

REU SU17 GIRARD PRICE

Meagan Price
Claflin University
mprice@claflin.edu

Max Girard
Simmons College
maxinegirard@gmail.com

ABSTRACT

With the death of a loved one comes an overwhelming variation 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 grieverers 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 grieverers 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 grieverers 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 grieverers 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 grieverers, 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 a more 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*.

2.1 Digital Memorials and Social Media

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 usefulness in sharing information about the deceased and keeping their memory alive, but also point out the problematic situation of having information about the deceased show up on a griever's Facebook page, potentially causing more grief [11].

2.1.1 Control of the Account and Privacy Issues

There are many issues surrounding the privacy of social media accounts when someone dies. Problems arise about who should be in control of the accounts of the deceased [4]. While social media and digital memorials are useful in some people's ability to cope with the loss of loved ones, the problems that arise regarding what happens to the deceased person's accounts can cause even more stress and grief [5]. Brubaker and Callison-Burch explore the relevance of creating legacy contacts before one's passing which 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].

2.2 Normalizing Grief

Although everyone experiences grief, losing a loved one requires that people restructure their lives to accommodate for their loss. Understanding grief and the loss of a loved one takes time, and it is not something people ever recover from. There are different ways for individuals to come to terms with the loss of a loved one. [2]. While many people feel isolated and alone, research has found that sharing stories with others who have experienced similar losses allows people to create connections and to share their struggles and experiences [7].

2.2.1 Peer Support

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].

2.2.2 Self-Help Tools

While having support and resources from others is useful and critical for many people's grief process, it is also important 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 unique experiences with grief [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, and grieving style.

2.3 Asymmetrical Relationships

Although a loved one may have passed, research studies found that many people continue relationships with the deceased [9]. Their 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]. The bereaved may call, text, email, and post about the 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. The bereaved may be on Facebook, and their loved one's page may come up which can cause uneasiness.

2.3.1 The Difficulty of Ending Relationships

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].

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.

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

4. RESULTS AND DISCUSSIONS

5. REFERENCES

- [1] Brubaker, J. R., and Callison-Burch, V. 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, ACM (New York, NY, USA, 2016), 2908–2919.
- [2] Dominick, S. A., Irvine, A. B., Beauchamp, N., Seeley, J. R., Nolen-Hoeksema, S., Doka, K. J., and Bonanno, G. A. An internet tool to normalize grief. *OMEGA - Journal of Death and Dying* 60, 1 (2010), 71–87.
- [3] Foong, P. S., and Kera, D. Applying reflective design to digital memorials. *SIMTech'08* (2008).
- [4] Lingel, J. The digital remains: Social media and practices of online grief. *The Information Society* 29, 3 (2013), 190–195.
- [5] Locasto, M. E., Massimi, M., and DePasquale, P. J. Security and privacy considerations in digital death. In *Proceedings of the 2011 New Security Paradigms Workshop*, NSPW '11, ACM (New York, NY, USA, 2011), 1–10.
- [6] Massimi, M. 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, ACM (New York, NY, USA, 2013), 1169–1180.
- [7] Massimi, M., and Baecker, R. M. Dealing with death in design: Developing systems for the bereaved. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '11, ACM (New York, NY, USA, 2011), 1001–1010.
- [8] Moncur, W., and Kirk, D. An emergent framework for digital memorials. In *Proceedings of the 2014*

- Conference on Designing Interactive Systems*, DIS '14, ACM (New York, NY, USA, 2014), 965–974.
- [9] Odom, W., Harper, R., Sellen, A., Kirk, D., and Banks, R. Passing on & putting to rest: Understanding bereavement in the context of interactive technologies. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, CHI '10, ACM (New York, NY, USA, 2010), 1831–1840.
- [10] Paulus, T. M., and Varga, M. A. 'please know that you are not alone with your pain': responses to newcomer posts in an online grief support forum. *Death Studies*, 10 (2015), 633.
- [11] Rossetto, Kelly R., L. P. J., and Strauman, E. C. Death on facebook: Examining the roles of social media communication for the bereaved. *Journal of Social and Personal Relationships* 32, 7 (2014), 947–994.
- [12] Sas, C., Whittaker, S., and Zimmerman, J. Design for rituals of letting go: An embodiment perspective on disposal practices informed by grief therapy. *ACM Trans. Comput.-Hum. Interact.* 23, 4 (Aug. 2016), 21:1–21:37.
- [13] Swartwood, R. M., Veach, P. M., Kuhne, J., Lee, H. K., and Ji, K. Surviving grief: An analysis of the exchange of hope in online grief communities. *OMEGA - Journal of Death and Dying* 63, 2 (2011), 161–181. PMID: 21842664.