# Toward the Development of a Monitoring and Feedback System for Predicting Poor Adjustment to Grief

Wan Jou She, Laurie Burke, Robert A. Neimeyer, Kailey Roberts, Wendy Lichtenthal, Jun Hu and Matthias Rauterberg

Additional information is available at the end of the chapter

### **Abstract**

Losing a loved one is a fundamental and ubiquitous life experience that is often characterized by a certain period of grief and emotional distress. Although the majority of the bereaved can cope with grief resiliently, around 1 of 10 individuals could experience an unusually protracted and intense response referred to as prolonged grief disorder (PGD) following death of a loved one. PGD is associated with work and social impairment and heightened risk of severe medical and psychological conditions. Current means of diagnosis requires a minimum of 6 months to confirm and identify PGD and is discrepant with the fact that the bereaved may need psychotherapeutic intervention in a more timely manner. Contemporary studies have outlined prospective risk factors that could cause poor bereavement outcome, which can potentially contribute to early identification and prevention of problematic response to grief. Self-monitoring applications have been developed and broadly implemented in a vast spectrum of mental and health-related interventions and self-managing processes. This study presents the conceptualization and development of an Internet-based screening method designed by the researchers and psychotherapists that aims to provide meaningful and quantitative feedback in the early phase of the grief and to support decision making in the bereavement process through monitoring the susceptibility to problematic grief outcome.

 $\textbf{Keywords:} \ bereavement, prolonged grief \ disorder, self-monitoring \ system, Internet-based bereavement \ support$ 



### 2

### 1. Introduction

Self-management is often considered one of the critical factors that contribute to promoting a better medical or mental health care outcome [1-8]. Applications specifically designed for this purpose are widely implemented in a spectrum of medical and psychological conditions ranging from self-exam of blood pressure and heart rate through screening methods to identify depressive symptoms or assess the level of posttraumatic stress. Users of self-managing applications are not only more informed about their health-related conditions but also more empowered to act as an active role in the health care processes [9, 10]. In 2015, the Wall Street Journal pointed out the frequent implementation and the explicit benefits of self-managing applications in certain medical practices such as cardiovascular rehabilitation program and cancer pain management [11]. The advantage of utilizing self-managing applications in the medical and psychological care procedures is that these applications are more accessible and integrated to users' everyday life experiences. They are often characterized by low cost, connectivity, anonymity, nonstop availability, and opportunities for a self-paced health care approach. For health care service providers, the versatile data gathered or reported from the applications facilitate better monitoring of the users' health-related behaviors and are informative to further studies of the health conditions when compared and analyzed with data from a large group of users.

In the context of bereavement, studies as early as in 2004 have demonstrated that more than half of the bereaved used online bereavement support, and such resources yield potential in preventing and protecting the bereaved from further mental disorders [12–14]. However, as Krysinska and Andriessen warned in one of their papers, most of the websites created by professional bereavement organizations are not immediately available or credited from the search, rendering the quality of online bereavement support and the authenticity of information under question [15].

Accordingly, this article takes a focus on designing a self-management application in bereave-ment-related contexts and presents the conceptualization and development procedures of it. We start by introducing the context of usage, followed by the process of conceptualizing two approaches to attend the needs in bereavement context. These two approaches were further prototyped into two applications, and one of which was selected for further development and evaluation. In the end, this paper reports a preliminary evaluation of the selected application and elaborates its potential to serve as both a data collection instrument in the future studies and a self-monitoring system for the bereavement process.

# 2. Context of usage-bereavement

Bereavement refers to an individual's adaptive process following the loss of a loved one through death. The process is characterized by a variety of emotional responses (e.g., grief and distress) and cognitive crisis (e.g., meaning reconstruction), as well as heightened risk of syndromal medical conditioning and social and occupational impairment. It is also a fundamental

and life-changing event that almost everyone will encounter in his or her lifetime. The prevalence and ubiquity of loss and grief are reflected in studies showing that most individuals will have experienced at least one loss by early adulthood (e.g., 60% have lost a friend; 81% have lost an extended family member; Herberman et al., 2013). Losing a loved one through death is frequently reported as one of the most stressful life events and was formally rated as the most stressful event in the Holmes and Rahe Stress Scale.

Looking from the other side of bereavement, it is a natural mechanism that helps individuals to gradually come to terms with the potentially overwhelming loss and to continue living a productive life in which the deceased is recognized in a different form of existence. The majority of bereaved coped with grief resiliently, and some of them even adopted so well that they further experienced enhanced meaning and spirituality post loss. However, a noteworthy percentage of bereaved, around 1 of 10 bereaved individuals, could experience a protracted and intense response to their grief referred to as prolonged grief disorder (PGD) [16].

