Modern Bereavement: A Model for Complicated Grief in the Digital Age

Anna N. Baglione [1]**, Maxine M. Girard**[2]**, Meagan Price**[3]**, James Clawson**[1]**, Patrick C. Shih**[1]

[1]Department of Informatics
Indiana University
Bloomington
{abaglion, clawsonj, patshih}@iu.edu

[2]School of Library and
Information Science
Simmons College
maxine.girard@simmons.edu

[3]Department of Mathematics
and Computer Science
Claflin University
mprice@claflin.edu

ABSTRACT

The experience of grief and death is an inevitable part of life. Grief, a natural response to death, can be a challenging and emotionally taxing journey. Bereaved individuals often feel lost in a fog, unaware of resources available to them and unsure of which resources could be useful for supporting their healing process. Complicated grief, a more intense form of grief that extends beyond six months following the death of a loved one, presents both a unique challenge and a design opportunity for the HCI community. In this work, we present the results of a survey and interview study on the technological practices of complicated grievers. Based on themes found in the data, we propose a new model for complicated grief in the digital age, consisting of the following phases: *Fog*, *Isolation*, *Exploration*, *Immersion*, and *Stabilization*. We then present a set of design considerations for designers seeking to create tools for complicated grievers navigating their unique grief journeys.

Author Keywords

Grief support; bereavement; online health communities; in-person support group; grief loop; health care journey

ACM Classification Keywords

H.5.m. Information Interfaces and Presentation (e.g. HCI): Miscellaneous

INTRODUCTION

Coping with the loss of a loved one is rarely easy. Bereavement, the period of mourning following a loss, can prove a long and tiresome journey riddled with confusion, frustration, and loneliness. Grief, known as the "the primarily emotional (affective) reaction to the loss of a loved one through death" [39], is indiscriminate. It affects individuals of all races, creeds, and socioeconomic statuses. The United States alone had over 2 million deaths in 2014 [19]. Thus, upwards of several million people likely experience grief *each year*.

In recent years, prominent individuals in academia and industry have promoted a greater awareness of loss and grief. Dr. Randy Pausch, professor of computer science and HCI at Carnegie Mellon, rose to fame after he delivered his "Last Lecture" (and later co-authored a book by the same name) during his fight with pancreatic cancer, which he eventually lost [12]. Apple pioneer Steve Jobs left behind a lasting legacy that has lived on in books, movies, and the widely-shared graduation speech he delivered at Stanford University [37]. Most recently, Sheryl Sandberg, chief operating officer of Facebook and wife of the late Dave Goldberg, raised awareness of loss, grief, and resilience after her husband's sudden death through her book, *Option B* [36].

Despite the growth in public awareness of loss and bereavement, profound stigma continues to accompany grief. During bereavement, grieving individuals seek acceptance, support, compassion, and understanding [40]. However, they can face judgment and a lack of understanding from their peers and even their family, especially if their specific loss carries social stigma (for example, loss due to a loved one's suicide) [9]. Consequentially, the bereaved sometimes turn to grief counseling to receive the support and validation. While grief support has traditionally taken the form of counseling or local, face-to-face groups, the rise of standalone, forum-based grief websites [2] [17] and virtual groups on social media sites like Facebook has contributed to a diverse and rapidly-growing community of online grievers. This shifting landscape of grief in the digital age highlights the multitude of ways the bereaved seek out grief support and illustrates the importance of access to a wide variety of resources to cope with loss.

One form of grief that has garnered increased awareness within the research commmunity in recent decades is **complicated grief**. Also known as *prolonged grief disorder (PGD)*, complicated grief is "debilitating" grief that continues beyond the first 6 months after the death and that entails "intrusive thoughts...painful yearning", denial, and loneliness, among other symptoms. [32]. It is distinct from so-called "normal" grief because it is more intense, lasts longer, and profoundly hinders the griever's day-to-day functioning. Complicated grief presents both a unique challenge and a design opportunity for the HCI community, as it remains largely unexplored in the HCI literature.

In this work, we address the knowledge gap regarding specific coping behaviors associated with complicated grief and

how these are realized through the use of technology. We approach complicated grief through a behavioral and holistic lens, seeking to answer the following questions: (1) What kinds of technology do complicated grievers use while grieving? (2) How is technology currently used to assist the complicated grievers in coping with loss? and (3) What differences in support do complicated grievers experience in online versus in-person grief support groups? We highlight the contribution of this research as follows:

- Understand how complicated grievers use technological interventions to cope

- Compare online and offline grief support groups and examine transitions between these support systems

- Introduce a behavioral model of the bereavement journey

- Present implications for designing systems that support the bereavement journey

We review previous work in the grief and technology space. We then present the results of our survey and interview study and introduce a model of complicated grief for the digital age. Finally, we present a set of design implications for those working with and designing for complicated grievers.

RELATED WORK

Models of Bereavement
Kubler-Ross's "Five Stages of Grief" model is perhaps the most widely-recognized attempt to characterize commonalities in the way people deal with loss; these are *denial*, *anger*, *bargaining*, *depression*, and *acceptance* [21]. Other stage- and phase-based models soon followed. Horowitz proposed six phases of mourning, which included *outcry* (the initial reaction to the grief), *denial*, *intrusion* (the unpleasant thoughts, emotions, and experiences that accompany grief), *working through*, and *completion* [18]. Rando later proposed a detailed model consisting of the three phases of *Avoidance*, *Confrontation*, and *Accommodation* coinciding with six major mourning processes collectively known as the "six R's": *Recognize the loss*, *React to the Separation*, *Recollect and re-experience the deceased and the relationship*, *Relinquish old attachments*, *Readjust*, and *Reinvest* [34].

