

# Technology as an Effective Tool for Grief

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## ABSTRACT

Bereaved individuals often feel lost in a fog of grief (citation). Many people enter the grieving process not knowing what resources are available to support them(citation). In this paper, we present the results of our research regarding griever's use of technology. We surveyed (N=OF PARTICIPANTS) from online and in-person support groups with the in-person groups being primarily from the Bloomington, Indiana area. We used iterative inductive analysis and open-coding to analyze the survey data in order to identify reoccurring themes in participant responses. Our results show that the common needs for coping include: connection, research and reading, legacy, and in-person versus online support . Based on these common themes, we prototyped a mobile application to support the bereaved and those close to them.

## Keywords

bereavement, grief, technology, support, legacy

## 1. INTRODUCTION

Coping with the loss of a loved one is never an easy task, 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 griever's shift over time(citation). This shift in needs creates difficulty for Human Computer Interaction (HCI) designers to develop technologies to assist with the grief process. Grieving is a universal experience, and affects everyone in some point of their life. Because this is such a vulnerable time for the bereaved, they need strong support systems to back them. Social media provides a form of support for the bereaved as its prevalence in society increases. However, there is a lack of technologies that focus on supporting the bereaved through each step of their grief journey. Current research in this area investigates grief and bereavement by understanding what grief is and the common behaviors of the bereaved [9]. Each person must figure out the best way to get through this journey on their own.

There are several resources currently available to support, and encourage the bereaved. These resources include that of online and in-person support groups, digital memorials, *Lifeline*(citation) and tool kits (citations). During the grieving journey, it is very common for the bereaved to feel alone and isolated [14]. 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 their feelings are normal [10]. Therefore, designing a technological tool that will promote communication and understanding of how to cope with the death of a loved one is our goal.

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 have to acknowledge numerous considerations before designing and introducing technological tools to the bereaved because this is a sensitive time[7].

Since there is a 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's, but it had drawbacks, including a lack of separation between media that may trigger a griever and media that would not [7]. Commonly used mediums for the bereaved include social media, digital memorial pages [3, 8], and online grief support groups [6]. Though these are all outlets for coping, there are a limited number of tools that specifically cater to the needs of the bereaved.

Due to the lack of technological tools to support the bereaved, we believe that direct feedback from griever's through interviews will provide a strong foundation for a potential grief support tool [3].

We conducted our research to empathize with individuals and to understand grief journeys from their perspective. We want to perceive how griever's feel about in-person in comparison to online support groups. We also want to find out when and why they use technology. As a result, we will design an application to accommodate their physical, mental, social, and emotional needs.

Throughout this paper we answer the following questions: (1) How do people use certain technologies through the grieving process, (2) How do we improve communication with griever's and non-griever's, and (3) What are the needs of

the bereaved? We aim to understand the behaviors of the bereaved and understand the functionality of technology in the grief process. We provide the following contribution to this area of research: We present a prototype of a mobile application that will assist the bereaved with their grief. We also provide detailed insights related to 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 [9]. The ways in which the bereaved handle death continues to shift to more of a technological experience. It is important to understand the role that technology plays in people's experiences with grief and the tools they require to assist them in their ability to cope with their losses [4]. 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, which serve to memorialize the dead, are often used by the bereaved to remember the deceased [8]. For many people, having the ability to continue communication with those who have passed is a natural part of their grieving process. 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. Rossetto's 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 [12].

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 [4]. 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 [5] for those left behind. 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 [1]. 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 [8]. For those with differing views on how to handle the digital content of the deceased, it can be difficult to come to a compromise on the appropriate action to take regarding the digital content [5].

Since understanding grief and the loss of a loved one takes time, it can be challenging for people to recover and accept death. During this time bereaved seek acceptance, support,

compassion, and understanding [14]. 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 to the bereaved [10]. There are a variety of ways an individual can come to terms with the loss of a loved one [2]. Research has found that sharing stories with others who have experienced similar losses allows people to develop connections and share their struggles and experiences [7]. 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 [6].

While having resources and support from others is an assisting factor of many people's grief process, it is also influential for the bereaved to have resources that 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 [2]. Technology with a one-size-fits-all type of approach will not work for everyone because of differences in coping style, cause of death, personality, and grieving style (insert citation).

Many people continue relationships with the deceased [9]. Asymmetrical relationships exist as 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 the bereaved [4]. The bereaved may call, text, email, and post about the deceased as though they are still alive [9]. It is also difficult 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.

Use of social media and technology can make it hard to let go of a loved one. Many people experience a desire to preserve their relationships with the deceased [9]. While social media may benefit and support the bereaved, social media tools such as Facebook may make it even more difficult to say goodbye to loved ones [12]. 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 make it harder to let go [13].

