New York, NY, USA, 2008. ACM.
- [2] Ruth M. Swartwood, Patricia McCarthy Veach, Jessica Kuhne, Hyun Kyung Lee, and Kangting Ji. Surviving grief: An analysis of the exchange of hope in online grief communities. *OMEGA - Journal of Death and Dying*, 63(2):161–181, 2011. PMID: 21842664.

- [3] Wendy Moncur and David Kirk. An emergent framework for digital memorials. In *Proceedings of the 2014 Conference on Designing Interactive Systems*, DIS '14, pages 965–974, New York, NY, USA, 2014. ACM.
- [4] Wendy Moncur, Miriam Julius, Elise Van Den Hoven, and David Kirk. Story Shell: the participatory design of a bespoke digital memorial. *Participatory Innovation Conference 2015*, pages 470–477, 2015.
- [5] Jed R Brubaker and Gillian R Hayes. We will never forget you [online]: An Empirical Investigation of Post-mortem MySpace Comments. *Cscw2011*, pages 123–132, 2011.
- [6] Jed R. Brubaker, Gillian R. Hayes, and Paul Dourish. Beyond the Grave: Facebook as a Site for the Expansion of Death and Mourning. *The Information Society*, 29(3):152–163, 2013.
- [7] Michael Massimi. Exploring remembrance and social support behavior in an online bereavement support group. In *Proceedings of the 2013 Conference on Computer Supported Cooperative Work*, CSCW '13, pages 1169–1180, New York, NY, USA, 2013. ACM.
- [8] Sally A. Dominick, A. Blair Irvine, Natasha Beauchamp, John R. Seeley, Susan Nolen-Hoeksema, Kenneth J. Doka, and George A. Bonanno. An internet tool to normalize grief. *OMEGA - Journal of Death and Dying*, 60(1):71–87, 2010.
- [9] Jed R. Brubaker and Vanessa Callison-Burch. Legacy contact: Designing and implementing post-mortem stewardship at facebook. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, CHI '16, pages 2908–2919, New York, NY, USA, 2016. ACM.
- [10] Michael Massimi and Ronald M Baecker. A Death in the Family: Opportunities for Designing Technologies for the Bereaved. In *Proceedings of the 2010 SIGCHI Conference on Human Factors in Computing Systems*, pages 1821–1830. ACM, 2010.
- [11] Michael Massimi and Ronald M Baecker. Dealing with Death in Design: Developing Systems for the Bereaved. pages 1001–1010, 2011.
- [12] Michael Massimi. Technology and the Human Lifespan: Learning from the Bereaved. *Interactions*, pages 26–29, 2011.
- [13] Holly G. Prigerson, Paul K. Maciejewski, Charles F. Reynolds, Andrew J. Bierhals, Jason T. Newsom, Amy Fasiczka, Ellen Frank, Jack Doman, and Mark Miller. Inventory of complicated grief: A scale to measure maladaptive symptoms of loss. *Psychiatry Research*, 59(1):65 – 79, 1995.
- [14] Andrew Futterman, Jason M. Holland, Patrick J. Brown, Larry W. Thompson, and Dolores Gallagher-Thompson. Factorial validity of the texas revised inventory of grief—present scale among bereaved older adults. *Psychological Assessment*, 22(3):675–687, 2010.
- [15] Gerta Dume. Exploring bereavement in albanian college students. Master's thesis, Ball State University, 2011.
- [16] Michael Robinson, E., Joseph Riley, Cynthia D. Myers, Ian Sadler, Steven Kvaal, Michael Geisser, and Francis Keefe. The coping strategies questionnaire: A large sample, item level factor analysis. 13:43–9, 04 1997.
- [17] Juliet Corbin and Anselm Strauss. *Basics of qualitative research*. Sage, 2014.