Individuals who suffer from PGD often feel "stuck" in the process of bereavement and find it hard to accommodate to a different lifestyle or the world without the deceased. PGD can severely hamper an individual's psychological well-being, as well as the social functioning and physical health. In the extreme situation, individuals could experience strong suicidal tendency. For the individuals who suffer from PGD, psychotherapeutic intervention is mostly needed to support their adaptation and acceptance of the loss. On the other hand, performing grief counseling and therapy to normal grievers could yield deleterious effect and even disturb the natural bereavement procedure.

Since offering grief counseling to normal grievers is unwarranted, a screening method that helps to determine who will benefit from the psychotherapeutic intervention is of the primary importance. Psychologists have outlined the importance and pressing need of a trustworthy screening method, whereas the current PGD diagnosis instruments require a minimum 6 months to identify the PGD symptoms. The amount of time required to issue a PGD diagnosis and to allow psychotherapists' active involvement is discrepant with the fact that individuals who suffer from intense grief or suicidality may need psychotherapeutic intervention in a more timely manner.

The inability to identify potential PGD grievers in an earlier phase could also posit a negative implication on the development of preventive intervention and enhance the difficulty of attending the disorder after 6 months have elapsed. It could potentially explain why studies related to preventing PGD remained scarce and the effect far from warranted.

# 3. Two approaches to predict PGD symptoms in early phase

Assessing symptomatology and attending to the needs of grievers with severe emotional distress as quickly as possible is imperative. Various approaches were explored by previous bereavement-related studies to identify problematic self-evaluations and potentially traumatic characteristics that contribute to predicting poor adjustment outcomes to bereavement. These approaches can be briefly categorized into two groups.

4 Proceedings of the Conference on Design and Semantics of Form and Movement: Sense and Sensitivity...

The first group stems from the problematic narratives and coping strategies can potentially be detected through linguistic cues or behaviors post loss [17–20]. Examples of the first approach include negative self-evaluation such as thinking that the self is less worthy without the deceased and problematic coping strategies such as repetitive rumination of the deceased. The second group evaluates the traumatic loss circumstances and psychological states that can make the bereaved vulnerable to poor adaptation, all of which are often static at the time of loss and are harder to change [21–29]. Examples of the second approach range from traumatic death, lacking social support to the strong dependency on the deceased and an insecure attachment style.

Both approaches are informative for follow-up development of screening methods that could support grievers and psychotherapists to monitor the bereaved's susceptibility to PGD and to target the appropriate interventions in a more timely manner. A primary concern is that these methods remain in a highly theoretical and explorative phase and are in demand of empirical validation. In this regard, the applications developed should also serve as a means of evaluating and validating the proposed screening approaches. With this concept in mind, we propose two Internet-based applications that seek to empower the bereaved by providing meaningful feedback to the aspects related to their grief experiences and, on the other hand, collect useful data that contribute to further validation of the screening methods.

### 4. Method

### 4.1. The design and conceptualization of two prototypes of PGD screening methods

Two prototypes were developed using different approaches. The first prototype, My Grief Journal, was a technology-driven concept based on the available technological solutions and studying the related bereavement literature. The second prototype, Grief Inquiry Following Trauma, was developed with field experts and psychotherapists. The overall aim of both applications is to empower the users to gain knowledge and control of their bereavement-related decisions. To achieve this goal, the research team defined the following concepts that should be achieved by both prototypes:

- Target users: individuals who have experienced death of a loved one and would be interested in searching for support on the Internet, especially individuals who have experienced the loss very recently or less than 6 months ago.
- Deliverables: an Internet-based Product Service System (PSS) that provides meaningful, objective, trustworthy, and quantitative feedback of the various bereavement-related aspects.
- Portal: the application should be affordable, easy-to-use, and widely accessible through the computer and mobile devices.
- The system must collect only bereavement-related data from the users and generate personalized feedback based on the data collected.
- The feedback provided to the users must contain both positive and negative aspects of their grief situation and must come from the authentic sources.

 The prototypes should attempt to integrate and utilize the existing and validated measures as a starting point but should remain flexible for developing and validating new measures.