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 the bereaved throughout their grief journey. Digital memorials and social media, normalizing grief, and asymmetrical relationships should all be taken into consideration when designing a tool that will assist the bereaved through their grief journey [2].

## 3. METHODS

The goal of this project was to understand technology use among bereaved individuals in online and in-person grief support groups. Upon receiving approval from the Institutional Review Board at Indiana University, we sought out online grief support groups with at least 50 members to represent a variety of grief experiences in the study. To further explore the grief experiences of others, we reached out to

in-person grief support groups in the Bloomington, Indiana area.

### 3.1 Recruitment

Participants of this study were 18 years of age or older, who 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 social media outlets (i.e. Facebook) and by contacting facilitators of grief support groups. SOMENUMBER (95) people completed our survey. We conducted follow-up interviews with SOMENUMBER (6) of the participants who completed the survey in addition to SOMENUMBER (2) group coordinators. The majority of our participants were in the age range of 45-54 with the second most being between the ages of 35-44. 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 a blend of the Coping Strategies Questionnaire (CSQ), Inventory of Complicated Grief (ICG) and the Texas Revised Inventory of Grief (TRIG) [11]. We chose to use these surveys as they are well-established surveys in the grief research community that investigate the grief experience (provide some citations). This comprehensive survey consisted of 5-7 open-ended questions, and 13 questions with a Likert scale [2]. 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?”

Before sending the survey to participants, we conducted pilot surveys to ensure the wording of the questions was clear. The survey gave us a better understanding of people’s experiences with grief, particularly the role that technology plays in their grief.

#### 3.2.2 Coding

Using the open-coding method, we created a code book based on our survey results. We met after each iteration to discuss the reasoning of our codes with one another. 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

For those participants who indicated they would like to participate in a follow-up interview, we prepared more in-depth questions based off the survey responses we received. We

conducted semi-structured phone interviews with participants. After receiving consent from the participant we began recording the interview. SOMENUMBER (45) participants that took the survey volunteered for the follow up interview. We scheduled the interviews outside of the participants’ grief support group time and the interviews lasted between 30 and 60 minutes. In addition to follow up interviews with participants, we also interviewed facilitators of grief support groups to gain further insight into the grief experience.

## 4. FINDINGS

We successfully identified four prevalent themes based on the open-coding and iterative inductive analysis of our survey and interview responses. Our themes are as follows: 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 seek resources, buy books, and read articles to cope with the death. In addition to reading articles and books about grief, reading poetry and inspirational quotes were also mentioned in survey responses. Reading other people’s experiences also helped the bereaved as they were able to read a real person’s experience and relate to it.

### 4.3 Legacy

The idea of keeping the legacy of the deceased alive, often through the use of social media, showed frequently in our data. Facebook memorials and memories were often referred to when participants were asked about what technology they use to keep in contact with and remember the deceased. Participants went to events supporting the cause of their loved one’s death, 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”.

### 4.4 Online v. In-Person

As we asked our participants about their experiences in on-line 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 of time. The benefits of the in-person groups, in turn, were that they could see people face-to-face and develop stronger connections with other grievers. The major drawback of the in-person group was that it felt intense and overwhelming for many people as their grief is put right in front of them. Online they had the opportunity to choose when and for how long they participated in the group, but in-person groups are 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

We had a variety of respondents giving us a wider range of grief experiences to analyze. Despite the differences in people's grief, there is still a common need for a resource that is applicable to a variety of grievers that tailors to specific needs. Being able to support people throughout their grief experiences is no easy task.

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 about explaining their battle 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.

From our interviews with participants we found that it is typically the second year of grief that is the most difficult for people as the "fog" they were in when grief first set in had begun to lift.

### 5.1 Grief Application

By understanding the technology practices of the bereaved we decided that a mobile app would be the most useful and effective tool to construct. Based off 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 in an attempt to provide the most support possible to the bereaved.

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. In order 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.

As communication and connection were important factors

to consider, we decided to create a space for the bereaved to write their own stories and read others stories. All story posts are intended to be anonymous to protect the privacy of users.

Providing a central 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 out information. 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. Additionally, identifying vetted in-person and online grief support groups has been an important aspect of our mobile application.

We also created an area specifically for those who wish to support a griever. Trying to comfort someone can be a difficult task, so we provided resources for people to use to help them support their loved one. Unfortunately, the bereaved often feel as though non-grievers do not understand their current state. Non-grievers 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-grievers on what not to say to those in the grieving process.

### 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. FUTURE WORK

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

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