

Technology as an Effective Tool for Grief

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ABSTRACT

Bereaved individuals often feel lost in a fog of grief. Many people may enter the grieving process not knowing what resources are available to support them. In this paper, we present the results of our research regarding griever's use of technology. We surveyed online and local in-person support groups. We used iterative, inductive analysis and open-coding in Dedoose to analyze the survey data. We identified reoccurring themes in participant responses. Our results show that the common needs for coping include: connection, research and reading, legacy, and finding a personal preference for support groups. Based on these common themes, we prototyped a mobile application to support the bereaved and those close to them. The prototyped app centralizes resources for grievers and their support system.

Keywords

bereavement, grief, technology, support, legacy, life, death, technology design

1. INTRODUCTION

Coping with the loss of a loved one is never an easy task. During the grief process most people have to handle a range of strong emotions that could be alleviated by the use of technology. Therefore, it is necessary to develop technological tools to support the bereaved throughout their grief journey. Grief is a never-ending journey, and the needs of grievers shift over time [14]. This shift in needs makes it difficult for Human Computer Interaction (HCI) designers to develop technologies to assist with the grief process.

To better understand the grief community, we define the different types of grief people may experience. The types of grief relevant to our research include: anticipatory grief, normal grief, and complicated grief[3]. A person may experience anticipatory grief when they have to care for someone who has been given an end of life diagnosis (i.e. cancer, diseases, old age). Normal grief describes those who are able

to accept the loss. In contrast, complicated grievers have trouble accepting the death of their loved one. They often have intense thoughts about them long after the death [3]. In our study, many of our participants scored as complicated grievers.

Understanding how the phases of the grieving process could potentially effect grievers is insightful for this research study. The generalized phases of grief are shock and numbness, yearning and searching, despair and disorganization, and reorganization and recovery. These phases are fluid, and a person can transition between each at any point in their journey. Knowing the possible behaviors of grievers during their grief journey influenced the design for our mobile application prototype. After the death of a loved one, the bereaved may or may not experience numbness and apathy about current circumstances. As time starts to unfold they exhibit a range of emotions such as disbelief, anger, loneliness, envy, and guilt. Eventually, the intensity of the death becomes manageable, allowing them to continue living with the acceptance of loss [4].

Grief affects nearly everyone at some point in their life. Because this is such a vulnerable time for the bereaved, many need dedicated support systems to back them. Social media provides a form of support for some grievers as its prevalence in society increases. Research exploring the interaction between grief and technology exists but not to the point that we fully understand technology's role in grief. Current research in this area investigates grief and bereavement by understanding what grief is and the common behaviors of the bereaved [16].

There are several resources currently available to support and encourage the bereaved. These resources include online and in-person support groups, digital memorials, *Lifeline*[1], and tool-kits[2]. During the grieving journey, it is very common for the bereaved to feel alone and isolated [23]. It can be difficult for them to connect and express their feelings to those around them who care. Problems that arise during the grief process include trying to understand what one is feeling and whether those feelings are normal [17]. Therefore, we designed a technological tool that promotes communication and understanding of how to cope with the death of a loved one.

Due to the prevalence of technology and social media in our lives, it is logical to increase the use of technology for

grief support. Massimi and Baecker created an online tool specifically for griever, but it had drawbacks, including a lack of separation between media that could trigger a griever and media that would not [14]. Commonly used mediums for the bereaved include social media, digital memorial pages [9, 15], and online grief support groups [13]. Though these are all outlets for coping, there are a limited number of tools that specifically cater to the needs of the bereaved.

To understand how griever feel about in-person and online support groups, we conducted our research to empathize with individuals and to understand grief journeys from their perspective. We also wanted to find out when and why they use technology.

Many questions remain unanswered in this field, but we attempt to answer the following: (1) How do people use certain technologies through the grieving process, (2) How do we improve communication with griever and non-griever, and (3) What are the needs of the bereaved? We aim to understand frequent behaviors among the bereaved and the functionality of technology in the grief process. We provide the following contributions to this area of research: We present a prototype of a mobile application that centralizes resources regarding grief. We also provide detailed insights regarding interactions between the bereaved and their support systems.

2. RELATED WORK

Among existing literature about grief, there has been little focus on the integration of technology into people's grief journeys and the ways in which technology affects one's grief [16]. The ways in which many bereaved individuals handle grief continues to shift to more of a technological experience. Understanding the role that technology plays in people's experiences with grief influences the development of tools to support them with their loss [11]. To understand the grief process, we have identified three common themes throughout related literature about the bereaved and technology: *digital memorials and social media*, *normalizing grief*, and *asymmetrical relationships*.

