

# Exploring Remembrance and Social Support Behavior in an Online Bereavement Support Group

Michael Massimi

Microsoft Research Cambridge

mmassimi@microsoft.com

## ABSTRACT

Designing interactive systems that sensitively engage with end of life issues is a key challenge for CSCW as more and more people turn to the Internet to grapple with the realities of death. However, there are few studies that document how specific remembrance or support features of bereavement websites are used in a real-world setting. This paper describes Besupp, a website where bereaved individuals can participate in online support groups. Three support groups used Besupp in a ten-week long deployment study. Based on this study, I describe how participants perceived and used the remembrance and social support features of the site. These results form the basis for a set of implications regarding the design of technologies for remembrance, social support, and bereavement more generally.

## Author Keywords

Bereavement; remembrance; social support; support groups; thanatosensitive design; grief.

## ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

## INTRODUCTION

The death of a loved one is a challenge that we all encounter in our lives. Following such a loss, families face a wide array of challenges; dealing with finances, handling possessions and property, organizing memorial services, and consoling one another. Underscoring all of these activities is the grief that each individual endures as they struggle to adjust to a life without their loved one. For some people, talking with compassionate peers can be a helpful way to find strength, knowledge, and comfort. Support groups are a common setting where these needs can be met.

This paper describes the design of a website called Besupp that allows bereaved individuals to meet in online support groups. Working in conjunction with a community bereavement support centre, Besupp was built to support

two primary functions. First, it supports remembrance about the deceased by offering a place to host and share digital mementos. Second, it allows users to create profiles, share background stories, and converse with peers in an effort to create a social support environment.

Besupp was deployed in a ten-week long deployment study. It was used by three different support groups for bereaved parents, spouses/partners, and young adults. The ways in which participants used the remembrance and social support features of the website were explored through analysis of participant interviews and system logs. These revealed usage scenarios that speak to the relative merits of particular system features. Based on these results, I then share a set of implications for design. These implications contribute to ongoing discussions in three important topics of concern to CSCW and HCI: digital mementos and remembrance, online social support, and technology design for the end of life.

## RELATED WORK

Recent work in HCI and CSCW has begun to focus on how technology plays a role at the end of life. The term “thanatosensitive design” has been used to describe a design process that actively engages with issues pertaining to death and dying as part of the design concept [25]. I now turn to pertinent literature on online social support and remembrance.

### Internet-Based Social Support in Bereavement

Using the Internet for social support is a well-established practice. Much of the work examining social support has focused on health conditions such as cancer [2,31], caring for high-risk infants [22], or improving physical fitness [6]. While bereavement is not a health condition, it is also a life-altering occurrence. In the case of bereavement, online interaction can potentially impact five of Barrera *et al.*'s six forms of social support: behavioral assistance, intimate interaction, guidance, feedback, and positive social interaction [1]. In a survey of bereaved respondents, Lehman *et al.* found that contact with similar others, opportunities to vent, and expressions of concern were rated the three most helpful gestures during grief [16]. All of these opportunities can be found online [33]. Crafting and sharing narratives is a key part of these exchanges – “[t]hrough the use of storytelling, [participants] begin to

AUTHOR'S PRE-PRINT COPY

To appear at CSCW'13, February 23–27, 2013, San Antonio, Texas, USA.

make sense of their malaise, to take control of events formerly beyond their power of influence” (p. 391) [3].

However, support groups (whether online or face-to-face) are not necessarily effective for all bereaved people. In a systematic review of the literature on bereavement treatments, Forte *et al.* found that interpersonal support groups were not effective in a systematic review of the literature [8]. For example, Levy *et al.* found that levels of depression, anger, and stress for support group participants were not significantly different 18 months following the loss of a spouse from those who did not attend a group [18]. Indeed, Levy and Derby found that those who join such support groups report higher levels of depression, anger, anxiety, and stress, but are not significantly different from non-joiners in terms of perceived social support [19]. Picton *et al.* suggest that such groups are most effective for those with poor family support and within three months of the loss, but that the perceived need for support persists irrespective of time elapsed since the death [29]. Regardless of their efficacy, support groups remain a common and well-established platform for finding peer support.

### Technology and Remembrance of the Deceased

One survey and interview study found that technology frequently plays a role in how the bereaved remember the deceased [23]. Other work has shown that one of the key ways in which we mediate our relationships with the deceased is through objects [12]. In a series of home tours with bereaved individuals, Odom *et al.* present a rich description of how inherited items – both physical and digital – help supplement (or confuse) the relationship between the living and deceased [26]. Recent work has also questioned how we may support older adults in organizing their possessions to ease the bequeathal process [21]. For some, safeguarding symbolic objects indicative of the relationship with the deceased is of key concern – Volkan terms these special items “linking objects” [35].

Social networking sites are a primary platform for communication with the deceased and mourning. Drawing on continuing bonds theory [15], Getty *et al.* report on how Facebook users write on profiles of the deceased to keep their relationship “alive,” and to visibly perform activities associated with mourning such as remembering, sharing, and consoling [10]. In a larger-scale study of deceased MySpace users’ profiles, Brubaker and Hayes report similar findings and point out how these activities become part of larger, temporally-recurring rituals of remembrance, reflection, and socialization [4].

Photos play a clear role in remembering the deceased – scanning and organizing photos for a memorial service is a common task [23]. Increasingly, digital photos reside on both desktops and in the cloud; even so, using these photos for memorial purposes requires a great deal of “photowork” [13]. Using interactive devices to share these photos across time and distance is an increasingly common occurrence as

well and often helps to support storytelling [9]. In an examination of how older adults arrange their living spaces, photos of the deceased were frequently displayed in all parts of the home [17]. Photos play a key role in novel interactive devices designed to support remembrance, such as ThanatoFenestra [34].