More recent literature has demonstrated a shift from rigid stage- and phase-based models to models that account for fluidity and individualism within the bereavement experience. Stroebe and Shut's Dual Process Model of bereavement demonstrated the tendency of the bereaved to oscillate between reflecting on the loss and focusing on "restoration" [38]. Bonanno et. al's five distinct grieving patterns included "common grief, chronic grief, chronic depression, improvement during bereavement, and resilience" [3]. Gillies and Neimeyer's Meaning-Making model explored how individuals address questions of distress and identity post-loss [16]. Doka and Martin's work highlighted factors such as personality and culture as indicators of grief patterns. They also distinguished between styles of grieving, showing that *intuitive* grievers express their grief through emotions, whereas *instrumental* grievers express grief through action [10].

While these models have collectively examined the behavioral and cognitive components of grief in great detail, none are tailored to bereavement in the digital age, nor do they explicitly focused on complicated grief. Our contribution, a model of modern bereavement for complicated grievers, most closely aligns with Rando's phase and process-based model. However, we take Rando's observations a step further by focusing on the role of technologies as coping tools within the context of the bereavement journey, with a specific focus on complicated grievers. We also extend previous work's focus on individualized grieving to apply to expressions of complicated grief in both online and offline contexts.

Supporting the Bereavement Journey
The HCI community has largely focused on supporting the bereavement journey through digital memorialization and remembrance [14, 24, 26, 27] and expressions of grief online [5, 6, 11, 22, 40].

Digital Memorialization and Remembrance
Digital memorials have traditionally served as focal points for understanding the role a relationship with the deceased plays in the life of the bereaved. Odom et al. [30] and Massimi and Baecker [23] explored memorialization and remembrance by highlighting how loved ones carry on the deceased's legacy through digital and non-digital artifacts and means, such as photographs and musical instruments. Additionally, Moncur et al. examined the use of technology in what they deemed the "post-mortem" interval, which includes events such as the funeral itself [25]. For example, [25] showed how a funeral director might use an iPad to show a client how a forthcoming obituary for their deceased loved one might look. Beyond seeking an understanding of remembrance of the deceased, HCI researchers have proposed improvements to digital memorial design, to help the bereaved better honor the deceased. Moncur et al. developed a framework for digital memorials [27], and Moncur later utilized this framework to drive the creation of the "bespoke digital memorial", Storyshell [26]. Foong and Kera focused specifically on digital memorial creation through reflective design [14].

These works have tended to focus heavily on identity and relationships, but less so on specific coping behaviors. Moreover, while many of these works focus extensively on both technology-aided and non-technology-aided actions of memorialization and remembrance, few besides Massimi and Baecker [24] have explored mundane technology-aided tasks, such as communicating with friends or relatives on a regular basis via text messaging or email. Thus, while these works paint a portrait of who the bereaved are and what is important to them, an opportunity exists to deepen our understanding of how the bereaved use technology on day-to-day basis to cope with their loss.

The Expression of Grief Online
The rise of social networking sites (SNSs) has made online group interactions a critical focal point in bereavement-centric HCI research. Burke and Kraut found that connecting directly with similar others on Facebook (for example, through posts and messages) has a positive influence on well-being [7]. Brubaker et al. examined how MySpace [5] and

Original Factor Section	Item
Distraction	I use the Internet or a mobile app to help me find something pleasant to think about.
	I look at old digital photos or text messages to revisit pleasant experiences from the past.
	I listen to or create digital music.
	I view or create digital artwork
	I play or create video games, computer games, or apps.
	I take and/or edit digital photographs.
	I blog about things I enjoy.
	I subscribe to events on social media that I might enjoy.
Catastrophizing	Social media is overwhelming to me.
Ignoring Pain Sensations	I avoid looking up solutions to my pain online.
Distancing from Pain	I seek out artwork, music, or writing online that helps me characterize pain as something separate from myself.
Coping Self-Statements	I post things to my social media accounts to remind myself to be brave.
	I post things to my social media accounts to remind me that I can overcome the pain
	I post things to my social media accounts that remind me to not let pain stand in the way of what I have to do.
	Although it hurts to see others sharing happy things on social media when I am sad, I just keep going.
Praying	I use websites or mobile applications that help me try to understand my grief in light of my faith.
	I use websites or mobile applications to find prayers or spiritual texts that give me comfort.
	I use group messaging on my phone or social media to keep in touch with people in my spiritual circle.
Increasing Activity	I leave the house and do something, such as going to the movies, shopping, or going to a social media event I have subscribed to.
Hoping	I know that someday someone from my social media connections will be there to help me and the pain will go away for awhile.
Reinterpreting Pain Sensations	I put in headphones and listen to music when I perceive pain.