Social media use is prominent in our society, so the creation of digital memorials serve to memorialize the dead [15, 19]. For many people, having the ability to communicate with those who have passed is a natural part of their grieving process [16]. Rossetto et al. illustrate the paradoxical nature of using Facebook among the bereaved. They note the benefits of sharing information about the deceased to keep their memory alive. The study also points out the problematic situation of having information about the deceased show up on a griever's Facebook page (via Facebook memories or a post), which potentially causes a more difficult grief experience for the bereaved [21].

With the frequent use of social media comes issues pertaining to the privacy of social media accounts after someone dies. Determining who should be in control of the social media accounts left behind by the deceased can be problematic when multiple people wish to be the primary owner of the accounts [11]. Though social media and digital memorials often result after the loss of loved one, problems regarding what happens to the deceased person's accounts can cause

even more stress and grief for those left behind [12]. Addressing this problem, Brubaker and Callison-Burch explore the relevance of creating legacy contacts before one passes to determine how to handle certain accounts postmortem. Without the existence of legacy contacts, it can be difficult to determine what someone "would have wanted" as they are no longer there to speak on their own behalf [5]. Those who interact with digital memorials want to remember certain things about their loved ones, but as Moncur and Kirk note, there is a growing interest in self-memorialization in which a person determines what information will be available about them after their death [15]. For those with differing views on how to handle the digital content of the deceased, friction may occur as people try to compromise on the appropriate action to take regarding the digital content [12].

Understanding grief and loss often takes time, making it a potential challenge for people to recover and accept death [8]. During this time, it is common for the bereaved to seek acceptance, support, compassion, and understanding [23]. Although one's family and friends may try to comfort the bereaved, studies have found that being with others who have experienced a similar loss is more beneficial [17]. There are a variety of ways an individual can come to terms with the loss of a loved one [6]. Sharing stories with others who have experienced losses comparable to theirs typically allows people to develop connections and share their struggles and experiences [14]. The act of storytelling is often beneficial to the bereaved as sharing stories with others who have had similar experiences allows them to know that they are not alone [13].

While having resources and support from others is useful in many people's grief process, it is also valuable for them to have tools they can use on their own. As Dominic et al. discuss, allowing people to use coping tools at their own pace helps them to deal with their experiences with grief uniquely. Technology with a one-size-fits-all type of approach will not work for everyone because of differences in coping style, the cause of death, personality, and grieving style [6].

Many people continue relationships with the deceased [16]. These asymmetrical relationships exist since the dead cannot reciprocate the relationship. Lingel notes the existing differences between biological and social death. While a person may no longer be living, their memory may still be well and thriving in the mind of the bereaved. Trying to maintain social ties is common among griever [11]. The bereaved may call, text, email, and post about the deceased as though they are still alive [16]. It may be hard to find closure if the social media pages of the deceased are lingering among the living. A common example is that the bereaved may be on Facebook and encounter their loved one's page, causing uneasiness. Listening to old voice mails, having access to older pictures, and having technologies that allow the bereaved to interact with the deceased through social media makes it harder to let go [22].

3. METHODS

Upon receiving approval from the Institutional Review Board at Indiana University, we sought out online grief support groups, primarily from Facebook, with at least 50 members to represent a variety of grief experiences in the study. We

also reached out to in-person grief support groups in the Bloomington, Indiana area. We used surveys, open-coding, and semi-structured interviews in this study.

3.1 Recruitment

Participants of this study were 18 years of age or older, most had lost their loved one within the last five years, and had participated in online and/or in-person grief support groups. To ensure ease of accessibility and to have a more diverse pool of participants, we recruited through Facebook grief support groups and by contacting facilitators of in-person grief support groups. 95 people completed our survey. Most of our participants lost someone within the 1-2-year range. Many of our participants were in the age range of 45-54. Our survey results also showed that our participants were mostly female with only 3 male participants.

3.2 Approach

3.2.1 Tools

We administered our survey with Qualtrics using the Inventory of Complicated Grief (ICG) [18] and the Texas Revised Inventory of Grief (TRIG) [10, 7], and an augmented version of CSQ [20]. We chose to use these surveys as they are well-established evaluation instruments in the grief research community that investigate the grief experience. This comprehensive survey consisted of 5-7 open-ended questions, and 13 questions with a Likert scale [6]. The questions were inquiry for technology use as well as demographic data. Examples of questions asked were: “Do you ever use technology to continue to contact your loved one who has passed away? For example, do you still tag them on Facebook, text them, or email them?”, “Did you inherit any kind of digital property or technology from the person who passed away? For example, a computer, digital photos, music files...? If so, what?”, “Have you ever participated in an in-person grief support group? If so, how did/does your experience in this group compare to your experience in the online group?”