### COMMUNITY-BASED DESIGN

Since 2009, I have worked closely with BFO – a non-profit community organization that offers support groups to bereaved individuals. My involvement with BFO shares some similarities with action research, which involves “a circle of planning, action, and fact-finding about the result of the action” [20]. In this tradition, I seek not to make claims regarding the efficacy or wide applicability of the software we co-designed, but rather document the decisions that we made, why we made them, and how they played out in a real-world deployment. In order to unpack and critically examine this process, it is important to share three of BFO’s key organizational values<sup>1</sup>:

1. *Like-loss membership.* Multiple groups run simultaneously, and are organized based on the type of loss. Examples of recurring groups include: parents who have lost an infant, parents who have lost a young or adult child, individuals who have lost a spouse or partner, and young adults (ages 18-30) who have lost a parent or sibling. All members of a group – including the trained facilitator – must have experienced the same kind of loss. This value stems from the acknowledgment that those best suited to provide support must have experienced the loss themselves.
2. *Peer support.* The facilitators of the group are trained by BFO to ensure safety and respect among group members. Importantly, the facilitators are not professionals (e.g., psychologists, counselors, social workers). There is an emphasis placed on “not fixing:” the facilitators are only there to help start and guide discussion, not to prescribe actions or treatment for dealing with grief.
3. *One-on-one screenings.* Before attending a support group, each potential member must first complete a one-on-one interview with a BFO facilitator. During this session, the moderator judges whether the individual would be able to participate in a group effectively. The time between the death and the one-on-one varies from person to person, as does the time between the one-on-one and the beginning of the support group. This reflects BFO’s understanding that we all grieve differently, and on different timelines.

Support groups consist of 10 weekly sessions of 2 hours each. Each week has a pre-determined discussion topic,

---

<sup>1</sup> See [www.bfotoronto.ca](http://www.bfotoronto.ca) for more information about the organization and its values.

such as discussing the memorial service or funeral, and how to deal with friends and family members. Groups range in size from 5-12 people. As an organization, BFO maintains strict policies surrounding confidentiality and privacy. For this reason, observing support group sessions was not permitted. Instead, a series of focus groups were held with previous support group participants who responded to an ad placed in the BFO newsletter. These focus groups yielded a number of insights and considerations for design [24].

In order to build and maintain relationships with BFO, I also redesigned BFO’s website, and in so doing, learned a lot about organizational values and procedures through monthly meetings with their board of directors and communications team. Second, I conducted 4 one-on-one design sessions with BFO’s directors and volunteers. Potential design options were discussed, including a mobile phone application for “support anywhere” and a domestic ambient display that offered messages of support to residents who passed by it. These early participants were recruited through word-of-mouth and convenience, and were not part of the deployment study discussed below.

Feedback from BFO directors and volunteers resulted in the following design suggestions.

- The system should be a separate space away from Facebook, email, and other existing platforms. Participants wanted a “safe” place where feelings of grief could be expressed openly, without spilling over into their existing social networks.
- A website was considered the most appropriate form of technology. The rationale was that a website could serve the largest number of BFO clients because the web is an established technology that participants can integrate easily into their lives.
- The system should follow from the values established at BFO (outlined above). Groups should be organized according to like-loss membership and consist solely of peers (i.e., no “professional advice”). They should be moderated by a trained support group leader, and members should be screened to ensure they were emotionally ready to participate.

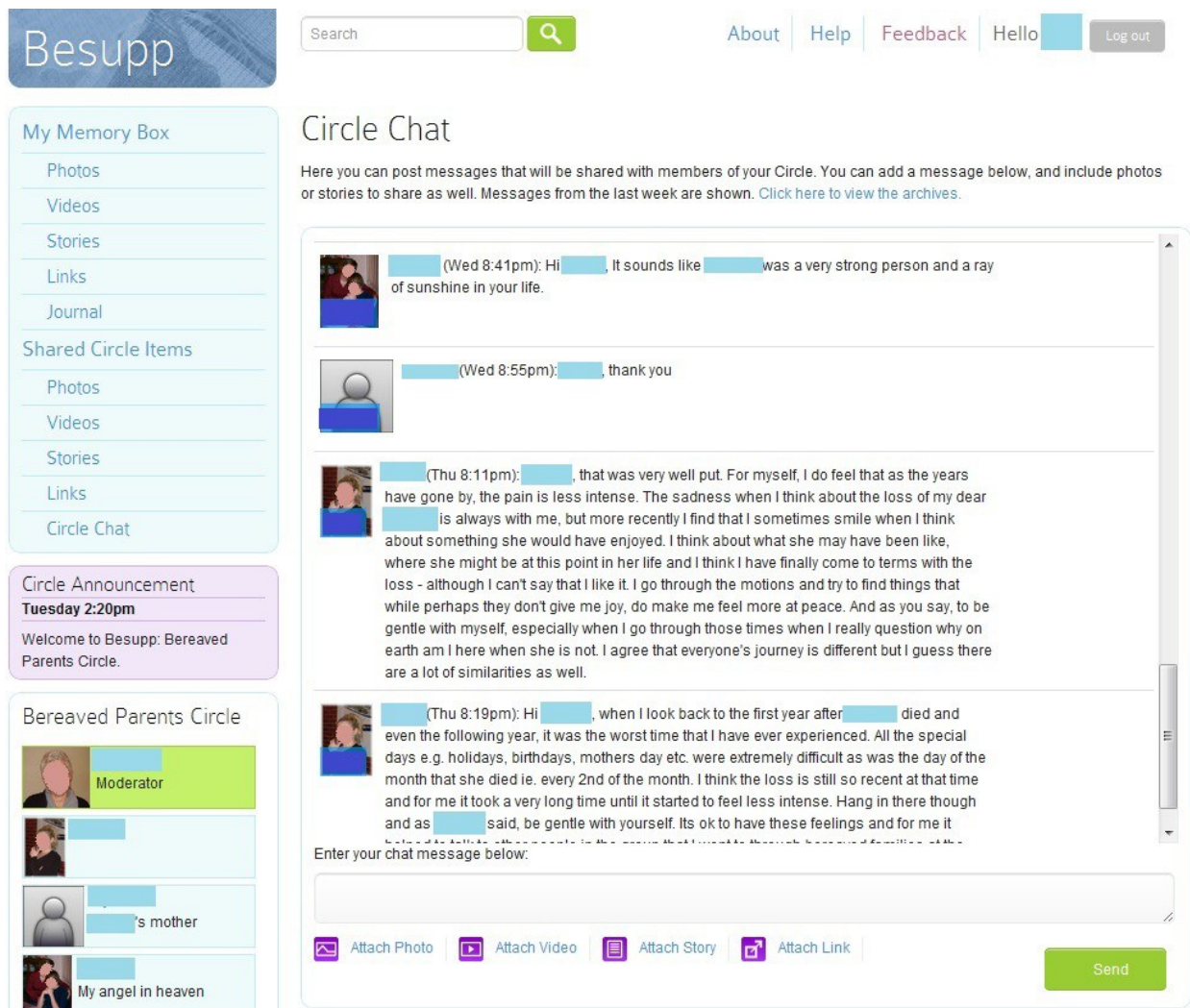


Figure 1. Besupp interface showing Circle Chat room (center) and main menu (left column).