### 4.2. External experts from the psychological field

Although the purpose of this project was not to develop an intervention of PCBD, due to the sensitive nature of loss and grief study, the team included one researcher specified on bereavement and post-loss meaning reconstruction and one psychotherapist specified on grief counseling. The external experts brought contribution to the design and phrasing of questions that were used in assessing the grievers' grief experiences and provided further opinions from psychological field on the ethics and design of the study. The author, as a lead investigator of this study, first proposed two prototype concepts based on previous literature review for evaluation within the team, and the final decision was made based on the practicality of the concept and the available technology that could facilitate the prototyping of the app.

Based on the suggestion of the IRB, to pilot test the app and gain users feedback from the concept, the team had recruited a certified thanatologist and grief counselor to facilitate the session. It was meant to avoid bias in interviewing the users and to maintain anonymity of the study. An interview protocol was drafted by the researcher and the psychotherapist to ensure the questions would not provoke excessive/harmful emotional responses. The interview was conducted in English, and all of the users were native English speakers.

### 4.3. My Grief Journal

The concept of My Grief Journal was inspired by studies concerning the self-narratives in the bereavement process and the meaning reconstruction theory. Narrative variables can be effective predictors of psychological health during bereavement and even of the outcome of coping with bereavement. Counting the relevant words in the written text was considered an effective approach to measuring the cognitive changes and emotional expression in the bereavement context. Many suggested endorsed that verbal materials carry more additional information about psychological phenomena and symptoms, which are often less detectable from self-report [19, 30]. For instance, consider the following two examples, "it's so hard to say good bye" and "I am lucky to have somebody that makes saying goodbye so hard." Both sentences included a negative statement but were framed in a different manner and hence reflected different appraisal to an event.

The researchers tested various available types of software and APIs to perform the keywords extraction and analysis and determine the positive emotions and negative emotions in the narratives. We used a narrative that described feelings in an indirect manner. For instance, "I am feeling terribly good today," or "...determined to enjoy her luxury of grief uncomforted." It was easy for human to understand but hard for programs to determine whether the sentence really described a positive perception or a negative one. The most precise software appeared to be Linguistic Inquiry and Word Count (LIWC). However, it was not available in command line interface (CLI) and the EULA prevented users from implementing it in a customized application. Other alternatives tested were NLTK in python, Afinn, and AlchemyAPI. In the end, IBM Alchemy API was implemented to extract meta-data such as concepts, entities, keywords, categories, sentiment, emotion, relations, and semantic roles. Unfortunately, there

6

was no corpus specifically trained for bereavement-related sentences or articles. Therefore, it could not be as precise as the corpus for movie reviews, tweets, or advertisement.

My Grief Journal was developed to store users' short articles (e.g., diaries) and analyze the sentiment of the article. The analysis will yield two types of results, providing a visualized feedback of the frequency of the emotional keywords detected in the article and determining the positive or negative valence of the keyword and its relationship to five types of emotions (anger, disgust, fear, joy and sadness). **Figures 1** and **2** showed the sample page and report of My Grief Journal. Unfortunately so far, there was no available corpus specifically trained for bereavement-related sentences or articles. Therefore, it could not be as precise as the corpus for movie reviews, tweets, or advertisement, which was an obvious drawback that obstructs the researchers from testing it with grievers. Only the developers and the research team members tested it. Developing My Grief Journal should include training the corpus with plenty of bereavement-related articles or sentences in order to determine how to precisely analyze the sentiment in the users' writing.

### 4.4. Grief Inquiry Following Trauma (GIFT)

The concept of GIFT stemmed from psychological studies related to prospective risk factors that could render grievers more vulnerable to PGD, such as low social support, low income, or traumatic death circumstances. A framework of risk factors was created based on literature review (see **Table 1**).



Figure 1. The entry page of My Grief Journal.



Figure 2. The demo visualization of keywords and the valence of the keywords.

All of the risk factors were reviewed by the researcher and the external experts [21, 24]. Two measurement tools were designed together by the researcher and the external experts in order to measure the risk factors. The team has further included another to-be-validated scale for identifying risk factors related to be reavement and loss circumstances. These three questionnaires were grouped into the major section, Basic Information. Basic Information consisted of questionnaires related to the participant's demographic characteristics and proposed predictors of bereavement distress (Table 1; scales #1-3). Six validated questionnaires were selected to provide feedback on bereavement-related perspectives. They measured respectively grief degree (PG-13), depression (CESD-R), post-traumatic stress disorder (PCL), resilience (CD-RISC-10), meaning making (ISLES-SF), post-traumatic growth (PTGI). These six questionnaires belonged to the secondary section named Monitor My Grief. Table 2 displayed a list of scales included in the application. The validated scales administered were, if not openly available, all requested or purchased from the respective researchers and consent acquired to use in the app.