3.2.2 Coding

Using the open-coding method, Dedoose, we created a code book based on our survey results. To do this, we read participant survey responses individually and applied codes to excerpts of the responses. We met after each iteration to discuss what we coded and the reasoning for our codes. After we came to a consensus about our codes, we moved on to complete the next iteration. We did a total of four iterations for our code book. The process included grouping codes with similar aspects and removing codes that were not reoccurring.

3.2.3 Follow-Up Interviews

We conducted semi-structured phone or in-person interviews with participants. After receiving consent from the participant, we began recording the interview. 45 participants that took the survey participants who were interested. We scheduled the interviews outside of the participants’ grief support group time and the interviews lasted between 45 and 90 minutes. In addition to follow up interviews with participants, we also interviewed two facilitators of grief support groups to gain further insight into the grief experience.

4. FINDINGS

We successfully identified four prevalent themes based on our analysis: connections, research and reading, legacy, and in-person versus online support.

4.1 Connection

One of the notable findings of our results was the desire of the bereaved to feel connected to others: they are not alone in their grief. Over 80 percent of our participants expressed how helpful it was connecting with similar others. Knowing that there are others going through similar experiences, is relieving for the bereaved. Participants also noted the constant desire of being able to connect to others who have lost their loved one to a similar situation (i.e. perinatal loss, suicide, or cancer). Although family and friends often try to support the bereaved, grievers noted that unless the family and friends have experienced the same type of loss, it is difficult for them to truly understand what the bereaved are going through.

4.2 Research and Reading

Researching and reading about grief and the experiences of other people’s grief was another influential finding of our research. The bereaved are often desperate for information to help them understand their grief or why they lost their loved one. They found resources, bought books, and read articles to cope with the death. Reading other people’s experiences also helped the bereaved as they could relate to others and find comfort. In addition to reading articles and books about grief, participants noted that they read poetry and inspirational quotes.

4.3 Legacy

The idea of keeping the legacy of the deceased alive, often using social media, showed up frequently in our data. Participants mentioned using Facebook memorials and memories when asked about what technology they use to keep in contact with and remember the deceased. Participants actively support events that raise awareness of what caused the death of their loved one for example, the Out of the Darkness walk for survivors of suicide loss. They also tagged their loved one on social media, or commented the name of their loved one on posts to commemorate the deceased. Many of our participants also used technology to continue contacting their loved one. The main forms of contacting the deceased were through texting, email, Facebook messaging, and calling. Participants expressed that were more likely to post about the deceased on birthdays, anniversaries, and “angelversaries”- the date of their loved one’s death.

4.4 Online v. In-Person Support

As we asked our participants about their experiences in online and in-person grief support groups, we gained significant insight on the benefits and drawbacks of both groups. People liked the availability of the online groups and how they had the ability to remain anonymous if they choose. The major drawback of the online group was that people felt that they could not connect with others as well as if they were meeting in person. Another drawback was that the online groups could become overwhelming over after a certain period. The benefits of the in-person groups, in turn, were that they could see people face-to-face and develop stronger

connections with other grievors. The major drawback of the in-person group was that it felt intense and overwhelming for many people as their grief is right in front of them. On-line they had the opportunity to choose when and for how long they participated in the group, but in-person groups were more direct. Belonging to groups that were specific to the type of grief the bereaved experienced was a primary concern for many of the participants. It allowed them to create stronger bonds with other people in their grief support groups.

5. DISCUSSION

Being able to support people throughout their grief experiences is no easy task. Our goal is to create a flexible resource that can assist grievors of diverse backgrounds.

Although we have many ideas of how to improve existing technology to support the bereaved, we must first hear what they would like to see in a technological support tool. We also must acknowledge numerous considerations before designing and introducing technological tools to the bereaved because this is a sensitive time [14, 8]. Due to the lack of technological tools to support the bereaved, we felt that direct feedback from grievors through interviews would provide a solid foundation for our grief support tool [9]. We have scratched the surface, but we need to dig deeper.

Being able to conduct interviews with participants and group coordinators was valuable to this study, as having a conversation with someone reveals much more than an online survey, no matter how comprehensive the survey was. Our participants were very passionate while explaining their battles with grief. One common example we heard was that grieving the loss of a child is significantly different than grieving the loss of someone who passed by suicide.

5.1 Grief Application

Based on our survey and interview data we prototyped an application that addresses the prevalent needs of the bereaved. We incorporated the common themes from the survey and interviews into the app to provide the most support possible to the bereaved.

5.1.1 How Are You Feeling?

Many participants described their early grief experience as being in a fog where they go through the motions of everyday life but they are not fully aware of what is going on. To help combat this, we have designed a rating scale for the bereaved to use when they first open the app. By asking how they are feeling, we hope the bereaved will become more aware of their emotions. Figure 1 illustrates the rating system users interact with.

