

REU SU17 GIRARD PRICE

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ABSTRACT

(INSERT CITATIONS, GRAMMAR) Bereaved individuals may have no idea which way to go or what resources are available. In this paper, we present the results of our research regarding griever's use with technology. We surveyed (N=OF PARTICIPANTS) from online and in-person support group participants primarily from Bloomington, IN. The method types of our study included iterative inductive analysis and open-coding in *Dedoose* software. Our results show that the common needs for coping include: connection, anonymity, and outlets for expression. As researchers, we need to know this to create technology to assist grievers during this sensitive period of their lives. Therefore, our end goal is to prototype a (*DIGITAL SCRAPBOOK) that combines the unique experiences of any person while also accommodating individual coping styles.

Categories and Subject Descriptors

H.4 [Information Systems Applications]: Miscellaneous;
D.2.8 [Software Engineering]: Metrics—*complexity measures, performance measures*

Keywords

bereavement, grief, coping, normalization, memorialization, technology

1. INTRODUCTION

Coping with the loss of a loved one is never an easy task which is why it is necessary to develop technological tools to support the bereaved throughout their grief journey. In such a sensitive time, it is critical that the bereaved have a strong support system to back them. With social media continuing to infiltrate our lives, there has been a focus on creating technologies for the bereaved to use throughout their grief journeys. Grieving is universal, and affects everyone in some point of their life. Grief is a never-ending journey, and the needs of griever's oscillate over time(citation). This creates difficulty for Human Computer Interaction (HCI) de-

signers to develop technologies to assist with the grief process. There is a lack of technologies to support the bereaved throughout their grief journey. Current research investigates grief and bereavement from the perspective of what grief is and common behaviors among the bereaved [9].

There are currently several resources for the bereaved to receive support their grief. These resources include that of online and in-person support groups, digital memorials, *Lifeline* and tool kits. During the grieving journey, it is very common for the bereaved to feel alone and isolated [13]. It can be difficult for them to connect and express their feelings to those around them who care. Each person must figure out how to get through this journey on their own. Trying to understand what they are feeling, and whether it is normal are all problems that arise during the grief process [10]. Designing technological tools that will assist the bereaved with communication and understanding of how to cope with the death of their loved one is a goal that we wish to achieve.

Numerous considerations must be acknowledged before designing, and introducing technological tools to the bereaved [7].

As previously stated, resources are available for griever's but there are minimal technological tools. The prevalence of technology and social media in our lives increases the use of technology for grief support. Historically, the most effective mediums for the bereaved have been social media, digital memorial pages [3, 8], and online grief support groups [6]. Though these are all outlets for coping, tools that specifically cater to the bereaved are limited.

Due to the lack of technological tools to support the bereaved, we hope that direct feedback from griever's through in-person interviews provide a foundation to build up ideas for possible tools to create [3]. We conducted our research to empathize with individuals, and understand their grief journeys from their perspective. As a result, we will be able to design tools that will accommodate their needs.(specify what info we are gathering about participants)

Throughout this paper, we answer the 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, (3) What are the needs of the bereaved? The research we provide adds the following contributions to this area of research. We will be prototyping a tool (give the

type of tool we want to create once we have decided what we want) that will assist the bereaved. We also contribute insights related to interaction between the bereaved and their support system.

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*.

Because of the prevalence of social media use in our society, digital memorials, which serve to memorialize the dead, often allow the bereaved to remember the deceased [8]. For many, having the ability to continue communication with those who have passed via social media is critical to their grieving process. Rossetto et al. illustrate the paradoxical nature of using Facebook among the bereaved. They note its benefit in 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, which potentially causes a more difficult grief experience for the bereaved [11].

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 are key components after the loss of loved ones; problems regarding what happens to the deceased person's accounts can cause even more stress and grief [5]. 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. There are a variety of ways an individual can come to terms with the loss of a loved one. [2]. During this process, people can also feel isolated and alone, however research has found that sharing stories with others who have experienced

similar losses allows people to create connections and share their struggles and experiences [7].

This creates a support system for the bereaved. There is a strong need among the bereaved for acceptance, support, compassion, and understanding [13]. Although one's family and friends may try to comfort the bereaved, studies have shown that being with others who have experienced a similar loss is more beneficial to the bereaved [10]. The act of storytelling can be extremely 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 support and resources from others is useful and critical for many people's grief process, it is also influential for bereaved to have resources that they can use on their own. As Dominic et al. discusses, 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).

Research studies have found that 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 [4]. Trying to maintain social ties is common among the bereaved [4]. Bereaved may call, text, email, and post about deceased as if they are living [9]. It is also difficult to find closure if the deceased's social media pages are lingering among the living. A common example is the bereaved may be on Facebook, and their loved one's page may come up which can cause uneasiness.

It is often hard to let go of those who have passed. 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 [11]. 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 [12].