The feedback that addressed the participants' result after taking the questionnaire was drafted for the six validated questionnaires in the Monitor My Grief section. Users who successfully completed the questionnaire will be presented a personalized feedback according to the score of each validated questionnaire. It was meant to adhere to the purpose of design of GIFT and to lessen participants' stress after taking the emotionally disruptive questionnaires.

Risk factors	Primary or potential risk factor	Details			
Social support level	Primary	Lacking social support is a salient risk factor that is highly related to problematic grief			
Discovering the body	Primary	Discovering the body or viewing the death scene (especially with traumatic nature) is a salient risk factor for PGD			
Satisfaction with the death notification	Primary	Dissatisfaction with death notification			
Pre-death dependency	Primary	High levels of pre-death marital dependency			
Attachment style	Primary	Avoidant/anxious/insecure attachment style			
Close kinship	Primary	Being a spouse or a parent of the deceased			
Gender	Potential	Female grievers are more susceptible to PGD than male grievers			
Ethnicity	Potential	Being non-Caucasian is regarded as a risk factor for PGD			
Educational level	Potential	Low education is connected to having more severe grief			
Income level	Potential	Insufficient income			
Type of loss	Potential	Losing a child of any age to a violent sudden death			
Anticipation of grief	Potential	Death is unexpected			
Prior losses	Potential	Prior losses			

**Table 1.** Risk factors suggested in the review papers.

Scale set	Scale name	To assess	
Basic information (including loss-related characteristics)	1. Background information	Demographic data, such as age, gender, ethnicity, religious affiliation	
	2. Complicated grief risk factors checklist (CGRF)	Proposed predictors of bereavement distress	
	3. Bereavement Risk Inventory and Screening Questionnaire (for the bereaved; BRISQ-B)	Risk factors of Prolonged Grief	
Monitor My Grief	4. PG-13	Grief severity	
	5. PCL	Posttraumatic stress	
	6. CESD-R	Depression	
	7. CD-RISC-10	Resilience	
	8. ISLES-SF	Meaning made of loss	
	9. PTGI	Posttraumatic growth	

Scales~#1-3~assess~bereavement-related~risk~factors.~Scales~#4-9~have~been~empirically~validated~and~are~widely~used~in~assess~bereavement-related~risk~factors.~Scales~#4-9~have~been~empirically~validated~and~are~widely~used~in~assess~bereavement-related~risk~factors.~Scales~#4-9~have~been~empirically~validated~and~are~widely~used~in~assess~bereavement-related~risk~factors.~Scales~#4-9~have~been~empirically~validated~and~are~widely~used~in~assess~bereavement-related~risk~factors.~Scales~#4-9~have~been~empirically~validated~and~are~widely~used~in~assess~bereavement-related~risk~factors.~Scales~#4-9~have~been~empirically~validated~and~are~widely~used~in~assess~bereavement-related~risk~factors~bereavement-related~riskbereavement research.

Table 2. Assessment instruments.

Personalize the questionnaire with the name of the deceased. An important feature for GIFT was that all of the questions were personalized with the name and gender of the deceased (replace "the deceased" or "the person I lost" into the name of the deceased) to engage the users.

Slider selection for Likert scale questions. Most of the Likert scale options were displayed in a horizontal slider to enhance the linear relationship of the options (see Figure 6 for an example). The handle will change color after an answer has been indicated (see Figure 7 for an example). When users access GIFT on a mobile, we choose to keep the two items in the left and right of a Likert scale question but allow users to review the default value after hovering or clicking on the pip on the slider (see Figure 8).

Add the option "not applicable" to the risk factor questionnaires. For scale #2 and scale #3, users were provided "not applicable" on the right of all of the questions. This was to allow them to better express themselves when the presented risk circumstances appeared not applicable to them and the options failed to help them to convey it (see Figure 9).

According to the IRB suggestion, the website was certified by SSL protocol protection, and all of the data collected in GIFT were coded and encrypted in order to ensure the security of the data.

### 4.4.1. Preliminary evaluation of GIFT

The research team evaluated both applications regarding the opportunities to yield trustworthy and quantifiable predictions in the earliest phase of bereavement. In comparison to My Grief Journal, which required a period of contemplation and was less precise in determining the positive and negative thinking style, GIFT exhibited better potential to offer users meaningful and objective feedback based on evaluating the factors that are relatively static and foreseeable even before the loss (Figures 3 and 4).