- The system should support common group activities based on current weekly sessions. These activities retelling the story of the loss, sharing mementos, and suggesting resources they have found personally helpful (e.g., books, websites, activity suggestions).

### SYSTEM DESIGN: BESUPP

Based on the design suggestions above, Besupp (short for “bereavement support”) was developed. Besupp is a custom website designed specifically for bereaved individuals seeking an online support group experience similar to the format offered by BFO (Figure 1). Key to the concept for Besupp is the notion of a “memento-based” social support group, where digital mementos can be included to augment or prompt discussion. Digital mementos are often valued for not only sentimental reasons, but because they serve an important role in communication [26,28]. Besupp’s functionality is divided into two corresponding feature sets: the Memory Box, and the Circle.

#### *Memory Box*

The Memory Box serves as a user’s private space on the website. Inspired by bereaved individuals who keep physical memory boxes and bring them to support group meetings, it provides a virtual container for mementos related to the individual’s loss. In order to share mementos, they must first be uploaded to the Memory Box.

Users can include five major types of mementos in their Memory Boxes: photos, videos, stories, links, and journal entries. Photos can be uploaded from the user’s computer or imported from an existing URL (e.g., from Facebook or Flickr). Videos cannot be uploaded due to technical constraints, but users can provide a link to the YouTube URL in order to import a video into the Memory Box. This also provides a method for users to include music in their Memory Box by linking to a YouTube video of a song. In the Memory Box, stories are comprised of a title and story text, and can be sorted according to creation date and title. Users can further include links to other resources on the web that they find meaningful or helpful; for example, creating a link to a website containing poetry. Finally, the Memory Box provides a private journal in which the user can record his or her thoughts. All of the mementos in the Memory Box can be edited or deleted at any time, and captions can be provided for photos and videos.

#### *The Circle*

The Circle is the shared part of Besupp. All items in the Memory Box, with the exception of journal entries, can be shared or unshared with members of the Circle. Users can then browse the collection of shared photos, videos, stories, and links. The Circle mirrors the Memory Box in terms of presentation and functionality for photos, videos, stories, and links.

Each user is assigned to one thematic Circle (e.g., bereaved parents), and can view a listing of the other people in the

Circle. Each user has a profile that is visible to all members of the Circle. If they so choose, users can provide a profile photo and basic background information (name, age, gender, email). Users can also set a brief “role” tag in their profile, such as “bereaved mom.” Finally, the profile contains a field for the user to enter their own background story.

Each Circle can contain one or more users designated as a moderator. Moderators are authorized by the site administrator to help monitor and guide members of the Circle. Unlike normal users, moderator messages appear in a highlighted color in the chat. Further, they can set a Circle Announcement that appears on each page in order to demarcate current topics the Circle is discussing.

The Circle Chat is, in many ways, the heart of the site. Circle Chat is a custom asynchronous, persistent chat system where users can post messages to all members of their Circle. Messages are displayed on the Circle Chat page for seven days before being moved to an archive page. When sending a message, users can attach items from their Memory Boxes; these attached items are automatically shared and displayed in line with the sent chat message.

### DEPLOYMENT STUDY

Given this design, a deployment study was conducted to answer the research question: “How do bereaved participants perceive, use, and value the remembrance and social support features in the system?”

Working with coordinators at BFO, we determined that the audience for such a website would be individuals who had previously completed a support group (and therefore had been screened in a previous one-on-one interview), but desired ongoing, long-term support. Three types of groups were identified as representative of BFO’s offerings:

- **Young Adult (YA):** youth between the ages of 18 and 30 who experienced the loss of a parent or sibling;
- **Bereaved Parents (BP):** individuals of any age who had experienced the loss of an infant or adult child, or of a child who was not carried to term;
- **Spousal and Partner Loss (SP):** individuals of any age who have lost a spouse or romantic partner.

BFO coordinators circulated a recruitment email to their database of YA, BP, and SP members with an original limit of 5 years since the loss. The initial response rate did not yield enough participants to meet BFO’s minimum support group size of at least 5 members. As such, the limit of 5 years was lifted and the recruitment advertisement was circulated a second time, yielding enough to conduct 3 simultaneous support groups using Besupp. Each group had a facilitator who completed BFO’s intensive facilitator training process and had moderated previous face-to-face groups. Coincidentally, all participants were female. In total, 19 participants used Besupp (Table 1). The number of

Group	Size	Photos Shared/Total	Stories Shared/Total	Messages sent
YA	7	12/16	0/1	62
BP	7	7/11	6/8	180
SP	5	6/6	5/5	39
Total	19	25/33	11/14	281

**Table 1. Besupp usage statistics by group. Links and journal were very rarely used and omitted from the table.**

years since the loss occurred varied among participants. The most recent loss occurred 5 months before the study, while the most distant was 19 years ago. Twelve of the 19 participants endured the loss less than 5 years ago.

**Method**

A ten-week long deployment study was conducted, with each of the three support groups (YA, BP, and SP). At the beginning of the study, all members of each group were invited to an in-person meeting, where they had the opportunity to meet one another and the researcher. After obtaining consent, each participant was given a demonstration of Besupp and provided with a set of instructions and a username and password.

Following the initial introduction to the site, each participant completed individual semi-structured interviews at the beginning, middle, and end of the 10 weeks. This resulted in a total of 56 individual interviews with the 19 participants that lasted between 30 and 60 minutes each (approximately 42 hours of interviews in total). Participants were asked to use the site in as realistic a manner as possible, and were compensated \$10 per week.