Table 1. New and Adapted Technology-Focused CSQ Items

Facebook [6] facilitate communal and individual expressions of grief. Brubaker et al. then presented the Legacy Contact addition to Facebook for managing and stewarding the online data the deceased leave behind [4]. Masssimi et al. created the Besupp website, which enables bereaved individuals to connect in a novel online space and broadens our understanding of their interactions in such a space [22]. Additionally, Dominick et al. created an internet-based tool designed to help uncomplicated grievers process their grief [11].

HCI researchers have created robust, functional tools to help the bereaved manage their grief in online spaces. However, to our knowledge, no prior HCI research has specifically focused on understanding and supporting those suffering from complicated grief. We argue that work focusing specifically on complicated grief is necessary, as complicated grievers represent a diverse population in perhaps the greatest need of support within the bereavement community. In this work, we utilize clinically-validated instruments to deepen our understanding of complicated grievers, their needs, and their technological practices.

METHODS

We created a survey and interview study designed to gauge participants' technological practices, coping strategies, experience in grief support groups, and overall progression through their grief journey. This study was approved by the Institutional Review Board at Indiana University.

Study Recruitment

We approached administrators of online grief support groups on Facebook, administrators of forum-based grief support websites including Grief in Common [17] and Beyond Indigo [2], and facilitators of in-person support groups in the local area near our university. We recruited participants for our study through group administrators, rather than directly approaching support group members, in the interest of protecting the members' privacy. Upon agreeing to participate in our research, participants were provided with a study information sheet and a consent form introducing our project and were then asked to complete a survey.

Survey

The survey consisted of questions adapted from three validated instruments: the Inventory of Complicated Grief (ICG) [33], the Texas Revised Inventory of Grief (TRIG) [13, 15], and the Coping Strategies Questionnaire (CSQ) [35]. In addition to these validated instruments, we included both new and modified technology-focused items in the CSQ. These questions investigated practices such as blogging as a distraction, listening to music when perceiving pain, and using mobile apps to find uplifting of comforting content, among other practices. The new and adapted technology-focused CSQ items are presented in Table 1. We also included open-ended questions to gauge the participant's experience in their support group, the kinds of technologies they used throughout

their grieving process, and what they found useful or challenging when using technologies to cope.

A total of 99 individuals responded to our survey. 93 respondents completed the TRIG, 76 completed the CSQ, and 69 completed the ICG. Respondents were members of a wide variety of grief support groups. Some groups were general, for anyone who had lost a loved one; others were for specific losses, such as loss of a spouse or loss of a loved one to suicide. The majority of the survey respondents were white (88%) Christian (71%) females (83%). Those aged 45-50 represented the largest proportion of the age distribution (31%), while those aged 65 and up represented the smallest proportion (6%). Nearly all (98%) of them had lost their loved one within the last five years. The majority of our participants were complicated grievers (91%). Table 2 shows that the average ICG score was approximately 42, well above the threshold score of 25 that distinguishes between uncomplicated and complicated grief.

Interview
We conducted follow-up interviews with a subset of interested survey respondents. Questions pertained to the nature of the individual's loss, experience in their support group(s), use of technology to contact friends and family, and use of social media for coping. Interviews lasted between 30 minutes and two hours; we conducted them via phone, Skype, and Facebook Messenger video chat.

A total of 11 individuals completed a follow up-interview, 9 of whom were support group participants and 2 of whom were local in-person support group facilitators. The nature of the deaths of the support group participants included suicide of a significant other (n=2), suicide of a child (n=5), and death of a child with disabilities (n=2, with n=1 death unrelated to the disability).

Data Analysis
We used a mixed-methods approach comprised of factor analysis of survey data and open coding of open-ended survey items and interview transcripts [8]. The ICG [33] and TRIG [13, 15] were scored based on the original scoring rubric. Since we adapted the CSQ [35] to include technological interventions, we applied factor analysis to group items into coping strategy clusters shown in Table 1, with Cronbach's alpha ranging from 0.7 to 0.95 indicating high scale reliability. We do not present item correlation and factor loading tables in this paper due to space limitation. For interview transcripts, the first three authors discussed emergent themes and iteratively refined as the coding process continued. We conducted a total of four initial iterations, with the first author reorganizing the codebook based on four emergent main themes, which we present in the Findings section below.

FINDINGS
Table 2 provides insight into the nature of our participants' complicated grief journeys. Our participants, while not necessarily angry, demonstrate high degrees of yearning, nonacceptance, and emotional response. These collectively indicate they have not yet been able to fully come to terms with the

Descriptive Statistics	
	Mean (Std Dev)
ICG	42.1 (12.1)
TRIG (Past Depression)	5.3 (1.3)
TRIG (Past Anger)	4 (2.3)
TRIG (Present Yearning)	6.4 (1.2)
TRIG (Present Non-Acceptance)	4 (2)
TRIG (Present Emotional Response)	5.6 (1.4)
Coping Strategy	
Tough it out	5.7 (1.4)
Digital Photo	5.2 (1.7)
Distraction	4.3 (1.5)
Spiritual Support	4 (2.1)
Praying	4 (2.4)
Coping Online	4 (2.2)
Catastrophizing	3.7 (1.6)
Artistic Expression (Music, Art)	3 (1.7)
Avoid Online	3 (1.8)
Ignore/ Distance Pain	2.4 (1.2)
Count # / Run Music Through Head	2.2 (1.7)
Faith in Doctor	1.7 (1.5)

Table 2. Descriptive Statistics

death; this may partially explain why our participants sought help via grief support groups.