Creating a tool that will allow the bereaved to remember their loved one while also allowing them room to let go 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 grief and in-person 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, had lost their loved one within the last 5 years, and had participated in an online and/or in-person grief support group. To ensure ease of accessibility and to have a more diverse pool of participants, we recruited through social media outlets (i.e. Facebook, Twitter) and by contacting facilitators of grief support groups. SOMENUMBER people completed the survey. We conducted follow-up interviews with SOMENUMBER of the participants who completed the survey in addition SOMENUMBER OF group coordinators. The age of the participants ranged from **x to z. ** v participants were female and **c participants were male.

3.2 Approach

3.2.1 Tools

We administered our survey on Qualtrics using a blend of Coping Strategies Questionnaire (CSQ), Inventory of Complicated Grief (ICG) and Texas Revised Inventory of Grief (TRIG). We chose to use these surveys as they are well-established surveys in the research community that investigate the grief experience (provide some citations). Our survey consisted of several open-ended questions, 13 questions with a Likert scale as mentioned in (**Dominick, 2010), and questions to gather 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?" Before sending the survey to participants, we conducted pilot surveys to ensure the wording of the questions was clear. The survey allowed us to gain a better understanding of the role that technology plays in people's experiences with grief.

3.2.2 Coding

Using the open-coding method, we created a code book based off our survey results which yielded a ____ % inter-rater reliability among three of the researchers conducting the study. We met after each iteration to discuss our codes with one another. After we came to a consensus about our codes we moved on to complete the next iteration. Four coding iterations were conducted to ensure this high inter-rater reliability.

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. Semi-structured phone interviews were conducted between the participant and at least one researcher. After receiving consent form the participant we began recording the interview to transcribe it after the interview. SOMENUMBER of our 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 found that it was in

our best interest to interview facilitators of the grief support groups.

4. FINDINGS

Through this study, we have identified four common themes. These themes were created based on 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 groups.

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.

Researching and reading about grief was another important finding of this survey. The bereaved are often desperate for information that would 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, poetry and music were other soothing resources.

The idea of keeping the legacy of the deceased alive, often through the use of social media, came up 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"/remember the deceased. Participants included, participating in events, tagging their loved one, or commenting the name of their loved one on posts as ways that they commemorate the deceased. (Many of our participants continued to contact their loved one through the use of texting, email, calling, and tagging their loved one on Facebook.)

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. The benefits of the in-person groups, in turn, are that you can 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 for many people as their grief is put right in front of them. Online they have the opportunity to choose when and for how long they participate in the group, but in-person groups are more direct and at times, more overwhelming.

One of the "surprising" results we found was that many people noted that they primarily posted about their loved ones on dates of significance such as anniversaries and birthdays.

Tailoring to different types of grief- especially in online groups

After transcribing in-person interviews, our findings suggest participants are interested in.... Our study also supports findings of previous studies that found themes such as digital memorialization, exchange of support.... (citation). We propose technologies that will... Our findings suggest....

5. DISCUSSION

Through this study, we have successfully been able to acknowledge sensitive topics of grief such as coming to terms with pain and facing the reality of a loved one's death. Most importantly we decipher what technology users use, how griever use technology, and we present design considerations of potential technology based on participant feedback.

We answered the questions

(1) How do people use certain technologies through the grieving process?

We found participants use social media to post pictures, find resources, and interact with others. They also use technology to revisit old media related to the deceased.

(2) How do we improve communication with griever, and non-griever?

Through interviews, we found that the bereaved feel as if non-griever are not understanding. Non-griever may ask insensitive questions, or try to compare their situations to the griever. To prevent this behavior, we felt it was best to "educate" non-griever on what not to say to those in the grieving process.

(3) What are the needs of the bereaved?

The general needs of a griever include: seeking resources, having someone who understands what they are going through, and having positive encouragement from family and friends.

Strengths of the study -Having variety of data, deaf participant, loss of baby, suicide survivors, multiple deaths over time. Being able to conduct in-person interviews, providing designs, and prototypes to the participants to have their feedback. Results in relation to other studies -Discuss themes we have found: i.e. memorialization, exchange of support, etc. Meaning and generalizability of the study -Provide more current feedback. Looked at the viewpoint/perspective of online support groups AND in-person support groups.

Unanswered and new questions

-At what point in the grief journey is it acceptable to introduce technology to the bereaved? Since participants are interested in photo sharing, and expressive, creative aspects, what

5.1 Grief Application

5.2 Limitations

Keeping the responses of our surveys and interviews in mind, we prototyped an app that we believe will assist the bereaved throughout their grief journey.

While our study provided us with an abundance of insight into the needs of the bereaved, we did face some limitations. One of the main obstacles we had to overcome was getting in contact with grief support groups and their coordinators. As a sensitive population, it is understandable that we were met with some resistance from groups. We also had two versions of our survey that were sent out. The second version

included demographic information. Since we did not demographic information from all participants we were not able to incorporate that information into our findings.

6. FUTURE WORK

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