REU SU17 GIRARD PRICE

Meagan Price
Claflin University
mprice@claflin.edu

Max Girard
Simmons College
maxinegirard@gmail.com

ABSTRACT
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
There is a need for new technologies for grievers to use to assist them throughout their grieving journey.

Promise/Problem- there is a lack of tools for grievers to use to help them with their grief journey

Obstacle- grief is such a unique experience and sensitive time in peopleâĂŹs lives that you need to tread lightly. Simply providing additional resources for grievers to use at their disposal

Tech hole- what tools are their for the bereaved- nothing good. With the prevalence of technology in our lives more people turn to technology for grief support- limited currently

Solution- listen to what grievers have to say and build from there

Contributions- 1)prototyping a tool to assist the bereaved 2)providing more information on the experiences of the bereaved which is an under explored community

2. RELATED WORK
Among existing literature about grief, focus increases on the integration of technology into people's grief journeys. As the ways in which the bereaved handle death continues to shift to a more technological experience, it is important to understand the roles that technology play in people's experiences with grief and the tools they require to assist them in their ability to cope with their losses. 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 to memorialize the dead is common. 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 [9].

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 [3]. 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. Brubaker and Callison-Burch explore the relevance of creating legacy contacts before one's passing 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. [7]. 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 [4].

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. As a result, every person experiences grief in their own unique way [2]. While many people feel isolated and alone, research has found that sharing stories with others who have experienced similar losses allows people to connect with others and to share their struggles and experiences [6].

2.2.1 Peer Support

There is a strong need among the bereaved for acceptance, support, compassion, and understanding [11]. 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 of their own is more beneficial to the bereaved. 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 [5].

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 [8] found that many people continue relationships with the deceased. 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 [3]. Trying to maintain social ties is common among the bereaved [3]. The bereaved may call, text, email, and post about the deceased as if they are living. [8]. 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. With the existence of social media tools such as Facebook memories, it can become even more difficult to say goodbye to loved ones [9]. 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 [10].

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 practices among bereaved individuals in both in person and online grief support groups. Upon receiving approval from the Institutional Review Board at Indiana University we targeted 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 while also reaching out to the online grief support groups.

3.1 Participants

Participants of this study were 18 years of age or older, and they 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 easy accessibility and to have a more diverse pool of participants, we recruited through social media outlets (i.e. Facebook, Twitter), fliers, and contacting facilitators of grief support groups. We did not to reach out to online support groups to study the relationships among the group members, but rather to recruit more people for our study. 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 a 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. About (**30%) 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.

In conclusion, we found that only (**20%) of our users manipulated technology for digital memorialization, (**10%) use it for "numbing the pain", and (**51%) used technology to reminisce/contact a loved one. In relation to our themes, we find the best type of technology to support individuals during the grieving journey would be a web-based tool. (include citations) Our data indicates...

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] Lingel, J. The digital remains: Social media and practices of online grief. *The Information Society 29*, 3 (2013), 190–195.

[4] 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.

[5] 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.

[6] 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.

[7] 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.

[8] 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.

[9] 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.

[10] 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.

[11] 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.