Beginning the Bereavement Journey
When Others Simply Don't Understand
For complicated grievers, beginning of the bereavement journey is often marked by tension between the bereaved and their support network, which can include family, friends, and even medical professionals. Table 2 shows, for example, that almost none of our participants had faith in their doctors. P37 touched on this finding when she described hiding her true feelings from her grief therapist, thinking that she might be better understood by those in her online support group:

"Even though I continue with a grief therapist, I've learned to hide feelings [I] can otherwise [express] freely in a group of suicide-bereaved moms. Even moms who are 10 or more years out can relate to the endless desire to die, jealous feelings about someone who's died from cancer, etc., and the inevitability of feeling this way for the rest of my days. A therapist would suggest a hospital, [which] would in turn suggest medication. It goes beyond that. So far beyond that." – P37

Our participants told story after story of feeling misunderstood by family, friends, and those around them following the death of their loved one. P86, for example, described her experience of feeling abandoned by her support network:

"People that I would have thought would have had my back...didn't...They didn't like who I had become. They didn't want to be around me. I'm sure they were concerned, but, I can't count the number of times that I was told by somebody that I thought would understand, or at least try to understand, 'You should be over this by now.'" – P86

Another participant, P54, whose boyfriend struggled with a drug addiction prior to his death by suicide, described her

family's lack of understanding and support stemming from their perception of her boyfriend:

"Everybody just thinks I should be ok...I'm not ok, because my whole entire life changed. But I just act like I'm ok, because...they're not supportive, so what's the point?" – P54

Interestingly, the second year following the death held great significance for several of our participants:

"The first year, I think you're so numb, and I think everybody is still walking on eggshells around you...and then you get to that second year, I think people start to do the, 'Oh, well it's getting easier, right?' So I think that second year is so much harder because everybody is wanting to pull you back into normal." – P15

P15's comments illustrate how our society places an expiration date on grief, whereas in reality the timeline for processing grief can differ greatly for each person (and, as we know, can be prolonged for complicated grievers).

P87, meanwhile, touched on how others often feel uncomfortable bringing up grief or even saying the name of the person who died. She spoke of the desire the bereaved have for others to simply remember their loved one:

"Child, father, mother, everybody's going to be different, but there's one thing in common that we all have: all you want is the acknowledgement that [the deceased] person lived, they existed, and they were cared about...That means so much [hearing], 'I feel your pain...Do you want to talk?' " – P87

In our interviews, experiences with family and friends after the death ranged from benign to hostile. One participant whose family lives abroad described how almost none of her family members came to the funeral. Another described how a family member asked whether she was still entrapped in her "pity party" over the death of her son, and recalled the time a friend likened the death of her loved one to the death of rescued cats - an event which apparently necessitated rapid recovery (the participant did not agree).

What we draw from these stories is that feeling misunderstood, disrespected, or wronged by those who constitute one's social support network immediately following the death ultimately renders grief a profoundly isolating experience, and may contribute to the development of complicated grief.

Seeking out Resources
Seeking out information on grief was an important part our participants' grief journeys. About 15% of the survey respondents indicated that they read some form of media, including articles and books on grief, stories about others' experiences, and even quotes and poetry. One of the in-person group facilitators whom we interviewed described what appears to be a generational difference in the kinds of resources the bereaved tend to seek:

"They're looking for books that have the answers for them as though they're going to find a book that solves that for them. That's more the over-50 population...the younger the people, the more I find technology being used." - F1

Our findings back up F1's claim that the bereaved may use online resources during their grief journey. While we did not focus on how children, young adults, and older adults grieve differently, future studies that focus on the generational gap and how technology could affect them differently may help us to better understand those that suffer from complicated grief.

Support Groups: An Escape from Isolation
Receiving little support from their immediate social networks, complicated grievers often turn to grief support groups in order to find their footing in the wake of the death.

Overview of Online Groups
91% of our respondents were members of online grief support groups. Over half (66%) of online group members found their group helpful in some capacity. P41 described how her online group helped pull her out of a deep isolation:

"[Parents of Suicide] was a real life-saver to me... I didn't want to leave the house. I was totally isolated, didn't want to talk to anybody...I found them and it was like...are you kidding me, there's other people who have gone through this...they've survived this? How is that possible?...I found such comfort from that group of people" – P41

Among the factors that online group participants mentioned when describing their appreciation of these groups were 24/7 availability, anonymity, the lack of pressure to participate, and lack of judgment. P86 described the overall feeling of acceptance and support she received from her online group:

"I ended up with people...that I had never met before [who] were my support, at three in the morning when I couldn't sleep, when I would start crying, when I would have a panic attack...they were there." – P86

Overview of In-Person Groups
Online groups, while popular, are certainly not the only avenue the bereaved travel in search of support. About 46% of participants had experience with an in-person counselor or group. However, far fewer in-person participants than online group participants characterized their experience as helpful— just 27%. The primary factor that stood out among participants who did find in-person groups favorable was the ability to interact with other grievers face to face and immediately:

"I much preferred the in-person support group...we can cry, we can relate to each other. We can look into each other's eyes, we don't have to say a word...that level of support is what I really really needed." – P41

When Conflict Arises...
While both online and in-person groups served as spaces of comfort amid the chaos of grief, not all experiences within these groups were restorative. Participants often described their internal conflict between receiving much-needed support and dealing with the very human reality of being present with so many others grieving their own unique losses:

"It truly depends on the day. For the most part, the people in the groups are there to support one another. They share their experiences and trek along this journey through hell, which

can give me hope at times. At other times, people bicker about what is allowed to be posted..." – P33

About 20% of online group members found their groups overwhelming or depressing, often due to the inundation of posts from other grievers. Mental health crises were not uncommon; several interviewees described the experience of seeking support from their online group only to have their post passed over in the interest of finding the member who was threatening to commit suicide. One pair of interviewees who are close friends described working together as gatekeepers, often logging on together to frantically reach out to group members in distress who were threatening self-harm.