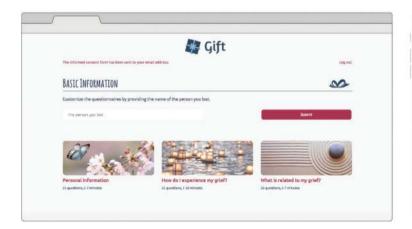




Figure 3. GIFT entry page.



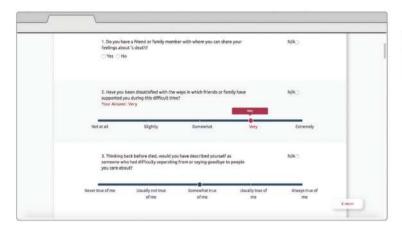




Figure 4. GIFT slider scale.





Figure 5. Gift personalized report.

2 of 13: In the past month, how often have you had intense feelings of emotional pain, sorrow, or pangs of grief related to the lost relationship?



Figure 6. A slider for Likert scale answer.

In the end, GIFT was selected for further development and implementation to validate the proposed risk factors with a larger base of participants. To gauge the applicability of the app in the real life situation and optimize the user experiences of using it, five sessions of protocol analysis were conducted in the United States with the patients of one of the collaborative psychotherapists. The approval to conduct the study with the bereaved patients and to deploy the application through the Internet was sought in the respective Institutional Review Boards from both United States and the Netherlands, in which the former is where the study will be conducted and the latter is where the app was conceptualized and developed (Figures 5-9).

In the protocol analysis session, participants were prompted to "think out loud" on an individual basis as they completed the questionnaires by a certified thanatologist, who is also a graduating counseling student. After completion of the scales, participants were interviewed with questions regarding their general experiences of using GIFT, the wordings of the application as well as of the personalized feedback they received after completing the scales from the second section (Monitor My Grief). The protocol analysis sessions were all audio recorded and completely transcribed. Each session was approximately 1.5 hour long, generating approximately 7.5 hours of recording from the interview and the notes from the interviewer.



2 of 13: In the past month, how

sorrow, or pangs of grief related

Your Answer: At least once a day

Several times a day

often have you had intense

feelings of emotional pain,

to the lost relationship?

Not at all

Figure 7. Slider response after an answer is indicated.



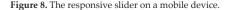




Figure 9. When user selects "N/A," it means that the statement could not apply to his/her situation.

## 5. Result

The protocol analysis sessions for GIFT pilot testing were all audio recorded and completely transcribed. Each session was approximately 1.5 hour long, generating approximately 7.5 hours of recording from the interview and the notes from the interviewer. All of the participants were from the United States. There were total five participants, including one male and four female grievers. Their socio-demographic data are displayed in **Table 3**. Almost all of the participants bereaved about the loss of a family member. Of the total, 80% have received formal education for more than 13 years and had their religion. Participants who considered religion important practiced religious activity more frequently. Except PA3, who experienced death of a loved one around 6 months ago, the other participants generally experienced death of a loved one for more than 6 months to receive psychotherapeutic support. Two of our participants experienced unnatural death of a loved one such as suicide or fatal accident, and 60% of our participants were in contact with the deceased almost daily before the death happened.

Participant	PA1	PA2	PA3	PA4	PA5
Gender of the participant	Female	Female	Female	Male	Female
Gender of the deceased	Male	Male	Male	Male	Female
Age of the participant	70	39	32	61	31
Age of the deceased	70	26	40	87	95
Relation to the deceased	Spouse	Sister	Partner/ fiancé	Son	Granddaughter
Marital status	Widowed	Married or living together in a committed relationship	Single	Married or living together in a committed relationship	Single

Participant	PA1	PA2	PA3	PA4	PA5
Years of formal education	17–20 years	0–8 years	13–14 years	17–20 years	15–16 years
Faith tradition (religious belief)	Christianity	Christianity	Atheism	Christianity	Buddhism
Regularity of religious activities	Daily	At least once per week	Never	At least twice per week	At least twice per year
Importance of faith	Extremely important	Extremely important	Not very important	Very important	Somewhat important
Prior experiences of death of loved ones in the past 3 years	3	0	0	1	2
Time since the loved one died	1 year and 4 months	1 year and 9 months	6 months	1 year and 4 months	11 months
Type of death	Natural anticipated death	Fatal accident	Suicide	Natural sudden death	Natural sudden death
For how long did the participant know the deceased	46 years	26 years	3 years	60 years	31 years
The frequency of contact before death	2–7 times per week	2–7 times per week	2–7 times per week	Every other week	Less often than once per month

Table 3. The socio-demographic data of the protocol analysis participants.

