

REU SU17 GIRARD PRICE

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ABSTRACT

With the death of a loved one comes an overwhelming variety of emotions, shock, and confusion. Daily, bereaved individuals must battle with feeling misunderstood, alone, and lost while also being strained by people suggesting it's time to "get over" the death. These factors make the grieving process hard to handle. Since grief is an untouchable subject, most griever may enter their journey feeling confused and often tend to isolate their emotions. Newly bereaved individuals may have no idea which way to go or what resources to look for. In this paper, we present the results of our survey and interview study and present a technology prototype that helps grievers understand their grief journey and provides them with an outlet to connect them with others to express their grief. We surveyed (N=OF PARTICIPANTS) from online, and in-person support groups in Bloomington, IN, and in neighboring cities located in south-central Indiana. This study used iterative inductive analysis and open-coding in the *Dedoose* software. Based on themes extracted from survey data, and feedback given from in-person interviews, we found... Results indicate grievers do in fact use different forms of technology during their grieving journey. More importantly, during this process, we found their needs for coping include: connection, anonymity, and outlets for expression.

We prototyped a SOMETHING that combines the unique experiences of any person while similarly accommodating each individual's coping style.

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

Although we try enjoy life, coping the with the loss of a loved one makes this goal difficult. 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 best categorized as a never-ending journey, and the needs of grievers oscillate over time(citation). This creates difficulty for Human Computer Interaction (HCI) designers to develop technologies to assist with the grief process. Research studies surrounding bereavement have been valuable in describing (*describing what). However, 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].

To date, there are several resources for the bereaved to support them with their grief including grief support groups both online and in-person, forums, digital memorials, *Life-line* 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 has to 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 critical.

Numerous considerations have to be acknowledged before designing, and introducing technological tools to the bereaved [7]. For example, a group of widowers may all have the same type of loss, but each person's experience differs. Technology for the bereaved has to be flexible enough to cater to each person's experience .

As previously stated, resources are available for grievers, 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 vague.

Direct feedback from griever 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)

Our contribution to this area of research 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. Since this is an under-explored community, we also include insights related to interaction between the bereaved and their support system. This research study, investigates the individual experience of griever. Through the context of 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, and non-griever, (3) What are the needs of the bereaved?

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*.

With prevalence use of social media in our society, digital memorials, which serve to memorialize the dead, are common [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 more grief [11].

With the frequent use of social media comes issues pertaining to the privacy of social media accounts after someone dies. Problems arise about who should be in control of the accounts of the deceased [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's passing which determine how to handle certain accounts post-mortem. 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 usually will not work for everyone because of differences in coping style, type of death, personality, and grieving style.

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.

As we have constantly stated, 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]. With the existence of social media tools such as Facebook, it can become 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].

Therefore, creating a tool that will allow the bereaved to remember their loved one while also allowing them room to let go is important. 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 is to understand technology use among bereaved individuals in both in-person and online 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 ensure that we represented 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 Participants

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. We targeted a total of SOMENUMBER groups comprising of SOMENUMBER people and SOMENUMBER people completed the survey. We conducted follow-up interviews with SOMENUMBER of the participants (**t females and g males) who completed the survey in addition to group coordinators. The age of the participants ranged from **x to z. ** v participants were female and **c participants were male.

3.2 Approach

We administered our survey on Qualtrics using 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 we used 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?" Our surveys also gave an option for participants to volunteer for follow-up interviews.

For those participants who indicated they would like to continue their participation in a follow-up interview, we prepared more in-depth questions based off the survey responses we received. We used individual, semi-structured interviews. 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. The interviews were conducted by one of the researchers. 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. All interviews were recorded and transcribed.

Using the open-coding method, we created a code book which yielded a — % inter-rater reliability among the 5 researchers conducting the study.

4. FINDINGS

Based on our survey results and participant responses to the in-person interviews we noticed the following themes:

- normalizing grief and relating to other grievers
- prevalence of reading and creativity throughout the grief process
 - books, resources about grief
 - poetry
 - music
- legacy
- social media
- notable things between in-person and online grief group
- texting, calling, Facebook messaging, emailing deceased
- Any surprising results

Though everyone experiences the death of a loved one uniquely, there are common themes that we found through open-coding, and iterative inductive analysis.

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 grievers use technology, and we present design considerations of potential technology based on participant feedback. After transcribing of 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....

Answers to study questions - **We answered the questions**

(1) How do people use certain technologies through the grieving process? By finding participants use social media to post pictures, find resources, and interact with others close to the deceased.

(2) How do we improve communication with grievers, and non-grievers? By assessing the common patterns, practices of participants during the grieving process.

(3) What are the needs of the bereaved? By in-person interviews, and finding they need voluntary interaction with others.

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 generalisability 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 Limitations

Limitations of our study were... weaknesses of the study -Difficulty to contacting grief groups since they are very private -Minimal demographic data

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