While fewer in-person group members (10%) than online group members indicated their group could be overwhelming or depressing, many explicitly expressed their distaste for their in-person group. Reasons for this distaste included feeling overwhelmed at physically seeing others' pain, feeling talked over, and feeling unable to relate to groups that were not tailored to their specific kinds of grief. More than one participant described attempting to go to an in-person group but being unable to speak:

"[I] have only attended...once and completely fell apart due to the stories told by the others involved. I could not even speak when it came to my turn to open up." – P95

"The idea of it was great. If I could just go sit, and not say a word, and just know that people get it, I would have done way better. But they want you to introduce yourself, and tell your story, and I'm not good at that (or I wasn't at the time)." – P54

Selective participation and self-preservation behaviors were common for online group participants. Several of them expressed their preference for their online group over an in-person group because the online group gave them the power to process their grief in their own time and on their own terms:

"I personally like the online better...because you can kind of go at your own pace...If I'm just scrolling through Facebook, I can go past [sad stories]. Whereas, in the in-person group, there's no way I'm getting out of it without crying my eyes out." – P54

Others highlighted how they could halt online interactions more quickly and easily than they could in-person interactions:

"The thing about online is, you have the option [to get out]. You might get upset, you might get hurt, but you can click that button...And you can get out of the group...But you can't do that face-to-face with somebody." – P87

The Risk of the Endless Grief Loop
Our participants undoubtedly exhibited a propensity for empathy, as evidenced by those such as the "gatekeeper" friends we mentioned previously. Unfortunately, this valuable capacity for connecting with others, combined with the depth of the pain of grief, often pulled complicated grievers into a seemingly endless cycle of mourning. This risk of getting caught in a kind of *grief loop* was notably elevated for online group

members. For example, one participant described her experience of being stuck in a mourning mindset as a result of participating in her online group:

"In the beginning of my grief I did a lot of the online support groups, and they were very helpful to me, but at the same time I think it was keeping me in the same frame of mind every day. I deleted a lot of the sites [sic], because it would make me feel more depressed reading their stories." – P44

Another participant described the tension between feeling stuck in one place in her grief journey and experiencing catharsis in reaffirming she was not alone in her pain:

"I don't feel as if many people on the online support group [want] to let themselves heal and...it makes me feel as if I don't want to heal. At the same time, it's comforting to know that other people are hurting as badly as I am. So it's a Catch-22. I don't want to continue feeling the way that others describe, but it helps reading about the pain that they're in." – P18

Yet another participant described the grief loop phenomenon as an instigator of role tension that caused her to withdraw:

"I joined a suicide support group two months after my husband died. It felt helpful at first...The relative anonymity was comforting to me...[and] when I didn't feel able to participate I wasn't pressured. Friends and family would pester me to do things and an online group lets you avoid that. As the numbness began to lessen, I withdrew more from the group and found it overwhelming to learn of a new suicide almost on a daily basis as new members joined. I still have difficulty in this regard and feel less and less that I want to keep identifying myself as a survivor." – P25

These experiences point to a potential risk to complicated grievers that is inherent in online grief support, a risk we might call *The Empath's Curse*. This phenomenon can cause particularly empathetic individuals to withdraw from the very groups they sought out for help working through their grief.

Other findings, however, point to hope for individuals who demonstrate resilience by resolving to break out of the grief loop. These individuals embody a strong sense of purpose with moving forward in their grief journeys:

"I believe the internet has helped me quite a bit in the past, but now I'm at a better place in my life, and I notice when I read and participate in groups such as these, I find myself getting depressed. I can't bring my son back, and know he would want me to be happy. I believe you can get sucked into that mode and end up staying [there]. That's not how I want to live." – P44

Community, Individualism, and a New Norm
Communal Bereavement and Growth
Our participants took an active role in constructing their new social support networks following their loved one's death. We found that online groups, in particular, may serve as an appropriate first step for those who want to connect with similar others but cannot yet tolerate face-to-face interactions. Thus, online groups may serve as a pathway to deeper, one-on-one

connections. For example, one participant described how her online group empowered her to eventually address her grief in an in-person setting:

"I know for me, the online support group – especially the specific online support group that I'm a part of – really helped me get to a point where I could do the one-on-one, face-to-face stuff." – P15

About 20% of the participants were also actively involved in social events designed to raise awareness of the nature of the death. For example, many of our interview participants were survivors of suicide loss and mentioned their involvement in the Out of the Darkness walk.

Participants frequently engaged in practices of legacy and remembrance that they shared with the community. For example, 18% of participants had a webpage or website for honoring their loved one. Other legacy-based practices included posting about the deceased, tagging them on social media, and writing about them. In fact, nearly a quarter (23%) of our participants mentioned tagging.