### 6. Discussion

The preliminary test of GIFT yielded fruitful data for future optimization. Since the three questionnaires from the background information were still under development, and the details of wordings and content refinement would not be of interest to the readers of this article, this discussion concentrated on the general experiences of using the app and participants' feedback on the applicability of this app in their bereavement process.

### 6.1. Participants' experiences of searching for support on the Internet

All of the participants were under bereavement intervention by professional therapist and trusted that they need professional counseling. We were particularly interested in participants' support seeking on the Internet, since this app was developed as an Internet-based app. Three out of five participants reported having searched for information related to bereavement or grief support on the Internet. One participant did not answer, and one indicated that she had never thought of searching for support on the Internet. The information on the Internet helped them to gauge their grief level or target the therapies that were available/ appropriate for them. One participant specifically stated that reading other people's stories about surviving traumatic loss was helpful. Another participant indicated that grief is too personal and looking for support on the Internet did not feel safe.

In general, Internet sites, blogs, and forums were resources that participants could turn to when they needed immediate answer to their questions or information related to grief counseling or coping strategies. However, it was still obvious that participants were mostly prone to find a therapists or "somebody" who knows grief to support them, implying that bereavement-related services or information on the Internet, disregarding the quality of it, could face the difficulty to gain trust from the users. It could also be because most of our participants knew that they needed psychotherapeutic support at the first hand and only used the Internet to help them gain access to the services.

### 6.2. Participants' general experiences of using GIFT

Most of the participants were satisfied with GIFT and found the feedback relevant, authentic, and reflective to their real situation and trustworthy. Some positive feedback pieces were as follows:

- GIFT was a tool for thinking and widens awareness of the bereavement-related aspects.
- GIFT was a tool that enhance self-referring from grievers who obviously need grief counseling
- Personalizing the questionnaires with the name of the deceased was really immersive, love
  it
- The process of using GIFT was therapeutic.
- The feedback was trustworthy and reassuring.
- The questionnaire results were similar to what the participant thought about herself, but it was more validating.

Some negative feedback pieces and suggestions were also reported:

- The session took too long to complete, and the data should be saved step by step.
- The feedback only presented shallow and "canned" responses to the questionnaires result.
- It should connect to useful resources in the end of the feedback (e.g., books, grief counselors).
- The fifth participant encountered enormous technical difficulties because of older version of hardware.
- Participants should be "guided" through the process instead of choosing what questionnaires they should do next. The navigation had to be more clear and straightforward.
- The application should allow participants to share the results with others (e.g., sending the report to their family or friends).

- The slider scale required some time to get used to, but participants grew accustomed to it after several questions.
- The instructions of the questionnaires needed to be highlighted and emphasized so participants would not oversee them.

### 6.3. The evaluation of the performance of the app

Based on the participants' feedback, there were several points to take into consideration for next stage app refinement.

The problem of various usage platform: GIFT was a Web application, and we tested it with different devices such as computer, tablet, and mobile phone. One participant was using an iPhone 5S, and the questions and answers were completely overlapped. The problem could be caused by the older version of browser that did not support libraries such as jQuery. Designers usually need to take into consideration of how much the application was backward compatible and make a clear suggestion to the users.

The difference between mobile navigation and large screen navigation: on the larger screen, the questionnaire were separated into two groups and placed horizontally within each group. This design generated confusion for the participants who used tablet or laptop. One the mobile devices, the blocks were naturally sorted from top to bottom and participants who used mobile devices did not have problems related to navigation.

The app should add a function to share the report with other people.

Format of date: In the U.S., it would make more sense if the date was formatted as "month/ day/year." In this question, we provided a date picker powered by jQuery. However, it should be noted that the date format had to accustom to the familiar format of the participants.

There should be a save button where participants can review the in-progress questionnaires. This feature was added later on.

The environment of using this app should be suggested in the welcoming message. One participant mentioned that she would not be able to complete the questionnaires at home with her kids, suggesting that participant would appreciate a certain period of engagement in the app.

The app will welcome the users with a note of how long they could expect to complete the app in one session. In the introduction of each questionnaire, we should also indicate a time range of how long users usually take to complete the questionnaire.

Keywords such as "in the past month" in some questionnaires should be enlarged/bold and highlighted with visible colors. Some of the questionnaires such as PTSD or CESD-R were designed specifically to inquire the participants' experiences in the past months or past weeks. These keywords should be stressed since without emphasizing these conditions, the whole questionnaire could not precisely measure the participants' experiences.