The semi-structured interviews collected responses to the two major functions of the system: remembrance (as supported by the Memory Box) and social support (as supported by the Circle). Using remembrance and social support as guiding constructs, a thematic analysis of the interview transcripts was conducted. In the rest of this paper, I focus on the interview data concerning these two themes, and then report on other emergent results.

**RESULTS: REMEMBRANCE**

In Besupp, the Memory Box was intended to help individuals reminisce on their own and share mementos with peers. Most participants thought the Memory Box made good use of an existing mental model regarding storage of loss-related mementos.

*“I like the term ‘Memory Box.’ I liked the idea...and the analogy of the physical box with pictures and notes. That totally makes sense.” - SP1, final interview*

While all participants found the site accessible and appreciated its design elements, there were more profound concerns regarding the inclusion of reminiscence as part of

the system concept. While the early design work and literature suggested that having a digital space for bereavement-related assets and activities would be valuable, participants' low usage rate and attitudes conveyed a different story.

*“I look at it more as a sharing tool. Like what I put in there, stories or something like that, I always share with other people. I don't think I'd just put stuff in there just for me. The only reason I put stuff in there was the way to get it into the shared part... On my own drive, I have a folder of poems I like and stuff like that. A folder of [my son's] stuff. I have that already in Word so I don't know, if I have that on my computer already, why would I put it on here?... I don't know if the site will run forever in reality. I know this will close, but if I were on a site like this I have no guarantee that it'd always be there. The only reason is to share it with other people.” - BP6, final interview*

As reflected by this quote, the Memory Box was subservient to the functions of social support, rather than a standalone tool for reminiscing. As a result, the Memory Box imposed an extra step when users wanted to directly share assets with other members of the Circle. Even then, including journals and links inside of the Memory Box revealed some confusion and a blurring of the distinction between talking about the loss, and talking about grief.

*“A lot of times when we're talking in the groups or even chatting, what is important is the emotions and the grief journey that the bereaved person is on... Memory Box puts that emphasis on the person that you lost, which is important, but... the journal would be about what is going on for you right now. That's not about memories. That's about me, and not about [my partner] at all.” - BP1, final interview*

In other words, some of the assets participants chose to include in the Memory Box were not actually mementos. Instead, they were resources or artifacts that arose in response to the loss (e.g., a link to a website for widows). Furthermore, participants were concerned about sharing aspects of a deceased loved one's life in a group context:

*“I'd do the sharing cautiously because you have this memory and I don't want to just put it out there. [My husband] was still a private individual. Though I am happy to share my grief...I don't want to just throw him out there as exhibit A. These are my relationships, not his.” -- SP4, final interview*

These quotes illustrate the distinction between the creation and maintenance of current relationships with members of the support group as part of the grieving process, and the private nature of mementos that come from the loss itself. The Memory Box prompted rumination about the loss rather than acting as a mechanism for coping.

*“Personally I am ready to start talking about the future... grief and loss are different things. If we're meeting to talk*

*about the loss, then that's the past, what they were like then. Grief is now. It's what we're doing now and what we will be doing for the rest of our lives.” - YA4, final interview, her emphasis*

Because participants wanted to focus on coping and sharing supportive messages, relatively few mementos were uploaded. Seventeen of the 19 participants said that they would include the Memory Box in future versions of the site. SP2 (whose loss occurred 1 year ago) disagreed, and found it too difficult to work with mementos due to the freshness of her loss:

*“I find it difficult. To put a memory or photos into the box you have to go through the pictures and all. Some things I don't know if it's too soon, or I'm still in the grieving stage or whatever. I just can't seem to look at pictures right now... I can't even look at them let alone upload them. I chalk it up to being that it's still pretty raw for me... I thought I could do it when I started. I thought it would help me, but can't even do simple things. It's just not good.” - SP2, final interview*

As shown here, the emphasis on working with digital assets was not always welcome. However, for some, uploading content to the Memory Box was a positive experience. YA2 described that going through her photos and stories gave her an opportunity to “focus on the good times,” while BP9 enjoyed the ability to “do stuff” and “create something new.” Indeed, stories and photos were the most frequently created mementos, and were often shared to ground and enrich these types of exchanges.

### **Stories**

As Table 1 shows, only 11 stories were shared in total, and no stories were shared in the YA group. However, all 19 participants wrote a “background story” as part of their user profile. In this context, stories served multiple functions. First, background stories helped participants get to know each other, and to recall the details of others' losses.

*“Some of the stories are quite brave. What people have gone through. Yeah, I think you can certainly identify with the losses.” - BP3, final interview*

Identifying with these losses was a key way that participants achieved a sense of normalcy about what they were experiencing during their grief (a common goal of grief support [5,7]). While no Memory Box stories were shared in the YA group, the moderator offered some explanation regarding her personal experience with them:

*“I wish people would have used [stories] more... but at the same time... anything I wanted to make public I put on the chat, so I didn't use the stories...I think there's a place for telling stories and we use those in the face-to-face groups as well. But the deeper connection comes when it opens up*

*to a conversation. That is what facilitates the deeper connection with people.” - YA1, final interview*

As YA1 points out, the goal of writing stories was to share them with other people. In other words, the stories that were told had audiences. In Besupp, stories in the Memory Box contained thoughts and questions, rather than narratives. For example, one participant in the SP group had a child with a man who died after they had split, and wrote a “story” to ask advice about her circumstances:

*“We are quickly approaching [his] 'death day' and I am never sure what to do. How do I mark that day? Is it time to take our 4 year old to the cemetery, or is she still too young? Do I send flowers to his parents or is a phone call a better idea?” - excerpt from a story written by SP5 on Week 2*

Posing these kinds of questions in a story then led to a conversation in the Circle Chat, as the group moderator explained:

*“It started discussion. When [SP5] shared her story, it was about the anniversary of the day her partner died. So that started a bit of a discussion on what to do in an anniversary.” - SP1, final interview*

This reveals something about one type of storytelling in bereavement support groups. In the lay sense, storytelling often refers to a narrative with a start, end, plot, characters, and so on. In this system, the stories were also used as ways to convey current or ongoing thoughts or experiences, with a goal of receiving feedback from the Circle -- something resembling a letter to an “advice column” more so than a “story.” Being able to link to a story directly from the Circle Chat appeared to help with this as well:

*“I think it makes sense if it's the kind of story where you want other people to comment on it, or you want to start discussion... a link you wanna say 'Hey this is interesting because...' and comment on it in some way.” - SP1, final interview*

Summarily, the background stories opened up opportunities for participants to introduce themselves and relate to one another. However, the storytelling that occurred is better characterized as unfolding in conversation rather than as a form of closed-ended narrative. While blogs and forums are not necessarily designed with grieving people in mind, their capacity for open-ended textual expression (e.g., a blog or forum post) is supported by participant feedback.