5.1.2 Share Your Story

As communication and connection with similar others were key factors to consider, we decided to create a space for the bereaved to write their own stories and read the stories of others. All story posts are published for others to see, and are saved in their “Story Box” to be visited later. The stories that are created by users can be classified by tags, and keywords. There are no limitations as to what can be said, and users have the option of posting stories anonymously. The

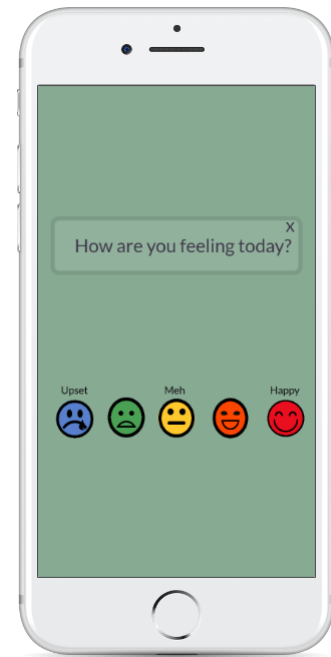


Figure 1: Rating system used in GS 4 Me application

main purpose of this feature is to encourage self-expression while also motivating interaction with others, catering to one of the most notable themes of our responses- expression. It also caters to the theme of legacy in that they have the opportunity to talk about their loved one.

5.1.3 Support Groups

Providing a convenient place to access resources for the bereaved to use has been a critical component of the app. One of the first steps in the process for a griever is to seek information. Participants expressed that they were desperate for information that would help them understand what they were going through. Figure 2 shows the page of facts grievors could read. We intend to prepare access to a variety of resources for the bereaved so they have information at their fingertips instead of having to scour the internet for what they are looking for.

During many of our interviews, participants said that participating in a grief support groups was extremely beneficial to them. Some participants preferred online groups while others preferred to attend in-person meetings. Feeling comfortable and supported in their groups was mentioned frequently throughout the interviews as well. Additionally, identifying trustworthy in-person and online grief support groups has been an important aspect of our mobile application. We decided that providing our users with a list of both online and in-person groups would allow them to try out a variety of groups to decide which ones best supported them with their journey.

5.1.4 Support a Griever

We also created an area specifically for those who wish to support a griever. Trying to comfort someone can be a challenging task, so we provided resources for people to use to

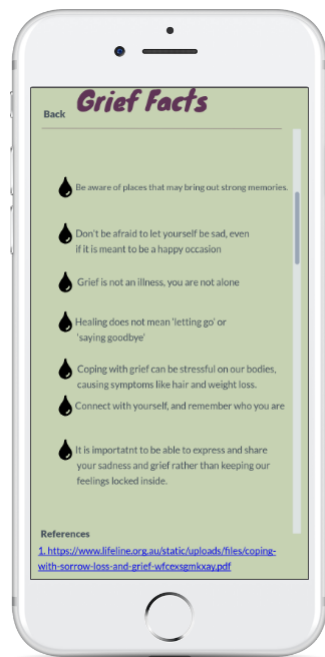


Figure 2: Fast facts for grieverers to read

help them support their loved one. Unfortunately, the bereaved often feel as though non-grieverers may not understand their current state. Non-grieverers may ask insensitive questions or try to compare their situations to the griever. To prevent this behavior, we felt it was best to inform non-grieverers on what not to say to those in the grieving process.

Essentially, we want to create an application that serves as a catch-all for grieverers and their support system. Since each person's grief is unique, providing resources for diverse types of grieverers and their loved ones is our goal. Because people need different resources at various times in their grief journeys, we implemented a variety of grief support tools in our prototype to ensure that grieverers of different styles have access to the tools they need.

5.2 Limitations

While our study provided us with an abundance of insight into the needs of the bereaved, we did face limitations. One of the main obstacles we had to overcome was getting in contact with grief support groups and their coordinators. As we tried to respect the grief community we had to tread lightly in how we contacted them to recruit for the study. We also had two versions of our survey, the original and an updated version with demographic information. Since we did not have the demographic information from all participants we were not able to incorporate that information into our findings.

6. CONCLUSION

The research gave us a better understanding of people's experiences with grief, particularly the role that technology plays in their grief. Creating a tool that will allow the bereaved to remember their loved one while also allowing them room to fully accept the death is important for supporting

grieverers. Digital memorials and social media, normalizing grief, and asymmetrical relationships are important considerations when designing a tool that will assist the bereaved through their grief journey [6]. We conducted a survey and then prototyped an application based on our findings.

Future work in this field will focus on creating and implementing our prototyped application. We are also interested in considering in incorporating music into the coping process to further support the bereaved. Additionally, we would like to look at the ways to incorporate music into the grief journey.

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