The sliders in the questionnaires were nice, but there should be instructions of how to operate the sliders and the default option needed to be considered with caution. Some of the questionnaires were designed with Likert scale responses. Since the items in a Likert scale usually had a linear relationship between each other, it was a conscious choice of the research team to use a horizontal slider that allowed users to slide between each "pip" on the bar. However, researchers need to be very cautious in choosing where to place the default option or not to place it. In the study, the default option was placed in the 3rd Likert scale item. For instance from "Strongly disagree" to "Strongly agree," the default option was placed in the middle "Neither agree nor disagree." However, when the participants had the same answer with the default value, they simply skipped this question and realized that they needed to click or slide on the slider when trying to submit the questionnaire. It is important to provide certain instruction at the beginning that informs users how to interact with the slider

It should be explicit that the question has been answered, and the participants should be able to review their answers.

### 7. Conclusion

Disregarding the obvious need to enhance the navigation and user experiences of the application, from the preliminary test, we could conclude that GIFT exhibits a good potential to be implemented in the early phase of bereavement and could empower the bereaved to be more attentive and autonomous to their grief response. Alone with the design of the application, a study was also planned to test GIFT with a larger base of participants and collect data that could be informative to validate the risk factors of PGD empirically. Modern technologies are more and more interwoven into our everyday life experiences. Grief was, and maybe still is, a highly private experience, but contemporary researchers have notified a growing phenomenon of bereaved individuals seeking social support and sharing their grief experiences or emotions on the Internet. Furthermore, the Internet likely also serves as a medium of communicating and connecting with the deceased. Examples are frequent addressing the deceased in a post on social media or talking to the deceased in a public forum. The effect of these phenomena remains unknown in both an intra- and interpersonal level but is by far worth heeding. More studies are being planned and will be presented elsewhere. We hope more results from the future studies can contribute to informing the field and professional practitioners how to better support the bereaved and facilitate positive health outcomes following the coping process of the bereavement.

# Acknowledgements

This work is funded by the Taiwanese Ministry of Education Funds for Studying Abroad. The authors want to thank Taiwanese government for sponsoring the study and Ph.D. project.

The authors also wish to address deepest gratitude to Laura Nelson for her professional execution in the protocol analysis sessions and to all the participants that contribute precious opinions regarding the contents and user experiences of the app.

### **Author details**

Wan Jou She<sup>1\*</sup>, Laurie Burke<sup>2</sup>, Robert A. Neimeyer<sup>2</sup>, Kailey Roberts<sup>3</sup>, Wendy Lichtenthal<sup>4</sup>, Jun Hu<sup>1</sup> and Matthias Rauterberg<sup>1</sup>

- \*Address all correspondence to: lave@lavendershe.com
- 1 Technical University of Eindhoven, Eindhoven, The Netherlands
- 2 The University of Memphis, Memphis, USA
- 3 New School for Social Research, New York, USA
- 4 Memorial Sloan Kettering Cancer Center, New York, USA

### References

- [1] Barlow J, Wright C, Sheasby J, Turner A, Hainsworth J. Self-management approaches for people with chronic conditions: a review. Patient Education and Counseling. 2002; 48(2):177-187
- [2] Chodosh J, Morton SC, Mojica W, Maglione M, Suttorp MJ, Hilton L, et al. Metaanalysis: Chronic disease self-management programs for older adults. Annals of Internal Medicine. 2005;143(6):427-438
- [3] Holman H, Lorig K. Patient self-management: A key to effectiveness and efficiency in care of chronic disease. Public Health Reports. 2004;119(3):239-243
- [4] Holmen H, Torbjørnsen A, Wahl AK, Jenum AK, Småstuen MC, Årsand E, et al. A mobile health intervention for self-management and lifestyle change for persons with type 2 diabetes, part 2: One-year results from the Norwegian randomized controlled trial renewing health. JMIR mHealth and uHealth. 2014;2(4):e57
- [5] Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. Arthritis & Rheumatology. 1993;36(4):439-446
- [6] Schwarzer R. Self-efficacy: Thought control of action. Taylor & Francis. 2014
- [7] Sterling EW, Silke A, Tucker S, Fricks L, Druss BG. Integrating wellness, recovery, and self-management for mental health consumers. Community Mental Health Journal. 2010;46(2):130-138
- [8] Lawn S, Battersby MW, Pols RG, Lawrence J, Parry T, Urukalo M. The mental health expert patient: findings from a pilot study of a generic chronic condition self-management programme for people with mental illness. International Journal of Social Psychiatry. 2007;53(1):63-74
- [9] Stinson J, Wilson R, Gill N, Yamada J, Holt J. A systematic review of internet-based self-management interventions for youth with health conditions. Journal of Pediatric Psychology. 2009;34(5):495-510