### **Photos**

Photos were the most commonly used type of digital memento in Besupp. Overall, participants shared 25 photos out of the 33 that were uploaded to the Memory Box (Table 1). Like stories, photos were used as a form of visual storytelling and as a way to share with the group.

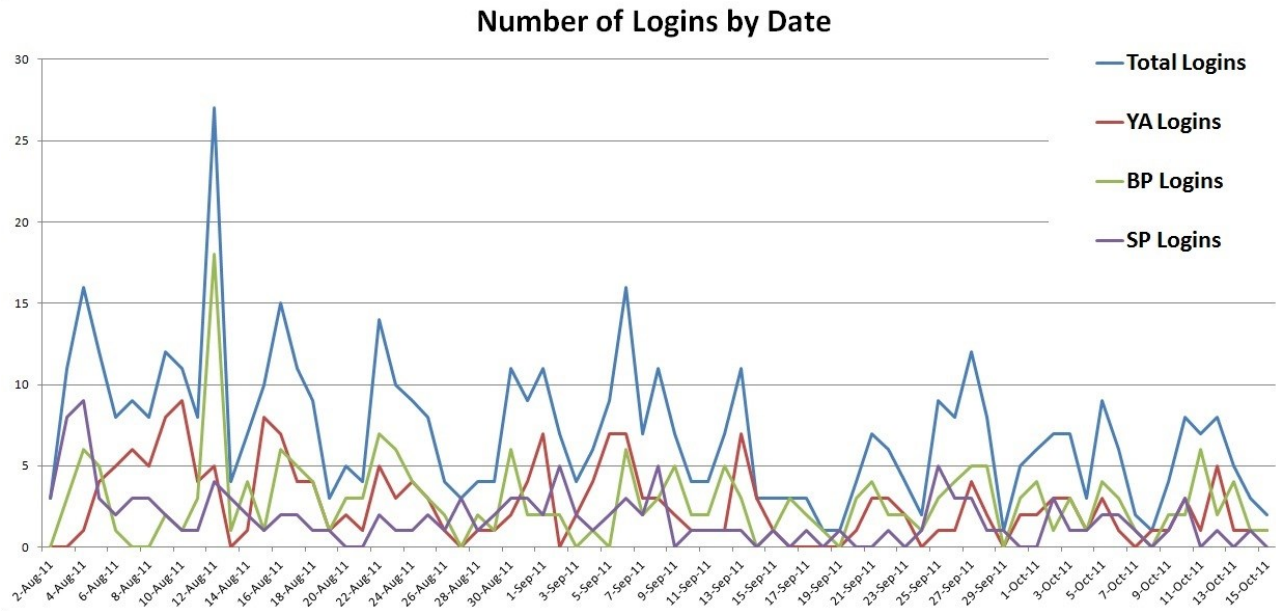


Figure 2. Number of logins per day over the 10 weeks of the study.

*“Yeah I mean the first thought was to put no picture. I liked the anonymity of it all. I felt quite guilty that I didn't have a photo of my mom or stepmom to share, so I thought that I should put **something**. The second thought was to put a picture of myself, but I felt silly doing that since the site is about more than just me... it didn't share enough of my story.” - YA1, interim interview (her emphasis)*

One of the main ways that this story was told was by uploading photos showing the user with the deceased person, foregrounding the nature of their relationship. In the Circle, 5 participants selected photos that showed themselves with their loved one, 4 chose photos of their loved one only, and 2 chose photos only showing themselves. In total, 9 of the 11 profile photos showed the deceased loved one. By saying that the site is about “*more than just me*,” YA1 suggests that the personal relationship she had with her mother and step-mother are important to share with others in order to successfully exchange support, and photos were a key way to expose this.

In performing this “visual storytelling,” several participants chose photos of only “happy memories.” Here, BP1 describes why she chose to upload two photos, one for each of her two sons who died:

*“It's a picture I really like because he's got such a devilish grin on his face. Even going through treatment [Son1] was such a happy child... I'm not especially fond of that one either but because [Son2] looks sad, his eyes are so sad, he looks a little hopeful.” - BP1, interim interview*

As noted in previous work concerning photos [14,27], BP1 consciously avoided photos where her loved one was frail, or sickly, and instead used photos to tell a particular kind of happy story. Indeed, photos needed to stand on their own as

forms of storytelling. As SP5 put it, looking at others’ photos sometimes felt “*one-sided*” because of a lack of context.

Summarily, even though mementos like stories and photos could be shared with the Circle, the results suggest that they should be interwoven more fluidly into a supportive exchange (e.g., uploading a photo to a Facebook wall), rather than standing alone in a separate part of the site. In turn, these exchanges can leverage how well stories and photos provide carefully-selected background information, and set the stage for more in-depth social support.

**RESULTS: SOCIAL SUPPORT**

Besupp provided a space for expressing emotions that was separate from existing relationships such as friends, family, or Facebook. Participants valued the ability to log on and “vent” to sympathetic others when they felt their needed to:

*“It was really late at night and it's not like I can call anybody. I don't want to bug anyone but I just needed to vent. So this was a way to just put it down somewhere. It felt like somebody was listening, could hear my frustrations because I wasn't going to bug anyone else with this.” - SP4, interim interview*

While Besupp provided a place to express these emotions, the lack of a timely response to these thoughts became problematic. Participants noted that the amount of activity on the site was less than they had expected and lower than a face-to-face group. Figure 2 demonstrates a pattern of use where a large number of logins occurred roughly once per week, followed by a period of relative inactivity.