Like Massimi and Baecker [23], we found photos to be of great importance in our participants' practices of legacy and remembrance, as evidenced by Table 2. 40% of survey respondents indicated they used photos to remember the deceased. Respondents spoke frequently of sharing or posting photos of their loved ones, often on a birthday or other important date, such as an "angelversary" (death anniversary). One of the facilitators we interviewed described how photo-sharing can help complicated grievers heal:

"We kind of encourage people to [share photos]...It's definitely cathartic. I think part of coping with grief and moving towards adjustment is [creating] a relationship with your deceased loved one. How are they going to be part of your life still? And leaving a legacy, honoring [them] somehow, helps with that." – F2

The practices of legacy and remembrance we observed point to a desire complicated grievers have to tell (and re-tell) their stories. Our other in-person facilitator touched on this point:

"When people get to share their story, there's a resolution that goes on by the repeating of the story...We operate by [telling] our own stories, and what we're learning as a result of the story that continues to evolve." – F1

Individualism in the Complicated Grief Journey
Regardless of the number of new friendships or social experiences our participants cultivated throughout their bereavement journey, they still valued having time and space to themselves to process their grief:

"I'm an extrovert by nature. I'm very open and talkative. But I've found my grief to be very private...An insatiable number of alone hours I need." – P61

Spirituality can be a highly personal aspect of bereavement. Table 2 shows that our participants were quite polarized in their spiritual practices: Some did activities like praying or seeking out spiritual support; others simply did not. Several participants described finding their faith as a source of com-

fort in their grief (though many felt confused about what they even believed anymore). Other participants described profoundly negative religious experiences: One participant described her pastor telling her that her son was going to hell for his "sin" of suicide. Another told how a counselor at her church claimed to know exactly how she felt, even though her situation was entirely different. These starkly contrasting experiences point to the need to further explore questions of faith and spiritual practice in the complicated grief journey.

DISCUSSION

What does Bereavement Look Like Today?
Our findings point to complicated grief as an individualized path fraught with emotion and soul-searching. Though grief is highly personalized, from the diversity of our participants' experiences we see a pattern emerge for the complicated grief journey. The start of this journey is marked by confusion and isolation brought on by post-mortem stressors, including stewarding the property left behind by the deceased and interacting with less-than-understanding family and friends. Consequentially, complicated grievers often turn to grief support groups, which can function as safe spaces to mourn and remember the deceased in similar company.

Participants' collective experience in both online and in-person support groups highlight the conflicted nature of the complicated grief journey and the role these groups play within that journey. Online groups may appeal to individuals who are not yet prepared to confront their grief among others in a physical space. However, due to the the rapid influx of information in these online groups, members may quickly become overwhelmed and reduce their participation or remove themselves from the groups entirely. In-person groups attract individuals who desire face-to-face interaction. However, these groups may to run a higher risk of driving new members away, whether due to the overwhelming nature of confronting others face-to-face, lack of groups tailored to the individual's specific type of loss, lack of individualized attention, or physical or geographic limitations (for example, if the nearest group is an hour's drive away).

Factors such as a group's demographic, the quality of its members' mental health, and its overall *modus operandi* can either unite its members or cause them to withdraw back into a state of isolation. In particular, there appears to be a turning point for some online group members. Different for each person, this is the point at which more resilient individuals begin to prefer and pursue face-to-face communication. In turn, the online group ceases to be a scaffold and fades into the background as a tool that can be accessed infrequently, when wanted or needed.

Moreover, more resilient individuals may form close friendships with those they have met through support groups, keeping in touch with these friends via messaging applications, email, phone, and even in person. From these intimate interactions with newfound friends who share in the pain of grief and the responsibility of resilience, complicated grievers may draw strength and allow themselves to grow from their respective losses.
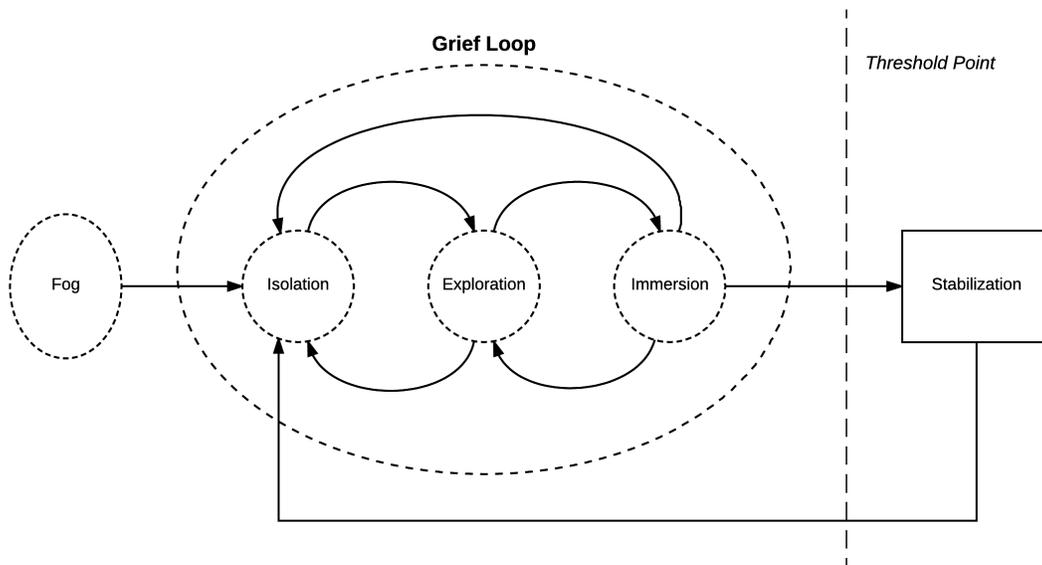
Figure 1. A behavioral model of grief

A New Model for Complicated Grief

Based on our findings, we present a present-day model for complicated grief, shown in Figure 1. This model consists of the following phases: *Fog*, *Isolation*, *Exploration*, *Immersion*, and *Stablization*.