- [10] Beatty L, Lambert S. A systematic review of internet-based self-help therapeutic interventions to improve distress and disease-control among adults with chronic health conditions. Clinical Psychology Review. 2013;33(4):609-622
- [11] Landro L. Doctors prescribe new apps to manage medical conditions. Wall Street Journal. 2015
- [12] Vanderwerker LC, Prigerson HG. Social support and technological connectedness as protective factors in bereavement. Journal of Loss and Trauma. 2004;9(1):45-57
- [13] van der Houwen K, Schut H, van den Bout J, Stroebe M, Stroebe W. The efficacy of a brief internet-based self-help intervention for the bereaved. Behaviour Research and Therapy. 2010;48(5):359-367
- [14] Krysinska K, Andriessen K. On-line support and resources for people bereaved through suicide: What is available? Suicide and Life-Threatening Behavior. 2010;40(6):640-650
- [15] Krysinska K, Andriessen K. Suicide bereavement online: Sharing memories, seeking support, and exchanging hope. Suicide Prevention and New Technologies: Springer. 2013:150-165
- [16] Lundorff M, Holmgren H, Zachariae R, Farver-Vestergaard I, O'Connor M. Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis. Journal of Affective Disorders. 2017
- [17] Bauer JJ, Bonanno GA. Doing and being well (for the most part): Adaptive patterns of narrative self-evaluation during bereavement. Journal of Personality. 2001;69(3):451-482
- [18] Capps L, Bonanno GA. Narrating bereavement: Thematic and grammatical predictors of adjustment to loss. Discourse Processes. 2000;30(1):1-25
- [19] Maercker A, Bonanno GA, Znoj H, Horowitz MJ. Prediction of complicated grief by positive and negative themes in narratives. Journal of Clinical Psychology. 1998;54(8): 1117-1136
- [20] Schnider KR, Elhai JD, Gray MJ. Coping style use predicts posttraumatic stress and complicated grief symptom severity among college students reporting a traumatic loss. Journal of Counseling Psychology. 2007;54(3):344
- [21] Burke LA, Neimeyer RA. Prospective risk factors for complicated grief. Complicated grief: Scientific Foundations for Health Care Professionals. 2013:145
- [22] Burke LA, Neimeyer RA, McDevitt-Murphy ME. African American homicide bereavement: Aspects of social support that predict complicated grief, PTSD, and depression. OMEGA: Journal of Death and Dying. 2010;61(1):1-24
- [23] Field NP, Filanosky C. Continuing bonds, risk factors for complicated grief, and adjustment to be eavement. Death Studies. 2009;34(1):1-29
- [24] Lobb EA, Kristjanson LJ, Aoun SM, Monterosso L, Halkett GK, Davies A. Predictors of complicated grief: A systematic review of empirical studies. Death Studies. 2010; 34(8):673-698

- [25] Lombardo L, Morelli E, Luciani M, Bellizzi F, Aceto P, Penco I, et al. Pre-loss demographic and psychological predictors of complicated grief among relatives of terminally ill cancer patients. Psychotherapy and Psychosomatics. 2012;81(4):256-258
- [26] Prigerson HG, Bierhals AJ, Kasl SV, Reynolds CF, Shear MK, Day N, et al. Traumatic grief as a risk factor for mental and physical morbidity. American Journal of Psychiatry. 1997;154:616-623
- [27] Romero MM, Ott CH, Kelber ST. Predictors of grief in bereaved family caregivers of person's with Alzheimer's disease: A prospective study. Death Studies. 2014;38(6):395-403
- [28] Stroebe MS, Folkman S, Hansson RO, Schut H. The prediction of bereavement outcome: Development of an integrative risk factor framework. Social Science & Medicine. 2006;63(9):2440-2451
- [29] Villacieros M, Serrano I, Bermejo JC, Magaña M. Social support and psychological wellbeing as possible predictors of complicated grief in a cross-section of people in mourning [Apoyo social y bienestar psicologico como posibles predictores de estado de duelo complicado en poblac de personas en duelo]. Anales de Psicología. 2014;30(3):944
- [30] Ericsson KA, Simon HA. Verbal reports as data. Psychological Review. 1980;87(3):215