Participants attributed this low rate of exchange to a range of factors. This included busy lifestyles, travel, and

technical difficulties. Participants also thought that the group was not big enough to keep discussion flowing (even though these numbers were on par with numbers in face-to-face groups). The following exchange occurred in the BP Circle Chat during Week 7:

**BP1 (moderator) (Tue 9:31am):** *I've also been thinking about this website and how different it is from the groups. I think if we could try and check in once a day, it would help. Otherwise when someone makes a post, it is kind of left hanging, particularly if it directed at someone specific, and that person doesn't check in for awhile. What does everyone think?*

**BP9 (Tue 12:51pm):** *Maybe we could meet once a week with a selected topic like the group did.*

This led to the BP group using Besupp to schedule a chat session where three of the members logged into Besupp at a pre-determined time. This real-time chat explains the relatively large number of messages sent by the BP group (180) in comparison to the YA (62) and SP (39) groups. In the follow-up interviews, participants reflected upon the real-time chat favourably:

*"The one day that we did make a date to go online and talk there were only 3 of us, but we did do the chatting for about an hour. That was really good. It was kind of like being in a group."* - BP2, final interview

Participants suggested a range of alterations to the system that might support more conversation: meetings might be more scheduled, or more participants might be involved in the group. Others thought that the chat system might support availability notifications and instant messaging.

In addition, participants wanted moderators to take more prominent roles in stimulating and directing conversation. Generally, the presence of a moderator in the Circle was seen as critical by both non-moderators and moderators alike. Moderators were primarily valued as safeguards against inappropriate or harmful behavior, but were most valued by participants when they took a direct role in structuring the discussion. Participants frequently remarked that the moderators should choose a conversation topic and ensure that people contributed to the discussion.

*"A lot to do with interaction from an admin. Someone to keep the conversation going. In this type of environment either creating a type of structure that everything follows, the way BFO does with Week 1 is Topic A, Week 2 is Topic B. And a topic list of 15 things or something for your admin. Then, every time the conversation died down then you can introduce something new to keep things going."* - YA3, final interview

The Circle Announcements were intended to help moderators create discussion topics. While the moderators were the three most active individuals on Besupp, there remained an inability to create and maintain a discussion.

### Self-Editing

Like many face-to-face support groups, sharing stories and emotions was a large part of the experience on Besupp. Choosing what to tell and share became a deliberated process. In interviews, participants frequently reported revising what they were about to say before sending it to the chat room.

*"In the face-to-face groups they were very careful to keep things moving... With the chat room people can dwell on whatever they choose to...I think it gives you a chance to work things through in more detail maybe than in face-to-face...You respond to your own stuff too in addition to other people."* - BP9, interim interview

In an online support group, the bereaved can carefully craft the image that they wish to convey to others. Unlike a face-to-face group where physical behaviors and expression can belie raw grief, a computer-mediated communication channel can hide, disguise, or alter these emotions by offering "hyperpersonal" methods of communication [36]. At the same time, using all of the available communication methods may result in "burn-out." Whether this ability to more carefully control the way that one responds to prompts in the support group is beneficial for particular types of grievors or purposes remains an open question.

### Helping Behaviors

While many of the activities concerning mementos were not heavily used, the Circle Chat offered a form of "something to do" that was more successful. Participants used the Circle Chat to offer support and give back, with little desire to "receive" it. For example, BP5 lost her son 16 years ago, and has since become an active member of BFO, volunteering to conduct one-on-ones. She saw Besupp as a place to share the wisdom of her experience:

*"I always thought the site would be good to share. Because talking and sharing helps you with your grieving process and helps others with the grieving process. It shows them they are not alone. That their feelings are similar. Many people think that their loss is so unique... I thought sharing would make the people understand that others have gone through this and they are better off after a certain period of time."* - BP5, final interview

The moderator of the BP group similarly described her motivation for volunteering as a moderator both in Besupp and in BFO groups:

*"Comes out of a feeling of being able to help others. I have been through so many of these things that I can show them that you can carry on, it's possible. With my experience, and it makes my experience meaningful."* - BP1, final interview



This form of group activity allows the bereaved to draw on their experiences within a safe environment. Designers developing social support systems might think about how to support this type of use case more fully.

**EMERGENT RESULTS**

In this section, I remark on results that emerged during interviews that refer to more general aspects of the system and/or study.

**The Effort of Addressing Grief Online**

The relatively low usage rate led to interesting conversations with participants about its efficacy, and how their grief - and need for support - fluctuated. Despite a perceived need for support, a barrier identified by participants was the large amount of emotional effort required to use Besupp. For some participants, this left them feeling drained and brought back negative emotions:

*“It was very hard for me emotionally and way harder than I thought it would be after hearing everyone’s story. I felt like... pretty upset about it truthfully. It was hard for me to come back...hearing all the sad stories again was really hard for me to take because I’m in a different place now... people using it seem to be getting a lot out of it but for me I’m just a bit heartbroken.” - YA4, interim interview*

In a way, this highlights the benefits of a weekly 2-hour support group: it limits the time that participants are exposed to thoughts and emotions of grief. The constant availability of Besupp shifted the onus of managing exposure onto the user, making it more difficult to disengage from these emotions.