Fog

Fog marks the beginning of the complicated grief journey, immediately after the death. This phase is marked by the tasks which must be accomplished following a death, such as handling the deceased's paperwork and arranging the funeral [25]. These tasks, along with the shock and/or sadness of the death, entrap the complicated griever in a "fog" of swirling emotions, including confusion, frustration, sadness, and anger.

Isolation

Isolation then ensues, due to the inability of the complicated griever's support network to adequately address their pain. During this phase, complicated grievers may withdraw into a state of loneliness and possibly depression. They may avoid conversations with friends and family, stay at home when possible, and feel as though nobody understands the pain of their grief.

Exploration

Wanting to emerge from their isolation, complicated grievers eventually begin the process of *Exploration*, during which they seek out both informal and formal support. Informal support may include reading materials (books, articles, blog posts, etc) or avenues of self care (for example, listening to music or playing games on one's phone). Formal support may include grief support groups or counseling. During this time, complicated grievers also acclimate to their chosen support structure. For in-person groups, this means attending a meeting for the first time; for online groups, this means beginning to read others' posts or posting one's own story.

Immersion

Next comes *Immersion*, when complicated grievers invest themselves in their new support structure. In person, this means returning to the group for regular face-to-face interactions; online, this means frequently reading posts and/or sharing information within the group.

Immersion naturally leads to the **threshold point**. This is the point at which complicated grievers venture down one of two main paths. They either become overwhelmed by their chosen support structure and withdraw back into a phase of isolation—thus, getting stuck in what we call the *grief loop*— or they may choose to move on to a different support structure. In-person group members may opt to leave their group and join an online group instead; conversely, online group members may opt to begin attending an in person group while remaining only tangentially involved in their online group. We note that *the threshold point appears to manifest sooner for in-person group members*; they will tolerate perhaps one or two meetings before moving on, whereas online members may remain in the background of their groups for awhile before leaving.

Stabilization

Finally, we reach *Stabilization*. While certainly not the end of the grief journey (which, according to many of our participants, is "lifelong"), this phase marks a period of resilience in which complicated grievers begin to fully own their identity as grieving individuals. They establish this ownership in a variety of ways, including maintaining and strengthening friendships with similar others they have met along the grief journey and, often, engaging in social events and practices dedicated to raising awareness of death and grief. "Stabilization" is not meant to convey a complete resolution to loss, but rather a state of being in equilibrium, able to function in the aftermath of loss on a daily basis without feeling debilitated by grief. This view stems from the literature-backed convic-

Phase(s)	Factor	Online	In-Person
Exploration, Immersion	Availability, Accessibility	High; 24/7; Anyone with an account can join	Medium; Usually Weekly / Bimonthly / Monthly; Depends on geographic location, physical limitations
	Specificity	High; Wider variety of groups tailored to griever's specific type of loss	Low-Medium; Limited by number of available groups in the area, resources of the hosting organization
	Intimacy	Low-Medium; Online groups can have anywhere from hundreds to thousands of members; Establishing one-on-one relationships with other members is key	High; Group size is usually smaller; Setting facilitates face-to-face communication
	Allowance for selective participation	High; Members can "mute" / block posts from others, scroll past content they don't want to read, only participate when they feel comfortable; Can also remove themselves from the group	Low; Members can walk out of group if need be, but this is uncomfortable; Cannot avoid face-to-face communication within group
Immersion	Risk of Information Overload	High, due to 24/7 availability & high empathy among members	Low-Medium, due to limited availability and more structured nature of group meetings
Threshold Point		High; Participants willing to stay in groups for what help they can receive on their own terms	Low; Participants unwilling to deal with pain of face-to-face conversations with strangers for prolonged period of time
Stabilization	Allowance for Forming & Maintaining Individual Friendships	High	High
	Allowance for Social Activism	High; Members may learn about / subscribe to local events through social media, follow pages for grief organizations, etc.	High; Members may learn of local events through group, form cohorts for group activism

Table 3. Phase-based comparison of online and in-person groups

tion that grief is not a disease to be cured but rather a lifelong condition to be managed [1] [28] [29].

We emphasize that these phases are neither static nor sequential; complicated grievers may move fluidly between phases, may experience certain phases more than once, and may occupy space in more than one phase at a time. We depict fluidity and dynamism in our model through the use of rounded, dashed outlines for all phases except Stabilization, which we depict with a solid, rigid outline; those who reach the Stabilization phase seem less likely to cycle back into (and remain stuck within) the *grief loop*. Moreover, the time spent in each phase can vary from person to person and context to context.