Additionally, while the creation of a separate space for bereavement activities was initially met with enthusiasm, participants remarked on how the website made social support seem more formal than it is in face-to-face groups. For example, YA4 felt she could not share certain items she associated with her brother because they were not somber enough for a bereavement website:

*“There are some songs he liked from the 90s, like ‘Mambo Number Five’ by Lou Bega. I thought about uploading that from YouTube, but I didn’t know how seriously to take it. That’s the problem with grief... I laugh a lot when I talk to his friends and we talk about happy memories. It’s not sad but there’s something about when you call it ‘grief support online’ that you should be doing your ‘grief work.’ And I’m not sure if Lou Bega has anything to do with grief work.” - YA4, final interview*

YA4’s hesitation to include a “fun” link in Besupp could be a result of participation in a study, but at the same time, it shows that the inability to monitor the reactions of others in real time makes it difficult to interpret the appropriateness of particular statements in a grief context. While the dearth of social cues in online systems is well-established, in this context it results in a flattening of the complicated emotions

ID	Years since Loss	Number of Logins
BP7	1	28
SP2	1	12
YA4	2	23
YA8	3	48
SP4	3	7
BP6	4	57
YA7	4	36
BP9	4	35
SP5	4	32
YA3	4	22
YA6	5	4
BP2	6	37
YA1	7	45
SP6	7	22
SP1	11	57
YA2	11	16
BP1	12	39
BP5	16	5
BP3	20	6

**Table 2. Number of logins per participant and number of years since loss. (BP1, SP1, and YA1 are moderators.)**

that the bereaved may feel. Systems for the bereaved must acknowledge that grief, while painful, is not the sole emotion to be felt or shared.

**Timing of the Study**

Most participants experienced their losses 2 or more years ago (Table 2). For this group of participants, Besupp was seen as a potentially useful tool, but not for them at the current stage of their grief journey. Rather, they believed it would be much more helpful closer to the time of the loss.

*“I like the idea to have it as an option again, given that I’m 4 years into grieving my mom. I don’t know that it would be as necessary for me, but... I’m thinking 4 years back I was searching desperately in the middle of the night and everyone was asleep. And I was online trying to find something... so I think it’s a necessary tool to have, but more for people who are freshly grieving. But again there are times where I’m like ‘Who do I talk to?’ and it’d be nice to know that it’s there, but I don’t know that I’d use it.” - YA2, final interview*

Many participants believed that they would have garnered greater benefit from Besupp if they had participated within 6 months to 2 years following the loss. Of the two participants who were within a year of their losses, one preferred face-to-face groups and the other had difficulty

finding any group at all from which she could derive value. The correlation coefficient between the number of logins and the number of years since loss was -0.45 (with moderators excluded), indicating there was a moderate negative relationship (Table 2). This medium correlation suggests that users with fresher losses logged in more frequently, and supports the idea that online support groups would be best applied within the first year after the loss.

### IMPLICATIONS AND CONCLUSIONS

Based on the results presented above, I conclude with a series of implications for the design of systems for social support, remembrance, and bereavement more generally.

*The value of digital mementos changes over time.* In Besupp, participants valued photos and stories for their ability to share common experiences and build trust. Following this initial “getting to know you” period, digital mementos became less useful resources in a support setting. Conversation in the Circle Chat replaced photos and written stories. This deployment study raises issues about audience, timing, and instrumental usage of mementos for HCI and CSCW researchers.

This shift towards conversation highlights the need for designers to more carefully *consider distinctions between loss and grief*. As participants pointed out, mementos helped to convey the loss, but can dredge up painful emotions. This runs counter to the purpose of social support – to find ways to cope with grief. To paraphrase YA4, loss was **then**, but grief is **now**. Systems for the bereaved (such as Besupp or online memorials) may inadvertently intermingle the two. Future systems should carefully consider how these two processes of remembrance and coping impact one another.

At the same time, *people who have learned to cope can find value in offering support to those with fresher losses*. For those further along in their grief, Besupp offered an opportunity to proffer compassion and experience to a group of receptive others. This raises a question of audience. When we design for the bereaved, we need not simply design for those who are currently in need, but also for those who have the compassion and desire to share their time and experience.

The study also showed that *systems should be designed for intermittent use*. While participants valued Besupp as a place to meet their support needs, engaging with the collective grief of the Circle was emotionally draining. Besupp was a place to unload thoughts and feelings, log out, recharge for a few days, and then revisit later. Indeed, what participants perceived as a low usage rate seemed to actually be a reflection of this cycle. As designers, we might consider what this means for the success of the systems we build. A low rate of adoption or usage is not necessarily a sign of poor design; on the contrary, it may simply be part of working within an ongoing coping process and journey towards self-support. Besupp is an

example of an application where value stems not from frequent use, but from the comfort of knowing it is available if needed. This is similar to other social networking sites, such as MySpace or Facebook [11,30].

In contest with this point, designers might *consider ways to mitigate burnout*. Because Besupp was always available, the onus for managing exposure to the Circle’s grief was placed on the participant. Designers might consider systems that are available only for brief amounts of time (e.g., once a week) or only in specific circumstances (e.g., while at home). Building these restraints into a system can limit emotional drain, and potentially ameliorate additional burnout from low rates of participation and conversation.

Finally, it is important to bear in mind that *technology operates among a rich set of supports*. At the outset, some participants saw Besupp as a potential replacement for a face-to-face support group, and were dismayed when the depth of perceived connection was less than in a face-to-face setting. The results support the idea that technology is not a way to replace face-to-face support groups. Rather, it is a complementary, optional component of a richer, more comprehensive set of practices and places for experiencing grief. Designers should consider how their system fits into an ecology of grief supports, including family, friends, peers, clergy, and counselors.

Overall, the design and deployment study presented in this paper contributes to a fuller understanding of the value, limits, and opportunities that technology presents in the context of bereavement. By shedding light on these topics, the CSCW community may be better able to address the needs of the bereaved, and those seeking social support in an online community more widely.

### ACKNOWLEDGEMENTS

Thanks to the study participants, Bereaved Families of Ontario – Toronto, the GRAND NCE, Ronald Baecker, Garry Ing, Carrie Demmans Epp, and Karyn Moffatt.

### REFERENCES

1. Barrera, M. and Ainlay, S.L. The structure of social support: A Conceptual and empirical analysis. *J. Comm Psych 11*, (1983), 133–143.
2. Bender, J.L., Jimenez-Marroquin, M.-C., and Jadad, A.R. Seeking support on Facebook: a content analysis of breast cancer groups. *J. Med Internet Res 13*, 1 (2011), e16.
3. Bosticco, C. and Thompson, T.L. An examination of the role of narratives and storytelling in bereavement. In L.M. Harter, P.M. Japp and C.S. Beck, eds., *Narratives, Health, and Healing: Communication Theory, Research, and Practice*. Routledge, 2005, 391–412.
4. Brubaker, J.R. and Hayes, G.R. “We will never forget you [online]”: an empirical investigation of post-

- mortem MySpace comments. *Proc. CSCW 2011*, ACM (2011), 123–132.
5. Buckle, J.L. and Fleming, S. *Parenting after the Death of a Child: A Practitioner's Guide*. Routledge, 2010.
  6. Consolvo, S., Everitt, K., Smith, I., and Landay, J.A. Design requirements for technologies that encourage physical activity. *Proc. CHI 2006*, ACM (2006), 457–466.
  7. Dominick, S.A., Irvine, B.A., Beauchamp, N., et al. An internet tool to normalize grief. *Omega 60*, 1 (2009), 71–87.
  8. Forte, A., Hill, M., Pazder, R., and Feudtner, C. Bereavement care interventions: a systematic review. *BMC Palliative Care 3*, 1 (2004), 3.
  9. Frohlich, D., Kuchinsky, A., Pering, C., Don, A., and Ariss, S. Requirements for photoware. *Proc. CSCW 2002*, ACM (2002), 166–175.
  10. Getty, E., Cobb, J., Gabeler, M., Nelson, C., Weng, E., and Hancock, J. I said your name in an empty room: grieving and continuing bonds on Facebook. *Proc. CHI 2011*, ACM (2011), 997–1000.
  11. Graves, K.E. Social Networking Sites and Grief: An Exploratory Investigation of Potential Benefits. 2009. <https://dspace.iup.edu/handle/2069/215>.
  12. Hallam, E. and Hockey, J. *Death, Memory and Material Culture*. Berg Publishers, 2001.
  13. Kirk, D., Sellen, A., Rother, C., and Wood, K. Understanding photowork. *Proc. CHI 2006*, ACM Press (2006), 761–770.
  14. Kirk, D.S. and Sellen, A. On human remains: Values and practice in the home archiving of cherished objects. *ACM Trans. Comput.-Hum. Interact. 17*, 3 (2010), 1–43.
  15. Klass, D., Silverman, P., and Nickman, S. *Continuing Bonds: New Understandings Of Grief*. Taylor & Francis, 1996.
  16. Lehman, D.R., Ellard, J.H., and Wortman, C.B. Social support for the bereaved: Recipients' and providers' perspectives on what is helpful. *J Consult Clin Psych 54*, 4 (1986), 438–446.
  17. Leonardi, C., Mennecozzi, C., Not, E., et al. Knocking on elders' door: investigating the functional and emotional geography of their domestic space. *Proc. CHI 2009*, ACM (2009), 1703–1712.
  18. Levy, L.H., Derby, J.F., and Martinkowski, K.S. Effects of membership in bereavement support groups on adaptation to conjugal bereavement. *Am J Comm Psych 21*, (1993), 361–381.
  19. Levy, L.H. and Derby, J.F. Bereavement support groups: Who joins; who does not; and why. *Am J Comm Psych 20*, 5 (1992), 649–662.
  20. Lewin, K. Group decision and social change. In E. Maccoby, T. Newcomb and E. Hartley, eds., *Readings in Social Psychology*. Holt, Rinehart, and Winston, 1958, 197–211.
  21. Lindley, S. Passing on memories in later life. *Proc. CHI 2011 Workshop on Bridging Practices, Theories, and Technologies to Support Reminiscence*, (2011).
  22. Liu, L.S., Hirano, S.H., Tentori, M., et al. Improving communication and social support for caregivers of high-risk infants through mobile technologies. *Proc. CSCW 2011*, ACM (2011), 475–484.
  23. Massimi, M. and Baecker, R.M. A death in the family: opportunities for designing technologies for the bereaved. *Proc. CHI 2010*, ACM (2010), 1821–1830.
  24. Massimi, M. and Baecker, R.M. Dealing with death in design: developing systems for the bereaved. *Proc. CHI 2011*, ACM (2011), 1001–1010.
  25. Massimi, M. and Charise, A. Dying, death, and mortality: towards thanatosensitivity in HCI. *Proc. CHI 2009 Extended Abstracts*, ACM (2009), 2459–2468.
  26. Odom, W., Harper, R., Sellen, A., Kirk, D., and Banks, R. Passing on & putting to rest: understanding bereavement in the context of interactive technologies. *Proc. CHI 2010*, ACM (2010), 1831–1840.
  27. Odom, W., Pierce, J., Stolterman, E., and Blevis, E. Understanding why we preserve some things and discard others in the context of interaction design. *Proc. CHI 2009*, ACM (2009), 1053–1062.
  28. Petrelli, D. and Whittaker, S. Family memories in the home: contrasting physical and digital mementos. *Personal Ubiquitous Comput. 14*, 2 (2010), 153–169.
  29. Picton, C., Cooper, B., Close, D., and Tobin, J. Bereavement support groups: Timing of participation and reasons for joining. *Omega: Journal of Death and Dying 43*, 3 (2001), 247–258.
  30. Roberts, P. '2 people like this': Mourning according to format. *Bereavement Care 31*, 2 (2012), 55–61.
  31. Skeels, M.M., Unruh, K.T., Powell, C., and Pratt, W. Catalyzing social support for breast cancer patients. *Proc. CHI 2010*, ACM (2010), 173–182.
  32. Sofka, C., Cupit, I.N., and Gilbert, K.R. *Dying, Death, and Grief in an Online Universe: For Counselors and Educators*. Springer Publishing Company, 2012.
  33. Sofka, C. Adolescents, technology, and the internet: Coping with loss in the digital world. In D. Balk and C. Corr, eds., *Adolescent Encounters with Death, Bereavement, and Coping*. Springer, New York, 2009, 155–174.
  34. Uriu, D. and Okude, N. ThanatoFenestra: photographic family altar supporting a ritual to pray for the deceased. *Proc. DIS 2010*, ACM (2010), 422–425.
  35. Volkan, V.D. The Linking Objects of Pathological Mourners. *Arch Gen Psychiatry 27*, 2 (1972), 215–221.
  36. Walther, J.B. Computer-Mediated Communication Impersonal, Interpersonal, and Hyperpersonal Interaction. *Communication Research 23*, 1 (1996), 3–43.