We summarize the benefits and drawbacks of online and in-person groups in Table 3. Note that the delineation between groups begins at the exploration phase; we begin with this phase in the table. Moreover, we list the most important factors within each phase and provide a rating (low, medium, high, or a combination of these) for each factor, for each type of group.

Design Considerations

Based on our findings and model, we present the following considerations for designing technologies for those suffering from complicated grief:

Provide avenues for increased availability and accessibility for both online and in-person groups

Emerging from Isolation requires complicated grievers to have a working knowledge of the resources available to them. Simply obtaining this knowledge can be overwhelming, given the chaotic nature of the period immediately after a death. Designers must consider ways to reduce the burden of information-seeking for complicated grievers. One approach might be building and maintaining a public online database of trusted local and online groups, and working with social media websites to help reduce the tedium of finding such resources. We note that this approach necessitates great caution and utmost consideration for user privacy, as grieving individuals constitute a vulnerable population in need of protection from predatory influences, especially online.

Create evaluation instruments to assist grieving individuals in choosing the right group type for them

Choosing between an online and an in-person group may be overwhelming for some complicated grievers. Existing validation instruments like the PHQ-9 [20] provide a quick and simple way to screen individuals for conditions such as depression and empower those individuals to seek help. HCI researchers should work with clinicians to create a similar validation instrument that assists complicated grievers in deciding whether an in-person or an online group might be a

better fit for them. Consideration should be given to which factors best determine group type fitness. Such factors might include availability of a computer or willingness to interact with others in person. More research should be done in this area to determine the most relevant factors.

Assist complicated grievers in locating support resources that are specific to the nature of their loss

We have seen repeatedly in our findings that connecting with similar others helped participants to normalize or validate their own grief. Moreover, we observed that those whose support group was too general (i.e., not tailored to their specific form of loss) were unable to completely emerge from the *Isolation* stage and felt that those around them did not fully understand their loss or emotions. Designers must provide avenues for the bereaved to seek out support that is specific to their type of loss. This could include providing advanced filters in the previously-described database, to help complicated grievers better refine their group options. Because in-person groups are limited by the constraints of the parent organization – such as limited time, space, and availability of group facilitators – designers should focus especially on providing such filtering capabilities for databases of in-person groups.

Reduce information overload in online groups

Information overload was a common problem in online groups and frequently caused group members to withdraw from the very resources from which they needed to receive help. Reducing this burden is critical for empowering the bereaved to move forward in their grief journey. One way to do so is designing or improving "snooze" feature that could be integrated into popular social media website such as Facebook. Existing apps such as Offtime [31], for example, facilitate snoozing of multiple apps at a time. A similar application tailored to the complicated grief community might include snoozing only bereavement-related posts and information for a certain period of time, or filtering out certain types of posts based on an individual's current emotional state (for example, posts containing primarily affective content, such as "I'm in tears tonight" and similar expressions of complicated grief).

Create tools for expressing grief through digital photographs

Our literature-supported finding that digital photos play a critical role in the grief journey illustrates an opportunity for HCI researchers to create digital-photo-specific tools for grief expression, such as photo albums for commemorating a deceased loved one's major life events. More importantly, these tools should facilitate easy photo-sharing, and should be capable of functioning as both standalone applications and extensions to existing online grief support platforms, such as Facebook groups and grief-specific forum websites. Such tools would support legacy and remembrance practices for both online and offline complicated grievers.

STUDY LIMITATIONS

Despite our efforts in contacting a wide variety of grief support groups, our participant population is largely homogeneous. Our findings thus may represent the bereavement process for one part of the general population (namely white, Christian, middle-aged females), but may not adequately represent the complicated grief journey for other demographic groups. Additionally, the majority of our study participants have chosen to remain active in online support groups, and we relied on their experiences in in-person groups to substantiate our claims about the differences between these group styles. Future studies that include a greater proportion of participants who participate primarily in in-person groups would be helpful for solidifying these differences.

FUTURE WORK

One area of grief research that remains relatively unexplored is the role of "creative" interventions, such as art and music, in expressing and coping with complicated grief. While our augmented CSQ included questions about music and arts-centric coping strategies, our results showed using art and music to cope was not a high priority to our participants. Several factors may have contributed to these results, including lack of distinction between creation and consumption of artistic and musical content and a lack of applications that support these forms of expression. We posit that an appropriate extension of our work would be to explicitly explore the role of creativity in the grief journey and to design arts-inclusive technological interventions for complicated grief support.

CONCLUSION

This work provides an in-depth look into how the bereaved navigate their grief in an increasingly digital world. We have introduced a behavioral model of the bereavement journey, compared online and offline grief support groups and examined the transitions the bereaved make between these support systems, and presented implications for designing systems that support the bereavement journey. In particular, we have reviewed the risk of the grief loop, and how online support groups can, if not designed carefully, contribute to prolonged suffering in bereavement.

These portraits of modern grief that we have presented are by no means comprehensive. A common refrain that we heard over and over from our participants is that "everyone grieves differently". The HCI community should heed this message and work to design technologies which respect the individualized nature of the bereavement journey. At the same time, we must provide avenues for the bereaved to connect with similar others and grow together in community. Through these efforts, we can equip grieving individuals with the tools they need to cope with their loss in the way that best fits their unique situation and goals.

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